The Source® for Alzheimer's & Dementia

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Printed in the U.S.A.
ISBN 0-7606-0373-1

About the Author

Pam Britton Reese, M.A., CCC-SLP, owns a private practice, CommunicAid Plus, where she provides speech and language services to children and adults. She is also an educational consultant to public and private schools.

Pam first became interested in Alzheimer's disease (AD) when her mother-in-law was diagnosed with the disease in 1993. Pam's consultant work with families as they struggle with AD led to the writing of this book.

The Source for Alzheimer's & Dementia is Pam's second publication with LinguiSystems. She is also co-author of *Autism & PDD: Social Skills Lessons.*

Dedication

For M. D. R., S. B. B., and N. M. B., with love

Acknowledgments

Much as it sometimes takes a team of individuals to care for a person with AD, it also took a team of people to help me write this book. I would especially like to thank Sandra Bond Chapman, Ph.D., of the Callier Center for Communication Disorders at the University of Texas at Dallas, who answered my many questions and graciously shared her knowledge about Alzheimer's disease with me and others. Her enthusiasm for the work of speech-language pathologists in the field of AD was a direct influence on my decision to write this book. Thanks also to Susan Rigby, CCC-SLP, for her professional suggestions; Susan McMillion Mason, attorney-at-law, for her advice on legal definitions; and Judy Cotton and Nena Challenner for their willingness to discuss the many issues that caregivers face.

To Joe Reese, for his encouragement, editorial comments, and creative help in the writing of this book, I offer my most grateful thanks.

Please note: All examples of people with AD used in this book come from my personal experience with AD. Some examples are composites; all have had names or distinguishing features changed to protect the privacy of the individuals. Thanks to all the families who shared their stories with me.

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Introduction

Staff at the assisted living center all knew Mrs. C. She was the resident "behavior problem." She continuously walked and paced in circles around her room. Her loud cries could be heard throughout the building. When the staff attempted to distract or redirect her behavior, she became increasingly loud and distraught. Nothing worked to calm Mrs. C. Finally, during a visit from a consulting speech-language pathologist, the SLP noticed that cold air from a large air vent was blowing directly on Mrs. C's chair. Once the temperature and air flow were adjusted, Mrs. C's problem behavior disappeared.

Do you know Mrs. C? Is she a resident at the facility where you work? Are you the staff member who works with her family? As communication specialists, SLPs are in a unique position to help patients with Alzheimer's disease (AD) and their families as they cope with the different stages of the disease.

I wrote *The Source for Alzheimer's & Dementia* to help the SLP who works with patients with AD whether they live in assisted living centers, skilled nursing facilities, or in the homes of their caregivers.

Section One gives background information on the history of AD, the brain and its role in memory and cognition, and a review of communication and behavior. This material may be copied and shared with caregivers.

Section Two contains techniques to help people with mild to severe AD maintain optimal levels of function as well as suggested environmental modifications to help the person with AD stay safe and oriented. An agenda and activities for a six-week caregiver training program is also in Section Two.

There are also four appendixes filled with useful information. Appendix One contains therapy materials (sample Schedules, Therapy Conversation Topics, sample Social Reminders, and visuals for Self-Care Activities.) Appendix Two defines other forms of dementia. Recommended books about AD, support groups, and web sites are listed in Appendix Three and Appendix Four.

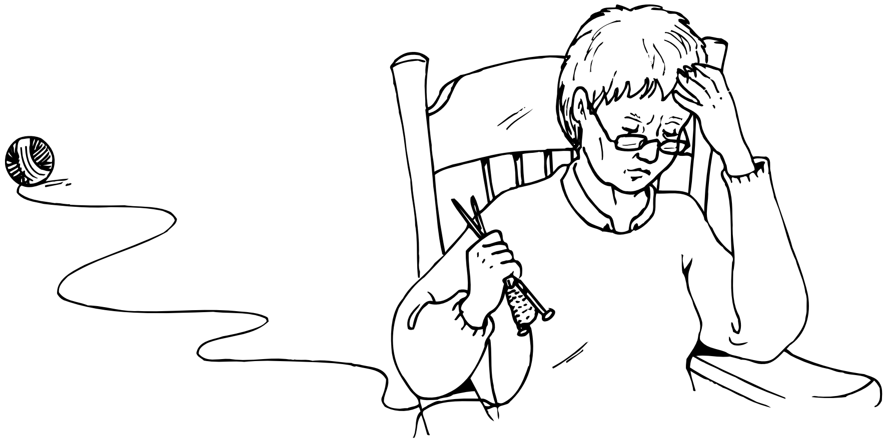
I have two goals for you as you use this book. First that you find the treatment suggestions in Section Two useful in your practice. I also hope that you will be able to share information from this book with family caregivers. Communication breakdowns remain the most stressful component of living with AD—affecting every corner of life. I believe that if caregivers understand the nature of communication and what happens when it breaks down, they will be better able to care for and enjoy the person with AD.

Pam

"I felt a clearing in my mind
As if my brain had split;
I tried to match it, seam by seam,
But could not make them fit.

The thought behind I strove to join
Unto the thought before,
But sequence ravelled out of reach
Like balls upon the floor."

-E. Dickinson



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Chapter One

> "I have lost myself."
>
> *-Auguste D., the first person diagnosed with Alzheimer's disease*

Background

Auguste D. was suffering from dementia. *Dementia* is a general term that describes a loss of cognitive and linguistic abilities in an adult. Cognition, problem solving, language, and the ability to do common tasks can all be affected. Dementia is not a disease. It is a group of symptoms. There are many different causes of dementia, some of which are treatable such as depression or certain thyroid problems. For this reason, a medical diagnosis is important. Two of the more common forms of dementia are Alzheimer's disease (AD) and multi-infarct dementia.

Alzheimer's disease	AD is the most common form of dementia. Half of the cases of dementia are attributed to AD (Weiner and Gray 1996). It is irreversible and progressive. Memory, language, judgment, and personality are all affected. Although the cause of AD is unknown, the plaques and tangles in the brain that are found upon autopsy confirm the diagnosis of AD. Are the plaques and tangles a cause or a symptom of the disease? Scientists are not sure.
Multi-infarct dementia	This type of dementia is caused by a series of small strokes. About 20% of dementia cases are caused by these small strokes (Aronson 1988). Symptoms vary depending on the area of the brain that is damaged. If the cause of the strokes is controlled, further damage can be prevented.

These two types of dementia are not mutually exclusive. Twenty percent of people with dementia may have a mixed cause (AD and multi-infarct dementia). Taken together, they account for 90% of dementia reported. Although the focus of this book is AD, information and strategies presented can also be used with individuals with multi-infarct dementia. Because of the prevalence of AD, the terms *Alzheimer's disease* and *dementia* are used interchangeably in this book to refer to the Alzheimer's type of dementia.

Characteristics of Alzheimer's Disease

AD will often go undetected in a person for many years. Families will observe certain problems, but explain them away as "Dad getting older," "losing his hearing," or "sad over the loss of his sister." Frequently it is only when the disease progresses to a more severe state that the families seek a medical diagnosis.

Common characteristics of AD include:

1. **A gradual onset of symptoms**
   Families will often be unable to pinpoint a particular day or time of onset as they might in the case of a sudden stroke. People with AD tend to have good days and bad days. On good days, families talk themselves into thinking that the problems were temporary. However, over time they notice the difficulties of symptoms increasing.

2. **A loss of memory**
   Everyone misplaces glasses or forgets to water the plants. The memory loss in AD is more severe and pervasive. The memory loss can be seen in:

   - *Confusion at work and home*. A person with AD may have difficulty staying employed because he is unable to complete the required work. A retired person may show confusion by using a gasoline can instead of a watering can to water the plants.

   - *Disorientation to time and place*. A person with AD may not remember how to drive home from a familiar place (e.g., the grocery store). She may not remember that it is Saturday and there is no need to dress for work.

   - *Putting objects in odd places*. The person with AD may find scissors he put in a cereal box and have no memory of putting them there.

   - *Problems completing daily living skills.* Instead of making the needed single serving of oatmeal, the person with AD makes oatmeal for 20 people, and then forgets it was made at all.

3. **Personality changes**
   Caregivers will often describe their loved one as "different." A dignified mother may curse repeatedly or a happy person may become angry for no apparent reason. Other words that may describe the personality changes are *suspicious* and *fearful*.

4. **A loss of speech and language**
   Language skills are lost throughout the course of the disease. Examples of this loss can be seen in:

   - *Finding the correct word to say (anomia)*. This is seen in the earliest stages of the disease. A grandmother in the early stage of the disease once said, "I didn't know that your car had a TV." She was talking about the radio.

     Others with AD will sometimes substitute meaningless or vague words (e.g., *stuff, things)* for the words they are unable to recall.

   - *Problems understanding language*. A patient may not understand complex, multiple-part directions (e.g., "After you are finished in the bathroom, get the extra blanket in the closet, and set the alarm for 6:45."). Even in the early stages of the disease, a patient may have problems understanding abstract language (e.g., " A bird in the hand is worth two in the bush.").

- *Problems with expressive language*. Persons with AD are described as "producing less information than normal, despite the fact that they produce as much language" (Ulatowska and Chapman 1995). The person with AD has problems maintaining a narrative. He often talks around a subject or wanders off the topic. Pronoun confusion is also seen. The problems of too much talking and too little talking are both described in AD.

  Language problems such as echolalia (repeating words said by others) and palilalia (repeating words you have already said) are also seen (Kempler 1995).

- *Problems communicating wants and needs*. All of the above problems can interfere with the ability of the person with AD to communicate his needs. Compound this with memory prolems and situations such as the following can happen:

  "Mrs. Smith has not had any water all day. She does not remember to take a drink, even though she is becoming dehydrated. She may even say she is hungry when she is thirsty or she may not remember to ask at all. Dehydration is often a problem for people with AD."

- *Problems in articulation.* Humming, groaning, or repetitive babbling may be the limit of the expressive output. Muteness is common toward the end of the disease.

5. **Poor judgment**
   Persons suffering from AD exhibit poor judgment in many areas of daily living. They may give out personal information over the phone, give money to strangers at the door, or have problems dressing (e.g., wearing their underwear on top of their pants).

6. **Loss of abstract thinking skills**
   Many of the things we do in our lives involve abstract thinking (e.g., balancing a checkbook; driving a car; planning, shopping for, and cooking a meal for four people). Sometimes the first sign of a problem is the loss of the ability to do a familiar task.

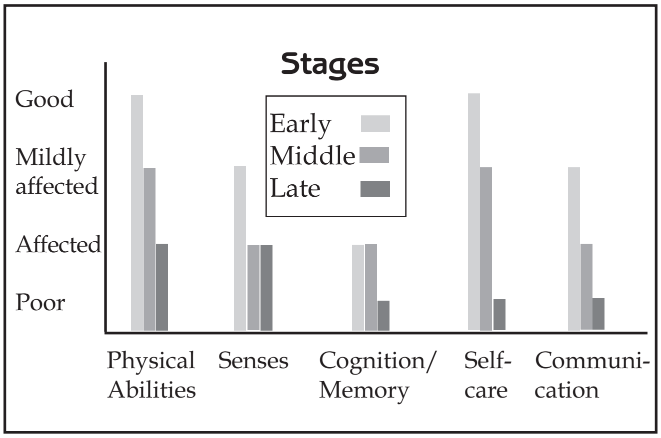
7. **Withdrawal from social activities**
   A previously sociable person may withdraw from conversations or activities. This may also be a symptom of the depression sometimes experienced by people in the early stage of AD.

8. **Perseveration**
   When a person does something repeatedly, that person is perseverating. This might be saying the same story over and over (verbal perseveration) or scrubbing the toilet again and again in one day (physical perseveration).

9. **Loss of tolerance for stress**
   The person with AD loses the ability to handle the abundance of information and stimulation in life. A visit from a beloved young grandchild may add enough noise and chaos to a room to cause that grandparent to have a loud outburst.

10. **Physical problems**
    Physical problems (e.g., gait disturbances and dysphagia) are usually not seen until the late stage of the disease.

AD is a progressive disease and looks different at different times. It is often described as progressing in stages, although at every stage patients exhibit strengths and weaknesses. The three stages are early, middle, and late. The following graph compares typical abilities and weaknesses in each stage. These remaining skills are important to keep in mind as you plan an intervention approach for those with AD.



Treatment of AD

Although there is currently no cure for AD, there is still much that caregivers and speech therapists can do. Many different treatment strategies are discussed in Chapter Seven, pages 59-69. Throughout the course of the disease, people with AD are more alert, sociable, and communicative with the proper types of support and therapy.

Alzheimer's Disease: Statistics

Alzheimer's disease (AD) is a progressive, degenerative disease of the brain and the most common form of dementia. Some things you should know about Alzheimer's disease:

- Approximately 4 million Americans have AD. In a 1993 national survey, 19 million Americans said they had a family member with AD, and 37 million said they knew someone with AD.
- 14 million Americans will have AD by the middle of the next century (2050) unless a cure or prevention is found.
- One in 10 persons over 65 and nearly half of those over 85 have AD. A small percentage of people as young as their 30s and 40s get the disease.
- A person with AD will live an average of 8 years and as many as 20 years or more from the onset of symptoms.
- U.S. society spends at least $100 billion a year on AD. Neither Medicare nor most private health insurance covers the long-term care most patients need.
- Alzheimer's disease is costing American business over $33 billion a year — $26 billion is the cost to business of caregiving (lost productivity from absenteeism of employees who care for family members with Alzheimer's); the rest is the business share of the costs of health and long-term care.
- More than 7 of 10 people with Alzheimer's disease live at home. Almost 75% of the home care is provided by family and friends. The remainder is "paid" care costing an average of $12,500 per year. Families pay almost all of that out-of-pocket.
- Half of all nursing home residents suffer from AD or a related disorder. The average cost for nursing home care is $42,000 per year, but can exceed $70,000 per year in some areas of the country.
- The average lifetime cost per patient is $174,000.
- The Alzheimer's Association has granted over $82 million dollars in research grants (since 1982).
- The federal government estimates spending approximately $400 million for Alzheimer disease research in 1999. This represents $1 for every $250 the disease now costs society.

The Alzheimer's Association is the only national voluntary health organization dedicated to research for the causes, cures, treatments, and prevention of Alzheimer's disease and to providing education and support services to Alzheimer patients, their families, and caregivers. For further information on statistics, please contact the Benjamin B. Green-Field Library at the Alzheimer's Association at (312) 335-9602 or greenfld@alz.org.

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"Tell me where is fancy bred?
Or in the heart or in the head?"

-Shakespeare, *The Merchant of Venice*

Possible Causes and Risk Factors

In 1906, Alois Alzheimer, a neuroscientist in Germany, performed an autopsy on a female patient. She had been his patient for years as she suffered from dementia. When he viewed her brain cells under a microscope, he discovered abnormal cells. Some of the brain cells were large and dark. These he called "senile plaques." Other brain cells looked like tangled threads. These he named "neurofibrillary tangles." Today physicians speak of the telltale neuritic plaques and neurofibrillary tangles of Alzheimer's disease (AD).

For thousands of years, people did not understand the importance of the brain. The heart, the stomach, and the gut were all thought to control our thoughts and our emotions. Our language reflects this lack of knowledge. Our hearts are broken or we have butterflies in our stomach, but in reality it is the brain that controls us.

In dementia, different parts of the brain are affected. In order to understand some of the symptoms observed in dementia, it is necessary to understand how the brain works. Research in recent years has provided a wealth of information on how the brain functions. This knowledge helps us understand the cause of the behaviors and problems exhibited by individuals with Alzheimer's disease and suggests strategies for intervention. This chapter briefly summarizes the structures of the brain, the functional organization of the brain, and how the brain works at the cellular level as known to date.

Brain Structures

Traditionally, the brain has been divided into six or seven parts whose borders are determined by some of the grooves (sulci) and ridges (gyri) of the brain. These parts, which can be viewed with the naked eye, include the left and right cerebral hemispheres. The two hemispheres are connected by white fibers called the corpus collosum. The corpus collosum sends messages back and forth between the hemispheres. Each hemisphere is divided into the following lobes:

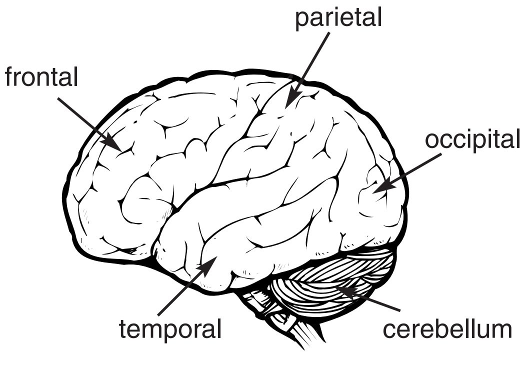
- **frontal lobe**
  This lobe is responsible for problem solving, organizing and planning, emotions, and personality. Here is where our "social control"

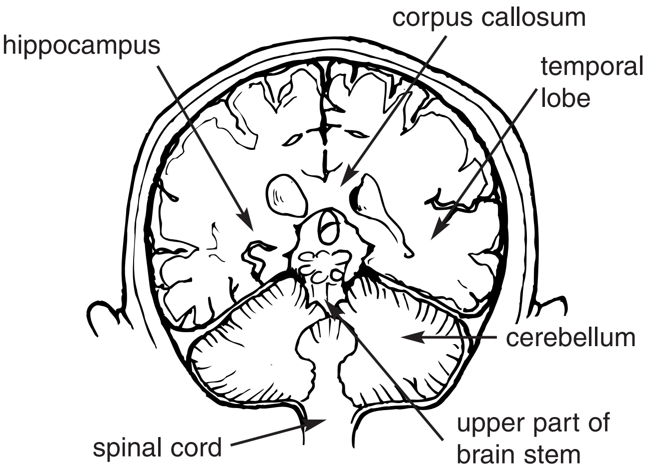
is found. Our frontal lobe keeps us from telling dirty jokes to Grandma!

- **parietal lobe**
  This lobe interprets and discriminates sensory input and body orientation in space. With a problem in this area, a person may not recognize a part of her body or may not be able to write.

- **occipital lobe**
  This lobe receives and interprets visual information. People with AD may get lost in familiar environments because of problems in the parietal-occipital areas that are responsible for guiding self-movement and maintaining spatial orientation (Tewetsky and Duffy 1999).

- **temporal lobe**
  This lobe receives and interprets auditory information. Problems hearing or understanding language can arise from disruption of the temporal lobe. If you peel away the temporal lobe, underneath it you'll find the hippocampus. The *hippocampus* is important for new learning and recent memories. If a person has damage to the hippocampus in both hemispheres, she can't learn anything new. (Hallet 1999).





There are other structures inside the brain, which like the hippocampus, cannot be seen from the outside. These include:

- **the limbic system**
  This system is thought to be involved with controlling emotions, memory, and certain aspects of attention. Some structures within this system (e.g., the mammillary bodies, the amygdala, and the hippocampus) are involved in some types of memory and the ability to learn new information.

- **the basal ganglia**
  These are thought to modulate movement and integrate sensory information.

- **the ventricular system**
  It is made up of four spaces filled with fluid within the brain. When brain cells are damaged or die (such as can happen in dementia), the ventricle spaces get larger.

These structures are made up of small groups of neuron cell bodies. They help send information between the higher cortex and the lower parts of the brain called the *brain stem*.

The brain stem is made up of three more parts of the brain:

- **midbrain**
  It contains nerve pathways and auditory and visual reflex centers.

- **pons**
  It is a respiratory center of the brain.

- **medulla oblongata**
  It controls the heart, breathing (e.g., hiccups), and the ability to swallow, cough, and gag.

The cerebellum is sometimes considered a part of the brain stem. It controls voluntary, coordinated movement.

Brain Functions

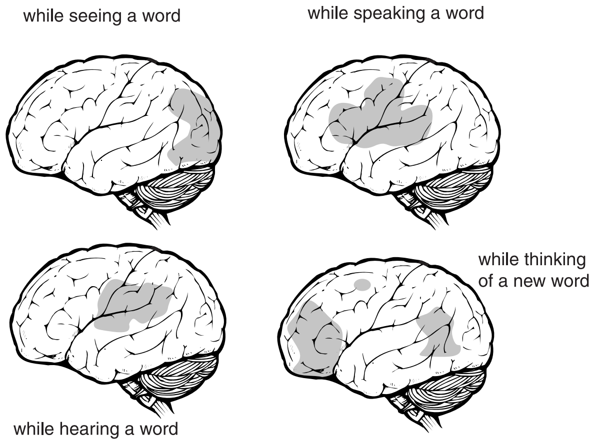
Another way to describe how the brain works is to consider the organization of the many different parts, all working together toward a particular goal or function. Modern imaging techniques (e.g., the PET scan) have revealed much information about how the brain functions. A PET scan tracks the blood flow in the brain and provides visual images of areas of the brain activated as the person thinks (Hallet 1999). Disruption of these interactions can be seen in some of the problems experienced by people with AD.

1. **The Motor System**
   The motor strip and premotor strip control motor movement throughout the body. The motor strip is located in the frontal lobe. Stimulation to the top of the strip causes movements in the legs, and stimulation further down, near Broca's area, controls movement of the face, mouth, and tongue. The basal ganglia and the cerebellum interact with the motor strip to help modulate movement. Only a small portion of the motor strip controls arm and leg movements, while a much larger portion of the motor strip controls the movements of hands and face which are very important for communication. The motor strip also receives information from the senses.

2. **The Sensory System**
   Many systems throughout the brain make up the sensory system. Two important systems for speech, language, and communication are the auditory and visual systems. Visual information is processed in the back of the brain in the occipital lobe. Auditory information is processed in the temporal lobe. Information from the sensory system is often compromised in dementia. The visual and auditory problems of people with AD will be discussed in Chapter Five.

3. **The Language System**
   The language system is located almost entirely in the left hemisphere for most people. Nancy Andreason, in *The Broken Brain*, describes neurologist Norman Geschwind's model for how the language system works. In his model, there are several specialized centers for language in the brain.

   Broca's area governs grammar and the organization of words into fluent speech. The angular gyrus stores information that recognizes language in visual form and Wernicke's area recognizes language in auditory form. Again, information from PET studies shows that other areas of the brain are activated depending on the language task (Fischbach 1992, Raichle 1992). (See the illustration on the next page.) In patients suffering from dementia, the language system appears broken.



Activation depending on language task

4. **The Memory System**
   The memory system (or rather systems) is located in many different parts of the brain (probably in both hemispheres). This is unique among the systems of the brain. Parts of the brain identified in the memory system (Andreason 1984) include:

   - the hippocampus
   - the mammillary bodies
   - the septal region of the limbic system
   - part of the thalamus

   If one of these parts is damaged on one side, memory can remain. However, damage to these parts on both sides of the brain destroys memory.

   The highest concentration of the telltale plaques and tangles of AD are found in the hippocampus. To understand how the memory system functions, the process or the "how" may be more important than the "where" or "what" (Calvin and Ojemann 1994). The "how" of memory function is discussed in more detail in Chapter Three.

5. **The Frontal System**
   The largest part of the brain, the frontal system, controls planning, organizing, problem solving, attention, personality, behavior, and emotions. This system too is affected in persons with dementia. Whether the damage is to the frontal system itself or to the communication pathways between the frontal system and other important systems has yet to be determined.

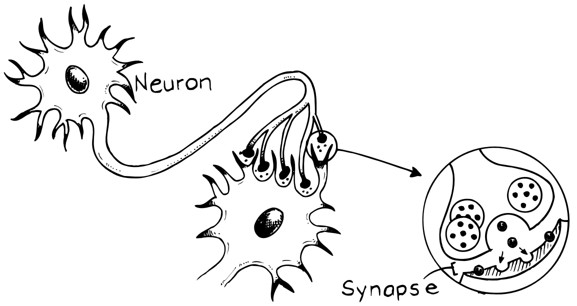
6. **The Neuroendocrine System**
   This system uses hormones to communicate with glands throughout the body. Aggression, appetite, thirst, sleep regulation, and the ability to adapt to stress and change are controlled by this system. Problems with appetite, sleep, and aggression are symptoms sometimes seen in people with dementia.

The Cellular Level

How then, do these different parts of the brain and different systems communicate? They send messages back and forth through the connection of billions of neurons. Chemicals in the brain called *neurotransmitters* are the messengers. Some neuroscientists have implicated a breakdown at the cellular level of the neurotransmitters as a possible cause of dementia.

Neurons have different sizes and shapes depending on their jobs. Neurons contain small branches (dendrites) that increase their ability to receive information and long tubes (axons) that send information to other cells.

Neurotransmitters are located in tiny sacs at the ends of the axons. When an electrical impulse travels along an axon, neurotransmitters cross a tiny space or *synapse* to a receptor site on the next neuron. Fifty neurotransmitters have been identified to date. Each neurotransmitter fits into its receptor site like a key in a lock (Hallet 1999).



Acetylcholine is a neurotransmitter used in the hippocampus and is thought to aid in forming memories. Acetylcholine levels are sharply reduced in people with AD. Other neurotransmitters are also found at lower levels in people with AD, but acetylcholine is the most reduced. When there are not enough neurotransmitters, nerve cells will, over time, deteriorate and die.

Once the neurotransmitter crosses the synapse and attaches to the receptor, it either activates a neuron or passes the message on to other cells. The message system relies on different proteins and problems with these proteins could interrupt the message. Two proteins, beta amyloid and tau, have been discovered to be associated with the plaques and tangles found in AD (DeKosky 1996). The plaques are made up of beta amyloid, a protein fragment, and other proteins. Tau is found in the tangles.

There are many theories about the role of beta amyloid. It may be toxic to neurons or cause certain chemical interactions that are fatal to the neurons. Scientists do know that beta amyloid is a piece of a larger protein called *amyloid precursor protein* (APP). APP usually helps maintain neurons. Enzymes, called *secrateses*, have been identified that act as scissors to clip off pieces of APP creating the shorter protein beta amyloid (Yan et al. 1999, Sinha et al. 1999, Vassar et al. 1999). All people have beta amyloid, but in people with AD, beta amyloid is not dissolved as it is normally; it is clumped together to create the plaques.

Recent scientific work (Patrick et al. 1999) has also helped with the understanding of how tangles are formed. The tau protein typically serves as a support system within neurons which helps neurons extend connections to other neurons. Something causes the protein to disintegrate and break loose from the neuron and make tangles which results in neuron death. Patrick et al. (1999) have identified a protein, p25, that converts an enzyme called *cdk5* from a benign enzyme to a deadly one which destroys neurons.

Understanding how the brain functions and what is going wrong can aid in communication. Unusual behaviors seen in AD can sometimes be explained by an understanding of brain anatomy. For example, vision problems would indicate possible involvement of the occipital lobe. Also a good understanding of brain function can help us see how much is actually preserved. A person who struggles to remember past events (episodic memory) may still remember how to do a physical task (procedural memory). The different types of memory are discussed in the next chapter.

Risk Factors

Not only do we not yet understand the biological processes underlying AD, we also do not yet know what causes the disease for some people.

Scientists have identified some probable risk factors to developing AD. Risk factors are behaviors or traits that make a person statistically more likely than someone without the risk factor to develop the disease. Risk factors are not necessarily causes of the disease. No factor has been identified as a definite cause of AD. Most scientists believe that AD probably has many complex and related causes:

1. **Advanced age**
   The longer a person lives, the greater the risk of developing AD. The figure rises from 3% of people ages 65-74 with AD to as many as 48% of people ages 85 and older (Evans et al. 1989).

2. **Family history**
   Any close relative (first degree) who develops AD increases risk.

3. **Genetics**
   Abnormalities of genes on chromosomes 1, 12, 14, 19, and 21 have been identified that are linked to AD in some way.

   - Chromosomes 1 and 14 are thought to be responsible for rare cases of early-onset AD.

   - Alpha-2 Macroglobulin (A2M) is a gene on Chromosome 12 which is possibly responsible for making someone susceptible to AD (Blacker et al. 1998).

   - The gene apolipoprotein E (APOE) on Chromosome 19 has three varieties: e2 (associated with reduced risk), e3 (associated with average risk), and e4 (associated with increased risk) (NIA 1996).

   - Chromosome 21 has the gene for APP (see page 18).

4. **Down syndrome**
   Down syndrome is caused by a mutation of Chromosome 21. People with Down syndrome produce extra APP which may be responsible for the plaques that develop in their brains as they age (Wisniewski et al. 1985).

5. **Women**
   Although more women than men have AD, this may or may not be related to the fact that women live longer than men (Bachman et al. 1992).

6. **Head injury**
   Head injury which causes a loss of consciousness (Roberts et al. 1991) or a minor head injury early in life (Schofield et al. 1997) may greatly increase one's chances of developing AD.

Other risk factors being investigated include cerebrovascular disease, ethnicity, depression, brain tissue inflammation, environmental factors (e.g., exposure to aluminum), low educational level, antioxidants in the diet, and the use of estrogen in women (Kuhn 1999).

Although we are unable to control the risk factors identified to date, further research can help us to better understand the nature of Alzheimer’s disease.

Chapter Three

"There's rosemary, that's for remembrance,
pray you love remember:
and there is pansies, that's for thoughts."

-Shakespeare, *Hamlet*

Memory

A half-remembered name, a misplaced purse, a missed appointment — everyone has experienced these kinds of memory slips. As people age, memory lapses of this type become more and more common. Memory has been thought of as pictures from the past, stored in a special place in our brains. This is not the complete story. Memory is not a separate item, but rather a system of different types of memories underlying our thoughts and actions and working together.

First consider that memories are sometimes defined by the amount of time they are held in our minds. There are situations in which a phone number is remembered only as long as it takes us to find it in the phone book and walk across the room to dial. When the phone call is finished, all memory of that number may be gone. This is an immediate memory. Short-term memory occurs when a student memorizes a long list of vocabulary words and remembers them long enough to take the test. A few weeks later, the student is unable to give all the definitions that he knew on the day of the test. A long-term memory is typically not forgotten over time. A memory of the first time you rode a bike or the phone number of your first house have been committed to long-term memory.

Memories are also defined by what is remembered. Remembering an event, like your birthday party when you were nine, is called *episodic memory*. In normal aging, some episodic memory is affected. Details of an event may not be remembered entirely or may be remembered later. Typically aging adults can benefit from memory aids such as notes to remember the details. In AD, however, entire events are lost. A person with AD may not remember an event that occurred just minutes before.

At a nearby assisted living center, the special activity of the day was a trip to go fishing. The staff prepared the participants for the trip and all shared a fun and exciting day. The participants returned to the center to enjoy a fish fry of the fish they had caught. Upon questioning during dinner, not a single person with AD remembered that they had gone on the fishing trip.

Although memory aids for episodic memory may be helpful in the early stages of AD, as the disease progresses, these aids are not as effective.

Remembering what something means or the concept, schemata, world knowledge, and linguistic competence is called *semantic memory* (Tulving 1972). Lexical memory is the memory of words. The semantic memory system helps us remember what a cup is and how it is used or the name of the latest teen movie star. In typical aging, recalling a word becomes more difficult, but the meanings of words are retained. We might experience frustration in that we know the word, but can't quite call it to mind. Later the word comes to us.

In AD, semantic memory is also affected. Initially a person with AD can still access semantic memory with cues. For example, if the person is unable to answer "What is a chair?" he may be able to answer "What do we sit on?" As the disease progresses, this ability too is lost. The person with AD will no longer be able to comprehend written or oral requests or instructions.

The memory of how to ride a bike or play a game of cards is called *procedural memory* (Bayles and Tomoeda 1995). Remembering how a task is performed is basic and automatic. We do not need to describe how to do something — we just do it. This type of memory loss is spared in typical aging and often not as severely affected in the person with AD as semantic and episodic memory until the later stage of the disease.

One family reported that a father with AD, who often withdrew from family gatherings, was still able to beat everyone at a game of Hearts, something which he had always been able to do. Another family reported that their grandmother with AD could still play certain melodies on the piano.

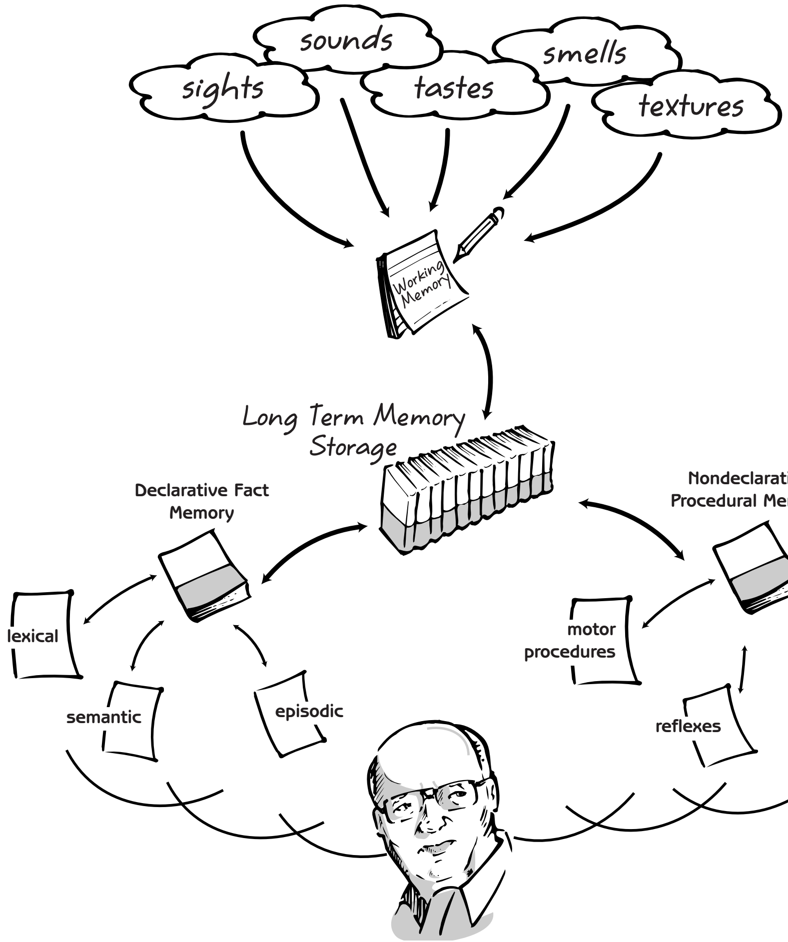
Working memory (Baddeley 1986) or active memory is the part of the brain that "focuses attention, makes decisions, and initiates action" (Bayles 1999). In working memory, there is a reaction to sensory stimulation which is stored for a brief time while the information is sorted out. Working memory is sometimes referred to as "the scratch pad of the mind" (Phillips 1999).

Finally we also have different systems for retrieving our memories: recall, recognition, stimulus-response, and learning by doing (Bayles 1999). Recall is the most difficult way to retrieve. The answer to "What is his name?" is a recalled memory. However, if you are asked, "Is his name Joe or Sam?" you only have to recognize the information when you hear it. In the stimulus-response system, something triggers the memory. Leaving your daily medication in sight by the coffee might trigger you to remember to take it when you are making your morning coffee. Learning by doing is what happens when we practice something over and over (e.g., riding a bicycle).

How might this all work together? Imagine that you are walking into a room. Your eyes see smoke, your nose smells a distinct burning smell, and your ears hear a loud buzzing noise.

All these sensations are stored briefly in your working memory. The smoke alarm triggers you to think something is burning (i.e., the stimulus-response system). From your long-term memory (i.e., the episodic drawer), you retrieve or recall the memory of the last time you forgot to set the timer for cookies and how the smoke alarm sounds. From the lexical drawer you retrieve the words "Burnt cookies!" From the procedural drawer you retrieve the memory that the last time you burned the cookies, you turned off the oven, took out the cookies with a hot pad (learning by doing system), scraped them into the garbage, and put the pan in the sink to soak.

All of these types of memory are called *stored memory*. How these memory systems work might look like this:



(adapted from Bayles and Tomoeda 1995, Bayles 1999, and Phillips 1999)

Certain types of memory are more spared in persons with AD (e.g., procedural). These memory types can be used in therapy and to facilitate the maintenance of certain daily living skills. Although a loss of memory is one of the hallmark signs of AD, it is not the only form of cognition that is affected. We must keep in mind, however, that memory underlies much of the thinking that people do.

Thought

Thought is also known as *cognition*. Bayles and Tomoeda (1997) define cognition as "stored knowledge and the processes for making and manipulating knowledge." They list the following as basic cognitive capacities:

- attention
- perception
- comprehension
- association
- sequencing
- reasoning
- symbolization
- expression
- memory

These cognitive capacities work together. We perceive and attend to the smell of fresh baked bread. We remember this smell from our childhood. We associate this sensation with a bread recipe we want to try soon and we throw back our heads, inhale, and say "mmmm." These events all happen within milliseconds. Fortunately these cognitive capacities do not fail at the same time or at the same rate. Those skills that remain can help compensate for those lost.

"A thought went up my mind today
That I have had before.
But did not finish,—-some way back,
I could not fix the year.

Nor where it went, nor why it came
The second time to me,
Nor definitely what it was,
Have I the art to see.

But somewhere in my soul I know
I've met the thing before;
It just reminded me t'was all—
And came my way no more."

-E. Dickinson

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Chapter Four

> "You see, but you do not observe"—Sherlock Holmes
>
> -Sir Arthur Conan Doyle, *Scandal in Bohemia*

Assessment and Diagnosis of AD

AD is such a devastating disease that it affects every area of a person's life. Yet in the early stages, it is difficult for families to precisely identify the problem. It is not uncommon for families to visit many different kinds of health care professionals in their search for what is wrong. One family took their father to an audiologist for a hearing evaluation because of the problems he had understanding language. Another man sought and received a diagnosis of depression from a psychologist. And in another case, a geriatric physician told a family not to worry about AD because their mother's confused episodes were just the result of normal aging. In all three cases, the ultimate diagnosis was AD. Unfortunately, by that time, the families had experienced quite a bit of frustration.

There are several reasons for confusion about AD. First we associate forgetfulness with normal aging. Although we all know the 90-year-old woman who lives alone, drives successfully, manages her finances, and even sends e-mail to great-grandchildren, we also acknowledge that forgetfulness is common for the majority of older people.

When is forgetfulness a problem? One common illustration is that if you forget where you put your keys, it is probably not a problem (except for the moment you need them!). On the other hand, if you forget what a key is for, then the problem is more severe.

Another reason for confusion is that by AD's very nature, there are good days and bad days throughout the course of the disease, even moments of lucidity in the final stages of the disease. On the "good days," families lull themselves into thinking the problem has resolved itself and that their loved one is better.

Another point of confusion for families is that some people who have some of the symptoms we associate with AD receive the diagnosis "mild cognitive impairment"(MCI). People with MCI have a memory impairment that is different from normal aging, but they do not show the same additional cognitive problems people with AD have (Petersen et al. 1999). It is not understood whether MCI is a separate, milder form of forgetfulness or if the same problem underlies MCI and AD. This question is under scientific investigation.

Frequently a caregiver will say, "If there is no cure, why do we need a diagnosis?" First families must realize that there are many causes of dementia and some of them are reversible. What looks like AD to the family may actually be symptoms of dementia caused by treatable medical problems such as depression, vitamin deficiencies, hypothyroidism, or a brain tumor.

A diagnosis of AD can also explain the symptoms. One caregiver stated, "I was actually relieved to finally get the diagnosis. I knew something was wrong and I was beginning to think that I was crazy!"

A diagnosis can also lead to appropriate medical treatment. Although there is no "cure," there are drug treatments available to slow the progress of the disease for some people, particularly in the early to middle stages.

Finally a diagnosis of AD lets the families know that they need to plan carefully for the future (Kuhn 1999). There is more information on the need for family planning in Chapter 8.

AD is a complex condition to diagnose. It has an impact on cognitive, communication, and social factors of a person's life. It can only be definitively confirmed when an autopsy reveals the hallmark plaques and tangles. And yet a probable diagnosis is confirmed 85% of the time with careful medical evaluation.

Because of the diffuse and complex symptoms seen in dementia, the information gathered by a multi-disciplinary team is necessary for diagnosis and treatment. The medical and health professions that can contribute to the assessment process are:

- physicians
- nurses
- psychologists
- speech-language pathologists
- audiologists
- ophthalmologists, optometrists, opticians
- physical therapists
- occupational therapists

Ripich (1995) suggests a protocol for differential diagnosis and assessment of symptoms of dementia:

1. case history
2. medical evaluation
3. behavioral assessment (behavior rating scales and neuropsychological tests)
4. language and communication assessment

Case History

A careful case history can be taken from either the person being tested or a family member or caregiver familiar with the person's background information. A typical case history includes information about current mental and physical functioning, prescription drugs, and family history. A case history for possible AD will also include information on education level, job history, and specific information about changes in personality, memory, self-care skills, and speech and language.

The Alzheimer Dementia Risk Questionnaire (Breitner and Folstein 1984) is an example of a case history that gathers complete information.

PRECAUTION: Healthcare professionals should be sensitive to previous experiences of the families. One caregiver, who had been in the course of a few months to 1) the family doctor, 2) two neurologists, 3) an optometrist, 4) an ophthalmologist, 5) an audiologist, and 6) a speech-language pathologist, said, "If one more person asks him what town we are in or to count by 7, I am going to scream!"

Medical Evaluation

Medical evaluations can be completed by the patient's primary physician. Other physicians experienced with AD include neurologists, geriatric specialists, and psychiatrists. Steps in the medical evaluation include:

1. **Mental Status**
   The physician first completes a screening of the patient's mental status: memory, receptive and expressive language, and simple calculations. This exam also takes into account educational background. Speech-language pathologists routinely use mental status tests. Some mental status tests commonly used include:

   - *Clinical Dementia Rating* (CDR) (Hughes et al. 1982). Evaluates orientation, memory, judgment, problem solving, home and hobbies, and personal care. Scored from 0 (normal) to 3 (severe dementia).

   - *Mini-Mental State Examination* (Folstein, Folstein, and McHugh 1975). Screens a person's orientation (e.g., person, place, time, memory, language, copying ability). Scored from 1 to 30. Bayles and Tomoeda (1995) recommend that an abnormal score is 24 and below.

2. **Physical Examination**
   Certain laboratory tests to rule out the possibility of diseases which produce AD-type symptoms (e.g., cardiac disease, thyroid disease, metabolic problems, anemia, diabetes, infection) are typically completed. These could include both blood and urine tests. The person's nutritional status and blood pressure are also evaluated.

3. **Neurological Examination**
   Speech; sensory function; and muscle coordination, tone, and strength are evaluated. Neurological problems such as Parkinson's disease or stroke can cause symptoms of dementia. The neurological examination can help differentiate between a stroke and AD.

4. **Brain Scans**
   These tests are sometimes part of the medical evaluation. These scans allow physicians to examine areas that are not visible with conventional X rays. CT scans and MRIs are the more commonly used brain scans.

   - CAT or CT (computerized axial tomography). An X-ray beam is pointed at part of the body and a computer analyzes the tissue density. This information can help detect a possible brain tumor as well as changes in the brain as seen in Huntington's disease and Pick's disease.

   - MRI (magnetic resonance imaging). Large magnets create a magnetic field and then a computer sends radio waves to the body and analyzes the cells' responses. A three-dimensional picture of the inside of the body is produced. An MRI can detect tumors, strokes, inflammations, infections, and degenerative disease. People with pacemakers or other magnetic implants are not allowed to undergo MRI testing.

   - PET (positive emission tomography). Radioactive materials are used to measure glucose and oxygen metabolism of different areas of the brain. A PET can differentiate AD from depression. This test is very expensive and used predominately in research.

- SPECT (single photon emission computed tomography). This test measures regional cerebral blood flow (rCBF) and is thought to be a less expensive substitute for PET. A SPECT image is quite colorful with red and white in the regions of high blood flow and blue in the regions of lowest blood flow. Different types of blood flow are seen in dementia with different causes (Weiner, Tintner, and Bonte 1996).

Once all other possible medical causes have been ruled out, the physician may diagnose probable AD. This type of diagnosis is called an exclusionary diagnosis. The exclusionary nature of the diagnosis of AD is demonstrated in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV). The DSM-IV (1994) is a system for differentiating between mental disorders. It is organized around five axes:

- Clinical Disorders
- Personality Disorders/Mental Retardation
- General Medical Conditions
- Psychosocial and Environmental Problems
- Global Assessment of Functioning

Dementia is located along Axis I: Clinical Disorders, but may also be found on Axis III: General Medical Conditions, depending on the cause of the dementia. Each diagnostic category (e.g., Dementia) is further divided into subcategories based on diagnostic criteria. Subcategories of dementia include:

- Dementia of the Alzheimer's Type
- Vascular Dementia (sometimes still called Multi-Infarct Dementia)
- Dementia Due to Other Medical Conditions

All the dementia categories above share common characteristics:

- memory impairment
- cognitive disturbances
- impairment of social or occupational functioning that represents a decline from the previous level

The categories differ primarily in the cause of the dementia. These differences are listed below:

Dementia of the Alzheimer's Type
- gradual onset
- continuous decline
- no evidence of central nervous system damage, systemic conditions, (e.g., folic acid deficiency) or substance abuse

Vascular Dementia
- symptoms of CVA (e.g., gait abnormalities, extremity weakness)
- laboratory evidence of CVA (e.g., multi-infarctions involving the cortex)

Dementia Due to Other Medical Conditions
- evidence from history, medical examination, or laboratory findings of other conditions which result in dementia such as:

  HIV
  Head trauma
  Parkinson's disease
  Huntington's disease
  Pick's disease
  Other medical conditions
  (e.g., brain tumor)

Behavioral Assessment

Behavior evaluations are used to measure functional loss and abilities in people with dementia as they relate to daily living activities (e.g., self-care, grocery shopping, taking medicine, using a calendar). Speech-language pathologists should know about behavioral tests and rating scales because:

- they help predict how the dementia may progress.
- they describe the patient's full range of behavior function which is useful when completing the communication assessment.
- they can support and aid interpretation of speech and language findings (Ripich 1995).

Neuropsychological Tests

These tests measure cognitive function. The National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA) recommend neuropsychological assessment as an important part of the diagnosis of persons with dementia (McKhann et al. 1984). In addition to assessing intelligence and memory, information should be gathered on attention, perception, praxis, reasoning, and language (Bayles and Tomoeda 1995).

Behavior Rating Scales

Neuropsychological tests provide information necessary for the evaluation of dementia; however, they say little about how well the person with dementia functions. Behavior rating scales (also called dementia rating scales) can provide information on how the person with dementia actually functions in daily life skills and describe how severely the person is affected. Behavior rating scales include:

- *Dementia Rating Scale* (DRS), also called (MDRS) (Mattis 1976). The DRS evaluates attention, initiation and perseveration, construction, conceptualization, and memory. It's useful in later stages of the disease.
- *Global Deterioration Scale* (GDS) (Reisberg et al. 1982). The GDS contains characteristics of seven stages including clinical descriptions ranging from normal to late dementia. It includes detailed descriptions of how a person functions at each stage.
- *Functional Assessment Stages* (FAST) (Reisberg et al. 1984). This scale has sixteen stages that correspond to the GDS. Daily function is evaluated.
- *Brief Cognitive Rating Scale* (BCRS) (Reisberg 1983). The BCRS evaluates five categories (axes):

  1) Concentration and Calculating Ability
  2) Recent Memory
  3) Remote Memory
  4) Orientation
  5) Functioning and Self-Help

Language and Communication Assessment

Evaluation of communication and language skills should always be an important component of a diagnosis of AD. For example, at the Callier Center for Communication Disorders (University of Texas at Dallas), Sandra Chapman and her colleagues are an important part of the diagnostic team that provides a differential diagnosis of dementia. Their work on macro and micro level analysis of discourse is revealing that subtle differences in discourse ability may be useful in distinguishing between normal aging, persons with AD, and persons with MCI (Chapman et al. 1999).

What should the assessment battery for dementia contain? Bayles and Kaszniak (1987) suggest measurement of:

- semantic memory
- inference/generalization
- discourse
- pragmatics, semantics, syntax, and phonology
- communication

A sample of tests available that meet this protocol include those specifically designed for use with patients with dementia:

- *Arizona Battery for Communication Disorders of Dementia* (ABCD) (Bayles and Tomoeda 1993). The ABCD is standardized for mild to moderately impaired persons. It evaluates mental status, verbal learning and memory, language comprehension and expression, and visuospatial construction. Subtests may be administered separately, depending on the information needed.

- *Functional Linguistic Communication Inventory* (FLCI) (Bayles and Tomoeda 1994). The FLCI evaluates communication in moderately to severely impaired persons. It assesses:
  1) greeting and naming
  2) writing
  3) following commands
  4) gesture
  5) sign and picture comprehension
  6) word reading and comprehension
  7) answering questions
  8) reminiscing
  9) pantomime
  10) conversation

- *Scales of Adult Independence, Language, and Recall* (SAILR) (Sonies 1999). The SAILR compares responses to family interviews and client interviews. It provides information on functional independence.

- *Severe Impairment Battery* (SIB) (Saxton et. al. 1993). This test analyzes attention, praxis, construction, naming, visuospatial perception, orientation, memory, and social skills.

Although not standardized for use with persons with dementia, some examples of tests which provide information about language abilities, semantics, phonology, and syntax can be found on the next page.

Measure	**Information**
Boston Diagnostic Aphasia Examination (BDAE) (Goodglass and Kaplan 1983)	expressive and receptive language
Western Aphasia Battery (WAB) (Kertesc 1980)	expressive and receptive language
Peabody Picture Vocabulary Test (Dunn and Dunn 1981)	semantics (comprehension)
Boston Naming Test (Kaplan, Goodglass, and Weintraub 1983)	semantics (confrontational naming)
Token Test (DeRenzi and Faglioni 1978)	syntax

Information about the client's reading ability is useful in planning possible intervention techniques. Reading can be assessed using:

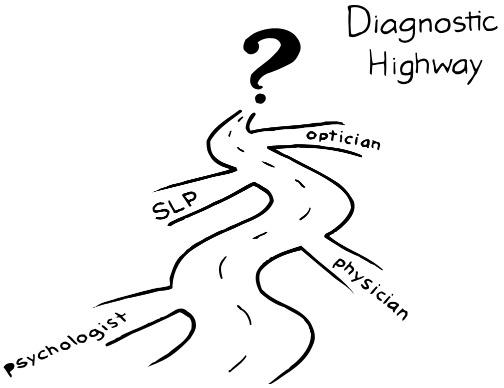
- Reading Comprehension Subtest of the ABCD
- Literacy Screening (page 36)

Informal assessment tools can provide diagnostic information and identify preserved abilities that can be used for therapy. The following forms are provided on pages 32-39.

- Discourse Checklist
- Literacy Screening
- Procedural Discourse Analysis
- Delayed Story Retelling Analysis

Summary

As we have seen, the road to a diagnosis of Alzheimer's disease can be a long and winding one for the persons affected and their families. People with the symptoms of dementia often merge onto the diagnosis highway at many different points. An SLP may be the first professional approached due to the pervasive language and communication problems experienced. Or an SLP may see a family after they have become exhausted (and at times, confused) by all the other experts they have seen. The information in this chapter can serve as a road map to families. SLPs are the perfect professionals to clarify diagnostic questions that arise.



Discourse Checklist

Name: ______________________ Date: ______________

Activity: __________________ Setting: ______________

Observation Time: __________ minutes

Instructions: Check the discourse skill observed.

Discourse Skill	**Yes**	**No**	**Sometimes**	**N/A**
Initiation				
Gains attention				
Greets others				
Asks questions				
For information				
For clarification				
For action				
Topic Maintenance				
Responds to questions				
Clarification				
Elaboration				
Eye Contact				
Turn-taking				
Easily interrupted				
Interrupts others				
Long speaking turns				
Nonverbal				
Proximity				
Too far				
Too close				
Nods head to acknowledge				
Gets attention (points, touches other)				

Comments: ____

____

____

Discourse Checklist (Sample)

Name: Katherine M.

Date: 3/15/00

Activity: Reminiscence group

Setting: seated around table

Observation Time: 15 minutes

Instructions: Check the discourse skill observed.

Discourse Skill	Yes	No	Sometimes	N/A
Initiation				
Gains attention			✓	
Greets others	✓			
Asks questions				
For information			✓	
For clarification		✓		
For action	✓			
Topic Maintenance				
Responds to questions			✓	
Clarification		✓		
Elaboration		✓		
Eye Contact			✓	
Turn-taking				
Easily interrupted				
Interrupts others	✓			
Long speaking turns				
Nonverbal				✓
Proximity				
Too far				
Too close				
Nods head to acknowledge				
Gets attention (points, touches other)				

Comments:

Procedural Discourse Analysis

Name: ______________________________ Date: ____________________

Instructions: Read the prompt provided (or one of your choosing). Record the patient's response. Identify the steps needed to correctly answer the prompt. Count the steps actually given by the patient. Analyze the ratio of nouns and verbs used. Assess fluency and word finding.

"Tell me how to make pancakes."

Patient's Response:

____

____

____

____

____

____

____

____

____

____

Ratio of steps included to actual number of steps: ____________

Fluency (circle): Good Average Fair Poor

Word Finding (circle): Good Average Fair Poor

(adapted from Chapman et al. 1999)

Procedural Discourse Analysis (Sample)

Name: James Davenport

Date: 5/20/00

Instructions: Read the prompt provided (or one of your choosing). Record the patient's response. Identify the steps needed to correctly answer the prompt. Count the steps actually given by the patient. Analyze the ratio of nouns and verbs used. Assess fluency and word finding.

"Tell me how to make pancakes."

Patient's Response:

Well, I never made pancakes too much. Here's what I do. You need [1] eggs, [2] flour, and [3] milk. [4] Put them in the pan . . . just a little bit. That would cook them, right? How many do you need? You need a thing, oh, a thing [5] to make them go over. You can [6] put them on a plate to eat.

Ratio of steps included to actual number of steps: 6/13

Fluency (circle): Good Average [✓ Fair] Poor

Word Finding (circle): Good Average [✓ Fair] Poor

(adapted from Chapman et al. 1999)

Literacy Screening

Instructions: Cut and fold the page where indicated to create a small book. Staple the left edge. Give the book to the client. Note if the client turns the pages. Record any comments the client makes which indicate he/she read the sentence. Note if one font size is easier for the client to read.

3

My dog's name is Spot.

2

I live in Sterk.

(Fold 1)

I have a lion.

4

My name is Nof.

(Fold 2)

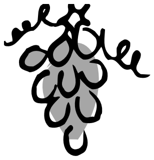
1

(Adapted from Bourgeois 1999)

Delayed Story Retelling

Instructions: Read this fable to the patient. Then have the patient immediately retell the story. Ask the patient to give the moral of the fable. Then have the patient retell the story after a 20-minute delay. Record the patient's responses on the analysis sheet, page 38. Details the client needs to remember are numbered. Count remembered details in each retelling.

The Fox and the Grapes



One afternoon a [1] fox was walking [2] through the forest and [3] spotted a bunch of [4] grapes hanging from a lofty branch.

[5] "Just the thing to quench my thirst," he said.

Taking a few steps back, the fox [6] jumped and just [7] missed the hanging grapes. [8] Again the fox took a few paces back and tried to reach them, [9] but still he failed.

[10] Finally giving up, the [11] fox turned up his nose and said, [12] "They're probably sour anyway" and [13] proceeded to walk away.

(The moral is listed for your use only, not the patient's.)

Moral: It's easy to despise what you cannot have.

Delayed Story Retelling Analysis

Name: ________________________________ Date: ________________

Immediate Retelling: ____

____

____

____

____

____

____

Details remembered: _____/13

Moral: ____

____

Delayed Retelling: ____

____

____

____

____

____

____

Details remembered: _____/13

(Adapted from Chapman et al. 1999)

Delayed Story Retelling Analysis (Sample)

Name: Sam R. Date: 7/3/00

Immediate Retelling: One day a [1]fox saw some [2]grapes on a tree. He wanted them 'cause he was [3]thirsty. He [4]jumped and jumped, but he [5]couldn't get them. He gave up because they were [6]sour and rotten. It's not good to leave fruit on the vine when it's time to harvest. Birds eat grapes.

Details remembered: 6/13

Moral: You should always keep trying.

Delayed Retelling: A fox wanted some, some, . . . they were a fruit. I don't know any more.

Details remembered: 1/13

(Adapted from Chapman et al. 1999)

> "Tis in my memory locked, and you yourself shall keep the key of it."
>
> -Shakespeare, *Hamlet*

Communication

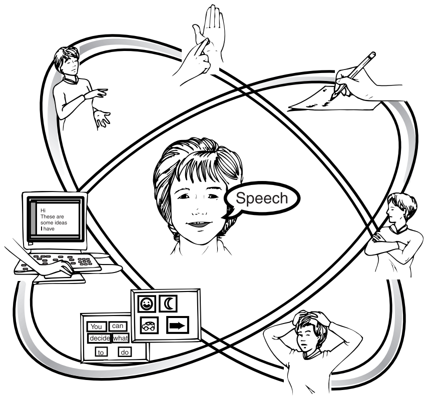
"Did you see those leaves? They turned into squirrels and flew away." The loss of language that is seen in people with AD is one of the most difficult to accept. The progressive deterioration from an occasional "lost word" in the early stages to the silence or gibberish in the final stages is frustrating to both the person with AD and the caregivers. It may seem that the language is locked with no key to be found. What families do not always realize is that although the verbal language is fading, there remain many other natural and effective ways for a person to both express his thoughts and understand what another is trying to say. The key for understanding is communication.

There are several important concepts to remember when considering communication:

- Two people are needed for communication: the person with the message and the person who receives the message. The two participants are constantly switching roles. One sends, the other receives and then the roles are switched.

- The sender has a reason to communicate. This is called the intent, the function, or the "why" of the message. We communicate to share information, to ask for something, to reject something, and to take part in social interactions. These reasons to communicate are seen even in very young children with only emerging language (Bruner 1981) and continue throughout a person's life.

- The sender has a way to communicate (the form of communication). Speech, gestures, sign language, and writing are forms that are familiar to everyone, but these are not the only ways to communicate. Vocalizing, looking, pointing, giving, photographs, line drawings, crying, whining, head or shoulder shaking, grimacing, aggression, and tantrums are all forms of communication.



Reprinted with permission from K. Harrington, *For Parents and Professionals: Autism in Adolescents and Adults*, East Moline, IL: LinguiSystems, Inc. 2000.

A breakdown in communication is often at the root of problems experienced by caregivers and those with AD. Communication breakdowns can be at best, irritating, and at worst, catastrophic. Situations that are considered communication breakdowns include repetitive talking, resistance or refusal to a request, crying out, screaming, moaning, and other catastrophic events (Santo Pietro and Ostuni 1997). Chapter Six, pages 51-58, discusses communication breakdowns in more detail.

Good communication techniques can often prevent or avert a communication breakdown. Remember, both the person with AD and the communication partner have these multiple ways available to them to send information.

In the early stages of the disease, the person with AD can help with communication. He probably knows the easiest listening and understanding situations. Noisy or distracting environments should be avoided. Helping the communication partner by saying, "I don't understand" or providing clues such as, "Say it again, please" or "Slower, please" helps keep the communication going.

As the disease progresses, the caregiver needs to take a larger role in the communication event. The caregiver can interpret nonverbal communication, change the way he talks, and/or change the environment to aid communication.

Talking Techniques to Aid Verbal Comprehension

One of the easiest ways to help a person with AD understand the conversation is to use people's names or nouns instead of pronouns. Compare the differences in these two conversation samples:

- "I couldn't believe it! She told her boss that he was out of line when he asked her to work late."
- "I couldn't believe it! Mary told her boss, Mr. Jones, that he was out of line when Mr. Jones asked Mary to work late."

Substituting the name of the individual for the pronoun clarifies the subjects of the conversation. Along the same lines, it helps to substitute the name of an object for the pronoun *it*:

- "Bring me the cup" is easier to understand than "Bring it to me."

Another way to aid comprehension is to use simple, less abstract vocabulary:

- "I was surprised! Mary told her boss, Mr. Jones, that he was wrong when Mr. Jones asked Mary to work late."

Easier still is to use short, simple sentences instead of long, complex sentences to express the same ideas:

- "Mr. Jones told Mary to work late. Mary was mad. Mary told Mr. Jones he was wrong. I am surprised!"

Using a different example, remember that sentences with an active voice are easier to understand than sentences with a passive voice:

- “The car hit the dog.” (active)
- ”The dog was hit by the car.” (passive)

One of the most difficult parts of understanding a flowing conversation between two or more people is the way conversation naturally shifts from topic to topic. A communication partner can inform the person with AD of the topic (e.g., “Dad, we’re talking about the beach trip.”).

Comprehension Techniques

- names, not pronouns
- concrete vocabulary
- short, simple sentences
- active, not passive voice
- state the topic of conversation

(adapted from Rau 1993)

Many people with AD can (and want) to continue to take part in conversations. Stating the topic or reminding them of the topic reduces the chances of an embarrassing off-topic comment and increases the chances of continuing conversation.

Talking Techniques to Aid Verbal Expression

Communication partners can also structure their language in a way to increase the verbal expression of a person with AD. The form of the question can have a marked effect on the response. Which question is easier to respond to?

- “What do you want for breakfast?”

- “Do you want cereal or toast for breakfast?”

An either/or question limits the overwhelming range of responses to two. Similarly, the format of yes/no questions provides information which scaffolds the response of the person with AD to a correct answer.

- “What did you do last night?” (harder)

- “Did you go to the movies last night?” (easier)

Another way to use questions to aid verbal expression is to ask relevant questions to keep the person with AD from losing track of what he is saying.

- “I went to coffee and Sue was there…those flowers…glory! Yesterday I sure did…”

Relevant question: “Did you have coffee at the center?”

- “I had coffee at the center with Sue and Jill.”

Relevant question: “Is Sue retiring from work?”

- “Yes, Sue is retired now.”

Being the communication partner can be a challenging dance. The partner must balance between allowing enough time for the person with AD to process the previous statement or question and reminding the person of the topic at hand. Count to 10 saying, “1 Mississippi, 2 Mississippi, . . . 10 Mississippi.” Ten seconds can seem an eternity in a conversation, but that is the amount of time that the person with AD may need to process before speaking.

Other techniques such as a topic reminder, a summary, or a rephrase of the message heard can bring the speaker back to the topic and reduce confusion to both communication partners.

Finally the communication partner needs to realize the joy of reminiscence. Reminiscence (sometimes called recollection or remembrance) is when a person looks back at past events in his life (Harris 1998). Persons with AD who can no longer discuss what happened yesterday or an hour ago due to short term memory loss can still take part in conversation about events that happened long ago.

Reminiscence is an important tool for another reason. Caregivers can record the stories told by the person with AD during reminiscence sessions early in the disease. In the later stages, caregivers can use these same stories as possible conversation topics or they can simply read the stories to the person with AD when words are no longer possible.

Time spent visiting with a person in the late stages of the disease can be difficult for families to endure because of the silence and non-responsiveness of their loved one. Reading favorite stories from the life of the person with AD helps to fill the silence and creates a time of sharing.

Expression Techniques

- Say it a different way.
- Allow processing time.
- Topic reminders.
- Relevant questions.
- Y/N or either/or questions.
- Reminisce!

(adapted from Rau 1993)

Nonverbal Communication

Nonverbal communication such as body language and expression (i.e., how things are said; the pitch, volume, and intonation) account for approximately 93% of any message (Devito 1993).

Other nonverbal signals include:

- facial expressions: What emotion is showing on the face?
- body position: How close are the communication partners standing to each other? Are they at eye level or is one person above or below the other person?
- body orientation: Are the partners facing each other or turned away?
- gesture: Are there hand or arm movements with the message? How many?
- touch: Is one partner touching the other with the message? Is it gentle? How expressive are the gestures?

(adapted from Santo Pietro and Ostuni 1997)

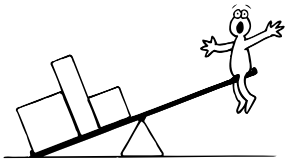
Mace and Rabins (1989) encourage caregivers to supplement their speech with body language (e.g., pointing and nodding).

Environmental Changes to Aid Communication

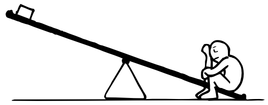
Communication does not happen in empty space. We are all constantly surrounded and bombarded by sensory information coming in from the environment around us. When we are healthy, we are able to filter out what is unimportant in the incoming signal and zero in on what is important.

This skill is increasingly difficult for the person with AD as the disease progresses.

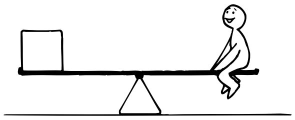
The environment around people with AD may directly influence communication. Too much stimulation can become very stressful; but too little stimulation can have a negative effect also. The person with AD is in the middle of a seesaw. If the balance is correct, he will be the most successful. Too much stimulation and the person with AD slides into an overwhelming atmosphere.



Too little stimulation and the person with AD slides into isolation and withdrawal.



The Perfect Balance



Evaluating the Environment

If communication breakdowns are reported, it is helpful to re-evaluate the environmental stimulation occurring. Environmental factors can be positive (smell of bread) or negative (a blaring radio). Negative environmental factors can increase stress and interfere with communication. Positive factors, on the other hand, can calm or decrease stress and at times, facilitate communication. Whether the person with AD is at home or in a facility, these factors need to be considered.

Environmental checklists for use at home or in a facility are found on pages 47-50. The questions are organized by these factors in the environment:

- visual
- auditory
- tactile/olfactory

Visual

In addition to normal changes in the eye which occur with aging, people with AD may have problems with depth perception (Calkins and Chavitz 1996). They may also have difficulty understanding patterns, signs, words, and objects that they see. It has been suggested that visual problems account for some of the disorientation seen in people with AD (Tetewsky and Duffy 1999).

First consider the individual with AD. Has he had an eye examination within the last two years? If the person with AD has glasses, does he wear them? Visual acuity should always be addressed.

Environmental factors which contribute to visual problems include glare, reflections, insufficient light, uneven light, insufficient visual contrast between two items (e.g., the cup on the counter, the printed word on a page), and visual clutter.

- Glare is caused when a direct source of light (e.g., sunlight, artificial light) bounces off a hard surface (e.g., vinyl floors, tabletops, windows) and restricts vision. Glare can be controlled by adjusting the light source. For example, you can adjust sheers, curtains, shades, or blinds on windows; adjust interior lights at the switch; or use different light wattage. You can also control glare by changing the reflective surface (e.g., adding tablecloths to shiny tables).
- Hard shiny surfaces also contribute to reflections. Windows can create reflections when the light inside is brighter than the light outside.

Reflections from windows and mirrors can be very distracting to a person with AD. The same treatments that help control glare in a room can reduce window reflections. You might consider covering a mirror or removing it from the wall.

- Insufficient light in a room can cause dark, shadowy areas in the corners of rooms. Some of the confusion caused in sundowning could be the result of too little light in a room as the sun goes down. (Sundowning refers to the increased restlessness and/or agitation in a person with AD which is frequently seen in late afternoon or early evening.) Placing several lamps around a room rather than relying on one central light can reduce shadows. Halogen lamps with 300- or 500-watt halogen bulbs aimed at the ceiling increase the amount of non-glare light in a room (Calkins and Chavetz 1996).

- Two-color factors are also important in the visual environment. Why are school busses yellow and stop signs red? We know that people more easily see red and yellow.

  Color contrast between objects occurs when the outline of an object stands out against its background due to a difference in color. Monotone colors in a room reduce the outlines that can be seen between objects. A white plate against a red or other dark cloth at the table is easier to see than a dark colored plate against a dark tabletop.

  Contrast is also a factor in written or visual prompts. The printed message should strongly contrast against the paper it's written on. A reminder note written in pencil will be more difficult to read than the same note written with heavy, black lines. Making the light in a room brighter can also help increase the contrast.

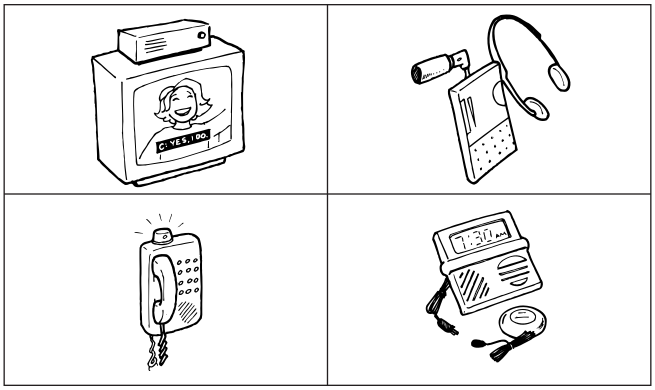
Visual cues to aid communication are discussed more completely in Chapter 7.

Auditory

As people age, their auditory acuity diminishes. This is no different for people with AD. In fact, people with dementia have a higher prevalence of hearing loss than normally aging individuals (Weinstein 1995). In addition, people with AD may have problems processing speech (Grimes 1995). A person who uses hearing aids prior to the onset of AD should continue to wear them, just as a person would continue to wear glasses after the onset of AD.

What about a suspected hearing loss in a person with AD? A person with AD can take part in an audiological evaulation with modifications (Weinstein 1995).

SLPs should be aware of the possibility of hearing loss in people with AD and that the use of personal hearing aids is not always successful in newly diagnosed hearing losses. However, many other options are available to help the person with hearing loss. Assistive listening devices can amplify sound, provide close captioning, or add visual or tactile cues to sound. Some examples of assistive listening devices are pictured below.



Environmental modification can aid auditory comprehension even if there is no diagnosed hearing loss. Background noise from radios, TVs, and appliances should be reduced or controlled. Sound bounces off hard walls and floors and can create a difficult listening situation. Materials such as carpeting on the floor or acoustic tiles on the walls or ceilings can reduce sound reverberations.

Tactile/Olfactory

Things you can touch or that touch you affect communication both negatively and positively. An unpleasant feeling fabric against the skin or an itchy tag on the back of the neck may be the cause of unhappiness in a person with AD. Conversely, a firm, strong touch alerts a person that you are near and ready to communicate. It is better to touch the person once you are in sight. An unexpected touch from behind can startle the person and provoke a negative reaction. A light touch is also sometimes unsettling.

Things you can touch help support language comprehension and prompt verbal expression in therapy sessions. Objects to touch can also be used in natural communication settings. For example, a cup can be a prompt that it is time to get a drink; a basket of clean towels can be a prompt that it is time to fold the laundry.

Things you can smell can have either a negative or positive effect on communication. Unpleasant odors can distract or upset. Some smells have very strong associations for people and can evoke memories. A sensory stimulation program for treatment of persons with late stage dementia includes the use of aromas (Whiteside and Zimmerman 1998).

Objects to hold and objects that have aromas with strong associations to events have been suggested whenever possible to use with the Conversation Topics, pages 102-155.

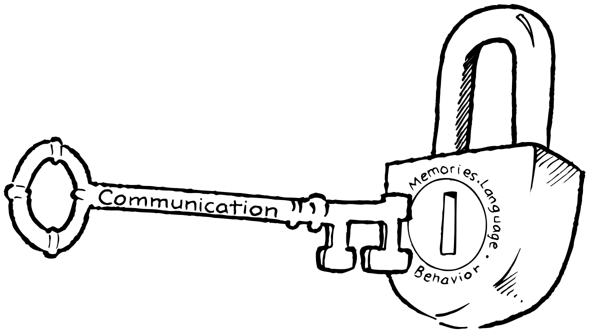
The Communication Key

The benefits of good communication skills and successful communication partners for people with AD are immeasurable. An ability to communicate enables people with AD:

- to maintain a sense of identity.
- to continue to take part in their own care, through the ability to give and receive information.
- to relieve loneliness and express fear and anxiety.
- to become a good communication partner for others.
- to increase cognitive stimulation for those with AD.

(Lubinski 1995)

Communication skills for persons with AD and their caregivers is a key to unlocking some memories, increasing verbal comprehension and expression, and understanding problem behaviors.



Home Environmental Checklist

Room ____________________________________ Date ___________________________

	Yes	No
Visual		
Is there glare from windows or lightbulbs without shades?		
Are there dark corners in the room?		
Is there more than one light source in the room?		
Are there curtains on the windows?		
Is there contrast between the chairs and floor, plates and table?		
Are rooms, drawers, and cabinets labeled with words or pictures?		
Is there pleasant visual stimulation at eye level?		
Auditory		
Is there too much noise from TVs or radios?		
Is the floor carpeted to muffle noise?		
Is it a noisy time of year? (e.g., extra people or children in the home)		
Is there noise from appliances? (e.g., dishwasher, washing machine)		
Is there outside noise? (e.g., lawnmower, leaf blower)		
Tactile/Olfactory		
Are hazardous items removed?		
Are appropriate items to handle available?		
Are there a variety of textures in the room?		
Are room odors pleasant?		
Space		
Is furniture arranged to support communication?		
Are there quiet places for conversation?		

Ways to Improve the Communication Environment:

____

____

____

____

Home Environmental Checklist (Sample)

Room linving room

Date 10/04/01

	Yes	No
Visual		
Is there glare from windows or lightbulbs without shades?		✔
Are there dark corners in the room?	✔	
Is there more than one light source in the room?		✔
Are there curtains on the windows?	✔	
Is there contrast between the chairs and floor, plates and table?	✔	
Are rooms, drawers, and cabinets labeled with words or pictures?		✔
Is there pleasant visual stimulation at eye level?		✔
Auditory		
Is there too much noise from TVs or radios?		✔
Is the floor carpeted to muffle noise?	✔	
Is it a noisy time of year? (e.g., extra people or children in the home)		✔
Is there noise from appliances? (e.g., dishwasher, washing machine)	✔	
Is there outside noise? (e.g., lawnmower, leaf blower)		✔
Tactile/Olfactory		
Are hazardous items removed?	✔	
Are appropriate items to handle available?	✔	
Are there a variety of textures in the room?	✔	
Are room odors pleasant?	✔	
Space		
Is furniture arranged to support communication?	✔	
Are there quiet places for conversation?	✔	

Ways to Improve the Communication Environment:

Need more light in living room (2 more lamps?)

Shut kitchen door when running dishwasher.

Put pictures of grandkids on wall by couch.

Facility Environmental Checklist

Name/Facility ____________________ Date ____________

Visual	**Yes**	**No**
Is there glare from windows or lightbulbs without shades?		
Are floors and furniture contributing to glare?		
Is there diffused lighting in the area?		
Can the light source be adjusted?		
Are there curtains on the windows to reduce reflections?		
Is there contrast between chairs and floor, plates and table?		
Do pictures, colors, or patterns label different areas?		
Is printed information at eye level and well contrasted?		
Is there pleasant visual stimulation at eye level?		
Auditory		
Is there too much noise from TVs or radios?		
Is there too much noise from institutional appliances? (e.g., ice machines, floor buffers)		
Do hard surfaces (e.g., floors, walls, windows, ceilings) have any acoustic treatment to reduce sound?		
Are PA systems or alarms too loud?		
Is there pleasant auditory stimulation available? (e.g., appropriate music, tapes of bird songs, ocean noises)		
Are there quiet areas for conversation?		
Tactile/Olfactory		
Are hazardous items removed?		
Are appropriate items to handle available?		
Are there a variety of textures in the room?		
Are room odors pleasant?		
Space		
Is furniture arranged to support communication?		
Are there quiet places for conversation?		
Is there enough seating for visitors?		
Are activity areas accessible?		

Ways to Improve the Communication Environment:

____

____

____

Facility Environmental Checklist (Sample)

Name/Facility ______________________ Date ____________

	Yes	No
Visual		
Is there glare from windows or lightbulbs without shades?	✓	
Are floors and furniture contributing to glare?	✓	
Is there diffused lighting in the area?	✓	
Can the light source be adjusted?	✓	
Are there curtains on the windows to reduce reflections?		✓
Is there contrast between chairs and floor, plates and table?	✓	
Do pictures, colors, or patterns label different areas?		✓
Is printed information at eye level and well contrasted?	✓	
Is there pleasant visual stimulation at eye level?	✓	
Auditory		
Is there too much noise from TVs or radios?	✓	
Is there too much noise from institutional appliances? (e.g., ice machines, floor buffers)		✓
Do hard surfaces (e.g., floors, walls, windows, ceilings) have any acoustic treatment to reduce sound?		✓
Are PA systems or alarms too loud?	✓	
Is there pleasant auditory stimulation available? (e.g., appropriate music, tapes of bird songs, ocean noises)	✓	
Are there quiet areas for conversation?	✓	
Tactile/Olfactory		
Are hazardous items removed?	✓	
Are appropriate items to handle available?	✓	
Are there a variety of textures in the room?	✓	
Are room odors pleasant?	✓	
Space		
Is furniture arranged to support communication?		✓
Are there quiet places for conversation?	✓	
Is there enough seating for visitors?		✓
Are activity areas accessible?	✓	

Ways to Improve the Communication Environment:

Put in request to maintenance for curtains or shades in sitting area.

Designate "TV off" times. Talk to Mr. R about problems noted under auditory.

Chapter Six

> "Human speech is like a cracked kettle on which we tap crude rhythms for bears to dance to, while we long to make music that will melt the stars."
>
> -Gustave Flaubert, *Madame Bovary*

Communication Breakdowns

Many, many sources discuss the "behavior problems" of people with AD. News stories of people with AD who are lost for days are common. Stories of people with AD acting violently toward caregivers are whispered. The average person would tell you that a person with AD "acts crazy" and it is this common belief that adds fear to the diagnosis of AD. Is the person with AD who repeats that someone is stealing her money demonstrating the paranoia of AD, or is she actually expressing fear at all she has already lost? What is seen as "behavior problems" may actually be a form of communication. To understand the message, the communication partner needs to examine the message or the intent of the communication.

Many of the behavior problems that are so hard to understand are the result of feelings we understand only too well.

> "Everybody is afraid. People try to erase children's fears by reading fairy stories, and the minute the child goes to school she is afraid to show her parents a paper with a bad mark. Fear of water. Fear of fire. Fear of animals. Fear of the dark. Fear of choosing the wrong career — all these fears became like the notes of a muted, tragic symphony."
>
> (adapted from Simenon 1992)

Not only fear, but anger, grief, boredom, anxiety, and loneliness are the messages being communicated. Gray-Davidson (1999) suggests that we should not use the words of the health profession: *paranoia*, *combative*, *perseveration*, and *hallucination*. These words get in the way of our understanding the message. She suggests rather that we replace:

- *paranoia* with *fear*
- *combative* with *angry* and *scared*
- *depressed* with *sad, grieving,* or *lonely*
- *delusional* with *misinterpreting*
- *agitated* with *fearful*
- *compulsive* with *underoccupied*
- *preseverating* with *repeating*

- *wandering* with *walking*
- *hallucinating* with *hearing and vision misperceptions*

Other factors can cause a communication breakdown. Hodgson (1995) reminds us that communication can also be disrupted by illness, dehydration, improper diet, reactions to medications, overmedication, and pain.

Many of the communication keys discussed in Chapter Five can help prevent communication breakdowns. In this chapter we will examine specific breakdowns, hypothesize about the intended message, and make suggestions to make the communication attempt successful. We have already discussed the keys of simplification, reducing choices, multiple cueing, correcting sensory impairment, and optimal environmental stimulation. In addition, most of the suggestions listed here follow the principals of nonconfrontation, reinforcement, minimizing anxiety, and distraction (Weiner et al. 1996).

Often careful observation of the behavior can reveal the cause of the communication breakdown. An analysis can indicate the trigger for the communication breakdown. The time of day, the environmental setting, and the activity can all be possible causes of a communication disruption. The steps to analyzing the communication breakdown are provided in the Communication Breakdown Analysis (CBA) form on page 57.

Anxiety

Anxiety is a state of uneasiness and distress about future uncertainties. This feeling is often a trigger for the other communication breakdowns. It can occur when the environment is overwhelming. Anxiety often underlies the repeated questions seen with AD. A mother who repeats, "When are we going to the doctor?" over and over cannot remember that she has asked the question before, but she is also expressing anxiety over the upcoming trip.

Communication Tips:

- Distract to an activity (using visual prompts).
- Don't tell about future events too far ahead.
- Analyze the environment during episodes of anxiety.

Apathy/Withdrawal

Apathy is seen when the person with AD loses interest in a favorite activity or withdraws from social situations. Sometimes this is a reaction to a feeling of abandonment when a person with AD moves to a care facility.

Communication Tips:

- Structure activities and provide assistance (See Activities, pages 67-68).

Catastrophic Reactions

Catastrophic reactions are when the person with AD overreacts unexpectedly with angry, wild outbursts. These could be caused by too much or too little stimulation or the caregiver being too hurried and forceful. They are frightening to the caregiver. This is one time that the caregiver needs to take specific steps. Feldt (1990) recommends using the Five R's:

- Remain calm.
- Respond to feelings.
- Reassure.
- Remove yourself.
- Return later.

A catastrophic reaction is a communication breakdown. Some of the communication tips listed here will help the caregiver keep a catastrophic breakdown from happening.

Communication Tips:

- Use the CBA form, page 57, to analyze the cause.
- Distract before the reaction occurs (using visual prompts).
- Avoid confrontations which can provoke catastrophic reactions.

Denial

An angry denial can be the response when mistakes are pointed out. It may also be expressing a denial of the losses that occur with AD.

Communication Tips:

- Distract (using visual prompts).
- Ignore.
- Avoid arguing.

Disruptive Vocalizing

This form of communication is seen in the late stage of the disease. Yelling, moaning, and babbling are some of the forms. The message may be that the person is feeling ill or uncomfortable.

Communication Tips:

- Analyze the environment.
- Use the CBA form, page 57.
- Consider the possibility of a medical problem, pain, or an illness.
- Use comforting sensory stimulation.

Depression

What is seen as depression in persons with AD may be apathy and withdrawal (see above) or may actually be depression.

Communication Tips:

- Refer for a medical evaluation to determine if it's true depression (medical treatments are available).
- Use the CBA form, page 57, to determine if there is a pattern to the depressive symptoms.
- Listen to any feelings expressed.
- Reassure.

Delusions

A delusion is an incorrect belief. A grandmother who believes her neighbors are a cult that hold seances at night (and they truly aren't!) is experiencing a delusion. These can often be frightening to the person with AD.

Communication Tips:

- You cannot convince a person with AD their belief is incorrect. Do not argue.
- Accept the statement.
- Reassure.
- Distract (using visual prompts).

Hallucinations

Similar to delusions, hallucinations are misinterpretations of sensory input of sight, sound, smell, and/or touch. Certain medications and illnesses, particularly with fever, can sometimes cause hallucinations. Sometimes hallucinations are frightening to the person with AD. Or sometimes the person with AD might calmly report seeing a little man on the ceiling fan as a matter-of-fact with no sign of fear and anxiety.

Communication Tips:

- Refer for a medical evaluation if you suspect medication or an illness is the cause.
- Do not deny its existence.
- Reassure.
- If frightened, you may need to use the Five R's (See page 52.)
- Try to orient to reality: "I am here" or "You're okay."

Incontinence

Incontinence, the loss of bladder and/or bowel control, is usually seen in the late stage of the disease. If it occurs earlier, it may be the sign of a medical problem or the result of a communication breakdown.

Communication Tips:

- Refer for a medical evaluation if experienced early in the disease.
- Change the environment (e.g., a label or picture symbol on the door, a night light in the bathroom).
- Add structure (e.g., suggest the person with AD go the bathroom every two hours). Reduce fluid intake in the evening.
- Use visual schedule "Use the Bathroom" on page 99.

Irritability

Physical or verbal expressions of irritability may be caused by fatigue, frustration (e.g., caused by lack of skill for an activity or word-finding problems), or a general feeling that something is wrong.

Communication Tips:

- Person with AD may benefit from a peer support group.
- Reassure.
- Encourage.

Paranoia/Suspiciousness

Paranoia is the fear that someone is "out to get you." For persons with AD, this is expressed as, "He's stealing my money," "Someone stole my car," or "She stole my jewelry!" This paranoia or suspiciousness is the expression of a fear of the many losses that are a reality (e.g., the loss of memory, the loss of language, the loss of skills, the loss of the ability to drive). These very real losses can lead to a feeling of fear or vulnerability. Sometimes it is also the result of environmental overstimulation or changes in the routine.

Communication Tips:

- Avoid arguing.
- Express empathy.
- Use the CBA form, page 57, to analyze possible environmental causes.

Pilfering and Hoarding

Pilfering (i.e., stealing) and hoarding (i.e., gathering and saving large quantities of objects or food) are communication breakdowns often seen in care facilities, but can also occur in homes. One grandmother had an enormous supply of bags of candies hidden away in her bedroom. Hoarding is an expression of fear and insecurity. It is related to pilfering, because the person with AD may have to steal things to hoard. Although these behaviors are difficult to prevent, they generally disappear later in the disease.

Communication Tips:

- Keep important items in a safe place.
- Don't argue or scold.
- Analyze the environment in a care facility. Are doors to private rooms labeled to reduce confusion?

Repetitive Requests or Statements

This communication breakdown is reported by caregivers as one of the most annoying. Memory problems contribute to this, but they could also be an expression of a feeling such as boredom, insecurity, and loneliness.

Communication Tips:

- Use external memory aids. (Chapter 7, pages 60-62.)
- Distract (using visual prompts).
- Give more attention.

Resistance or Refusal

Resistance or refusal to do a task (e.g., bathing or dressing) could be an expression of fear and insecurity. It could also be caused by a communication breakdown if the person does not understand the request.

Communication Tips:

- Use visual aids or body language with the request.
- Use Comprehension Communication Techniques (Chapter 5, pages 41-42).
- Reassure.
- Analyze the environment with the CBA form, page 57.
- Be flexible.

Restlessness/Agitation

Restlessness and agitation is seen as fidgeting, pacing, fussing, wringing hands, and rummaging. It is related to wandering and may have the same communicative function. These activities may be an expression of anxiety or fear. Memory problems may contribute to the restlessness (i.e., the person is looking for something and can't remember what it is). It can also be an early sign of a catastrophic reaction for some people. (See catastrophic reactions on page 52.)

Communication Tips:

- Distract (using visual prompts).
- Use the CBA form, page 57, to analyze the problem.
- Provide an appropriate activity. (See Activities in Chapter 7, pages 67-68.)

Shadowing

Caregivers sometimes report that the person with AD is "clinging," "hovering," following them from room to room, and/or standing close while the caregiver is working. It is an expression of insecurity, annoying to the caregiver, but also a passing phase.

Communication Tips:

- Reassure.
- Distract (using visual prompts).
- Give more attention.

Sundowning

Sundowning refers to a worsening in a person's behavior in the evening or night time. The person with AD is more agitated. Wandering or pacing can increase. Sometimes there is increased disorientation. Sundowning could be expressing tiredness, boredom, fear, loneliness, hunger, or be the result of the stress that builds up during the course of the day.

Communication Tips:

- Use the CBA chart, page 57, to analyze the environment.
- Provide a mid-afternoon snack.
- Give more attention in the evening.
- Distract (using visual prompts).
- Analyze the sleep pattern.

Wandering

The cause of wandering is poorly understood. It may be an expression of the anxiety and fear seen in restlessness (above) or the result of disorientation. It is a problem if the person with AD wanders away from a safe, supervised environment.

Communication Tips:

- Distract (using visual prompts).
- Provide activities. (Chapter 7, pages 67-68.)
- Make doors secure with locks.
- Paint or tape grids in front of doors. Persons with AD sometimes perceive the pattern as unsafe to cross.
- Enroll in the Safe Return Program. (Contact the Alzheimer's Association for details.)

The Communication Breakdowns and Communication Tips were adapted from Gray-Davidson 1999, Hodgson 1995, Kuhn 1999, Rau 1993, Santo Pietro and Ostuni 1997, Weiner, et al. 1996, and personal notes from an Alzheimer Association Caregivers Class.

Communication Breakdown Analysis

Name: ______________________________ Date: ________________

Setting: ____

Activity: ____

1. Describe the communication breakdown: ______________________

____

2. Describe what happened just before the communication breakdown (antecedent): _______

____

3. Describe what happened just after the communication breakdown (consequence): _______

____

Observe:

Environment
Light?
Noise?
Odors?
Temperature?

Activity
Waiting?
Unstructured?
Transition?
Specific activity?
Mealtime?

Antecedent
Difficult activity?
Wants attention?
Wants privacy?
Requesting?
Denying?

Consequence
Attention?
Redirection?
Verbal response (positive)?
Verbal response (negative)?
Physical Touch?
Ignored?

Analyze: ______________________________________

____

____

Communication Breakdown Analysis (Sample)

Name: Matthew C. Date: 4/08/01

Setting: lobby area

Activity: waiting for van to go home

1. Describe the communication breakdown: loud, disruptive, and repetitive shouting of "I want to go home."

2. Describe what happened just before the communication breakdown (antecedent): started pacing

3. Describe what happened just after the communication breakdown (consequence): ignored, but got louder and louder

Observe:

Environment Okay
Light?
Noise?
Odors?
Temperature?

Activity
Waiting? ✓
Unstructured? ✓
Transition? ✓
Specific activity?
Mealtime?

Antecedent
Difficult activity?
Wants attention? ✓
Wants privacy?
Requesting?
Denying?

Consequence
Attention?
Redirection?
Verbal response (positive)?
Verbal response (negative)?
Physical Touch?
Ignored? ✓

Analyze: This was a long time to wait for the van. Try: 1)visual prompt "The van comes at 5:00." 2) Keep Mr. C in activity area at table task until closer to time to go. 3) Develop memory book of photos for him to look at during unstructured wait times.

Chapter Seven

> "The past is hidden . . . in some material object . . .
> which we do not suspect. And as for that object, it depends on
> chance whether we come upon it or not . . .
> And suddenly the memory returns."
>
> -M. Proust, *Remembrance of Things Past*

Intervention

As recently as 1993, speech-language pathologists (SLPs) did not always accept patients with AD. One family reported that when they requested help for their mother at the nursing home, the SLP told them that she didn't work with AD patients because it was a progressive disease and nothing could be done to help. Fortunately for families grappling with the disease now, we have a better understanding of treatments that can be used during the course of the disease to ease the frustrations of caregivers and patients. Recent work done by talented SLPs is suggesting strategies for intervention. As Bayles and Tomoeda (1999) tell us, "the key to devising successful treatments for dementia patients is to reduce demands on impaired memory and capitalize on spared memory systems."

This chapter covers:

- external memory aids and strategies effective in the earlier stages of the disease
- therapy strategies to help patients in the middle stage learn small bits of new information to help improve their quality of life
- strategies for helping with swallowing and eating problems seen in patients with AD
- conversation topics for cognitive-linguistic therapy on topics such as sports, family experiences, and historical events
- social reminders for families experiencing common social problems
- activities of daily living and suggestions to structure and modify them to improve the quality of life for people with AD, including some visual prompts for self-care activities

External Memory Aids

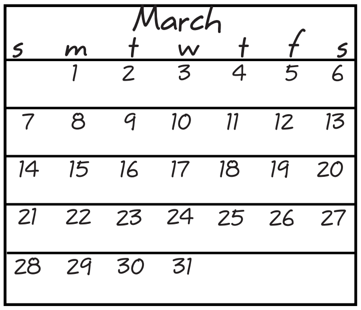
We all use external memory aids (e.g., calendars, shopping lists, memos, diaries). According to Hodgdon (1998), visual tools such as these can help people who have difficulty shifting and maintaining attention and difficulty blocking out background noises. These aids can help people in the early stage of AD, too, especially if the person with AD has used them in the past. Research over the last 15 years shows that memory wallets, memory books, memory cards, and other forms of written and picture reminders can help people even in the later stages of AD (Bourgeois 1990, 1991, 1994).

Reminder notes

Reminder notes can be used by the person with AD or the caregiver, but beware of the Post-it note curse! Too many notes left in too many different places can be very confusing. One family reported that a single line on an index card helped curtail repetitive questioning (e.g., "We're meeting Jane for lunch today"). Reminder notes should be discontinued if they confuse the person with AD.

Calendars

A monthly calendar in a prominent location can also be a good memory aid. But not all calendars are created equal. One family tells the story of purchasing a beautiful calendar with pictures of gardens, but the calendar was tightly wrapped with cellophane. Once they unwrapped it at home, they realized it wouldn't help Grandma because the monthly pages looked like this:



March

s	m	t	w	t	f	s
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

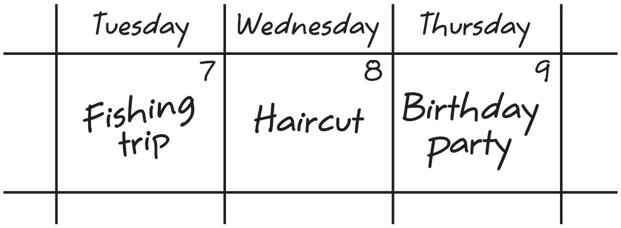
Instead a calendar should be large with a clearly defined box for each day. Although the calendar below has a clear grid and large numbers for the days, the decorative design makes it a complicated page to read.

March

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

The location of the calendar is important also. It should be in clear view and in a common, well-lit area. Another family that I worked with assured me that they had a calendar. When I visited the home, I found it folded up and stuck in a letter holder by the computer. Each day was covered with tiny, penciled activities. This calendar was functional for the caregiver, but not for the person with AD.

Monthly activity calendars are found in almost every nursing home or assisted living center. Although these calendars are often large and prominently placed, they are of little use for people with AD if they are filled with too much writing and too many activities. To be useful, calendars used at home or in a facility should have only personal, meaningful information.



	Tuesday	Wednesday	Thursday	
	7 Fishing trip	8 Haircut	9 Birthday party	

Establish a routine of directing the person with AD to the calendar when there are questions about day, date, month, or upcoming activities. Then the calendar can be used well into the disease and help alleviate repetitive questioning. Taping a strip of white paper over each week as it passes may also help prevent confusion. A daily calendar can be as simple as:

Hello!
Today is Tuesday.
February 15, 2004

Schedules
Schedules are often seen in nursing facilities, but seldom in homes. In both places a personal daily schedule can:

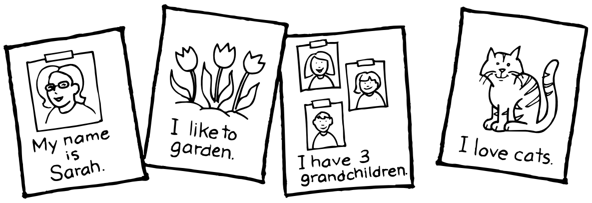
- reassure the person with AD about what is happening today
- be used to redirect and answer repetitive questions about daily activities
- remind and help calm the person about unexpected changes in the schedule

As shown on pages 96-100, schedules can cover entire days, special events, and activities the person with AD is having problems taking part in.

Journals or Diaries
If a person with AD is in the habit of keeping journals or diaries, then that is a skill he can continue as long as possible. There are support groups for people with AD that use journal entries kept by the members of the group. Every week the members write on a given topic and then share their entries with each other.

Labels
Labeling cabinets and drawers with large, clear lettering can help the person with AD continue to find things and function in an environment. Labels can also be used on family photographs and hung on walls (e.g., "This is my daughter, Cindy."). Adding brief text to the actual pictures in this way is often more useful than a large cumbersome photo album that stays in a drawer.

Memory Wallets and Memory Books
Memory wallets were first designed to describe personal information about the person with AD (Bourgeois 1990). The patients read the sentences, helping them engage in conversation. Memory wallets or books can take many different forms. Typically there is one sentence of personal information per page supported by a picture. These aids can be as small as index cards clipped together or as large as a notebook. Memory wallets are most effective when attached to the person with AD with a clip, necklace, or pin. A typical memory book might have the following information:



External memory aids are only useful if the person with AD uses them. Memory books may not be used if the person with AD can no longer gain information from reading.

Bourgeois (1999) described an informal strategy that she uses to assess ability to read. She puts two sets of sentences (each set with a different size of print) in a mock memory book. One sentence is on each page. She gives it to the person with AD and watches to see if he turns the page and if he makes a comment after each sentence. Then she knows he has read it.

Another common problem is that the person with AD does not remember to use the memory aid. The errorless learning and spaced retrieval techniques described below can be used to teach the person with AD to look at and use memory aids.

Errorless Learning and Spaced Retrieval

These two techniques strengthen cognitive associations by reducing the demands on episodic memory and relying on nondeclarative memory which is relatively spared (Hopper 1999). They are techniques which are effective when paired and are best used to directly teach information or procedures to improve the quality of life of a patient with AD. Errorless learning is an attempt to minimize the number of errors made by the patient in a given task. In spaced retrieval, a patient is told information and then asked to recall it repeatedly at ever increasing time intervals.

Errorless Learning

Baddeley and Wilson (1994) first described errorless learning in their work with patients with amnesia. They found that their subjects with amnesia learned faster when their mistakes were kept to a minimum. Clare et al. (1999) followed the errorless learning protocol with people with AD. They used errorless learning to teach a group with mild AD to learn the names and faces of the members in their social club. The patients were able to generalize the names from pictures to actual faces. Nine months later, they retained this knowledge. Errorless learning techniques can be used to teach patients with AD information (e.g., someone's name) or a procedure (e.g., taking a sip of water after bites of food to aid the swallow).

How does errorless learning work? Let's imagine you are teaching a patient with AD the name of her new roommate. You need a photograph of the roommate or the roommate herself. First you state her name, "Mary." Then immediately ask the patient with AD, "Is her name Mary?" Notice that this recognition task is much easier than a free recall task. Do not allow the patient to guess; you do not want any errors. You also need to teach the patient to pause before responding to help reduce impulsive wrong answers. Continue to ask if the person's name is Mary using spaced retrieval. (These procedures are described in the next section). Once the patient is successful, the question becomes, "What is her name?" In errorless learning, provide as many cues as necessary for a correct response. For example, you might say, "What is her name? It starts with M." Gradually remove the cues as the patient is successful. Remember that in errorless learning there is no guessing and no trial-and-error learning. When teaching new information, always give the correct information and when teaching a new procedure, always demonstrate the correct movements.

Spaced Retrieval

Spaced retrieval, or the process of continually recalling information over increasingly longer periods of time, is a well-known technique first described by Landauer and Bjork (1978). It can be used to teach pieces of meaningful and concrete information, compensatory techniques, or procedures to patients in the moderate stage of AD (Brush and Camp 1998). Patients with AD may not remember the therapy session, but they will remember the information learned. Thus, this technique is particularly successful with patients in the moderate stage of the disease as they do not become annoyed at the repetitive questioning by the therapist.

Brush (1999) suggests the following model for using spaced retrieval:

> Provide the information (as in errorless learning). Immediately ask for the information back and reinforce a correct answer with a positive comment. Then repeat the question at time intervals that double in length (e.g., immediate, 30 seconds, 1 minute, 2 minutes, 4 minutes, 8 minutes). If an error is made, the information should be repeated and the questioning resumed at the last successful time interval. For example, if the information was remembered after 8 minutes, but forgotten after 16 minutes, then repeat the information and ask for it again after 8 minutes.

Sometimes a patient may become stuck, unable to move beyond a certain time interval. If that happens, repeat the last successful time interval until it is learned before increasing the time interval again. Spaced retrieval is more successful if only one piece of information is taught at a time. Some patients may benefit from the addition of written cues which can then be faded as the patient is successful.

Spaced retrieval can be used to teach names, addresses, important dates, schedules, routes around the facility, safety procedures, compensatory procedures for swallowing, or transferring from wheelchair to dining room chair. It can also be used to teach a patient to use a memory book or other external memory aid.

Swallowing and Eating Problems

Dysphagia, or a problem with swallowing and eating, is sometimes seen in AD, particularly late in the disease. Symptoms of dysphagia include elevated temperature, drooling, weight loss, coughing or choking, refusing certain foods, pocketing of food in the mouth, pneumonia, dehydration, reflux, or complaints about swallowing difficulties (Swigert 2000). What causes these symptoms?

> Sometimes there are physical changes such as a delayed swallow reflex. Cognitive changes (e.g., decreased memory, attention, judgment) may also contribute to eating and swallowing problems. Finally environmental distractions may lead to the communication breakdowns (e.g., wandering, agitation, apathy) which can interfere with eating (Cleary 1999).

There are many excellent sources for information on the diagnosis and treatment of dysphagia. These include, but are not limited to:

- *Alzheimer's Disease and Nutrition* (1990) by S. Finn
- *Clinical Management of Dysphagia in Adults and Children, 2nd Edition,* (1994) by L.R. Cherney
- *Manual for Videofluorographic Study of Swallowing* (1993) by J.A. Logemann
- *Nutritional Aspects of Dementia, Especially Alzheimer's Disease* (1990) by G. Bucht
- *The Source for Dysphagia - Updated and Expanded* (2000) by N. Swigert

In addition to knowledge about the physiology of the swallow, SLPs need to identify environmental factors that affect the safety of the swallow. Factors to consider include:

- Is the person in a proper position for eating?

- Is the dining area loud or chaotic?
- Is there a television turned on in the dining area?
- Is the food cold?
- Is the meal provided promptly, without waiting?
- Is the person with AD frequently offered a drink?

The Feeding Behaviors Inventory (Durnbaugh, Haley, and Roberts 1996) can also be used to assess eating problems. This inventory codes resistive/disruptive behaviors, oral behaviors, patterns of intake, and styles of eating. SLPs can use observations such as these to consult with nursing homes and care facilities to improve the mealtime environment and plan for individual care plans.

Family caregivers too can benefit from information provided by an SLP on the optimum mealtime strategies in the home. Suggestions for caregivers include:

- Supervise meals.
- Be sure a balanced diet is eaten.
- Provide bite-size pieces of food, soft foods, and thick liquids that are easier to eat.
- Puree soup rather than serve chunky soups that may be confusing to eat.
- Serve food items one at a time.
- Remind the person with AD to put food in the mouth, to chew, and/or to swallow.
- Learn the Heimlich maneuver.
- Use the Social Reminder "Enjoying Meal Time" on page 165.

Therapy Conversation Topics
(Appendix One, pages 102-155)

As discussed in previous chapters, discourse is an early and continuing problem for people with AD. Conversation Topics were developed to help people with AD participate in a meaningful conversation with a therapist and/or peers or caregivers. Objects or pictures can be added to help people with AD comprehend language and focus their attention. Other senses can also be tapped to facilitate conversation.

Objects that have a distinctive feel or smell can at times spark an interaction (Whiteside and Zimmerman 1998, Hopper et al. 1998). Harris (1998) suggests using Scratch 'n' Sniff cards for stimulating the sense of smell in her reminiscence therapy sessions.

Auditory stimulation through music or stories is also an important part of setting the context for a conversation with a person with AD. The use of music with the Conversation Topics is highly recommended. Feil (1993) uses music as one of her validation techniques because familiar songs often remain when words are gone. In addition, "music provides structured reality, order, and predictability. It brings something familiar to the environment . . . ." (Clair 1996).

Not all music is created equal, however, for people with dementia. Dowling (1995) warns that synthesized music, nature tapes, rhythm bands, radio, a piano being banged on, and any music left on for more than a half-hour are not as enjoyable as carefully chosen recordings and songs. These multisensory components are used to "enhance functional communication and capitalize on spared recognition and procedural memory systems" (Mahendra 1999).

Conversation Topics include Daily Life (home and work topics), Entertainment (sports and other forms of recreation), and Time Line (historic news events). Each page outlines a conversation topic to use for individual or group sessions. Music and/or pictures or objects for stimulation are also suggested for each topic.

Two brief paragraphs about the topic set the context for the conversation. Level 1 context settings are short in length and use vocabulary and syntax that are easy to comprehend. They are appropriate to use with people who need a simple format for comprehension. Level 2 context settings are linguistically complex and more difficult. They are appropriate for use with people in the earlier stages of AD.

There are also sample yes/no questions and forced-choice questions that rely on recognition rather than recall memory if needed to increase participation. The questions provided are not meant to be used for evaluation, but rather as prompts to conversation.

How To Use Conversation Topics
Place suggested objects in a box, suitcase, trunk, basket, or other container. Feel free to use other objects appropriate to the topic. The objects suggested have more than one sensory component whenever possible. For the chosen conversation topic, use the following format:

- State the topic: "Today we're going to talk about baseball."
- Play the recommended musical selection and/or read the print selection to help set the context for conversation.
- Place memory prompts in the hands of the person with AD. Wait for a comment.
- If there is no comment, make a personal statement about the object. Wait again.
- In a group setting, pass the object to each person.
- Show the picture to the group or individual. Make a comment. Wait.
- Use a question provided if necessary to prompt conversation.
- Be prepared to enjoy and record some of the reminiscences you hear.

Social Reminders
(Appendix One, pages 158-167)

Social Reminders were developed to help caregivers with some of the common mistakes or problems that people with AD have. These problems are often referred to as "embarrassing" or "difficult behavior." More often the problems result from a miscommunication by one of the communication partners. Either the person with AD misunderstands a situation and is afraid or confused, or the caregiver has not been able to communicate effectively to prevent the problem.

Families report that people with AD will ask repetitive questions or make repetitive statements like "I want to go home" (when the person with AD is at home) or "I want to drive my car" (when driving has been taken away). Families also report problems with pacing, shadowing, hygiene, and using appropriate social manners, to name a few.

These behaviors are often the result of communication failures. Sometimes these problems can be alleviated by changing the environment or by distracting the person with AD to another activity. Social Reminders are just one more way to facilitate communication.

Social Reminders use many of the same principals as external memory aids. The text is brief and concise, and pictures are added to aid comprehension. Social Reminders are included on pages 158-167 as examples. You may use them if appropriate or as samples as you develop your own. Feel free to fill in the blanks with photographs or the names of individuals.

Social Reminders are best given to the person with AD to read just prior to the social event. Some Social Reminders reassure a person with AD (e.g., My Home) while others explain social situations (e.g., Eating Out) or new limitations (e.g., Driving).

Social Reminders can be used in nursing facilities or copied and shared with caregivers. SLPs play an important role in helping caregivers understand that social problems are communication breakdowns. Social Reminders are one way to facilitate the communication between a caregiver and a person with AD.

Activities for Daily Living

As adults, we all like to be able to take care of ourselves, take care of others, work, and contribute to society. People with AD are no different.

Maslow (1970) described a hierarchy of needs that people have. First are the basic needs of food, clothing, and shelter. If these needs are met, we then have a need for security. Higher on the hierarchy are a person's needs for identity, control, autonomy, self-esteem, the esteem of others, inclusion in a group or larger body, and meaningful communication and relationships. Our sense of worth is dependent on how we feel and how successful we are when we complete certain activities.

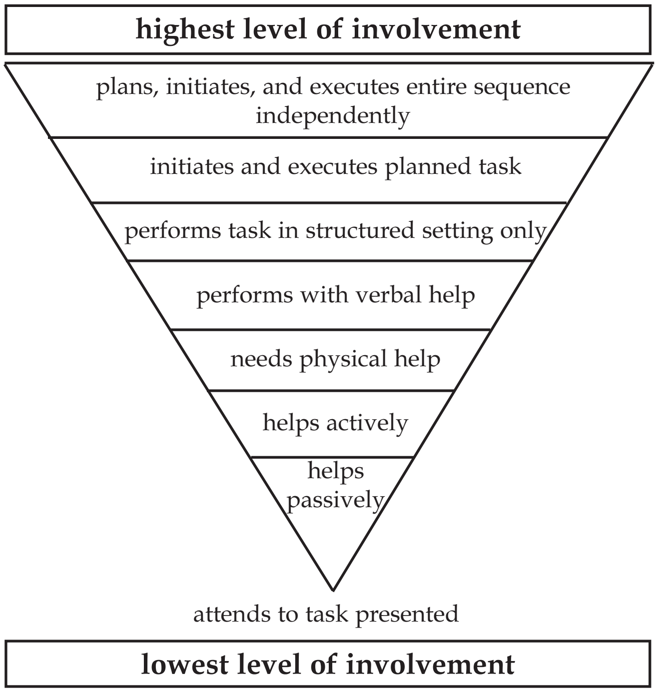
As the disease progresses, people with AD lose certain abilities. This tends to lead to a downward spiral from independence to dependence. Caregivers often take over an entire activity, leaving the person with AD with a sense of helplessness. The person with AD then feels worthless and loses the willingness to attempt activities. Caregivers at home might say, "He can't do anything anymore" or "What can we do all day long?"

Activities have been described as those needed for self-care (e.g., bathing, eating), referred to as activities of daily living or ADLs; and those which require more abstract thinking (e.g., shopping, paying bills, meal preparation), referred to as instrumental ADLs or IADLs (Lawton and Brody 1969). There are several tools to assess how well the person is able to complete ADLs. These include:

- *The Bartel Index* (Mahoney and Bartel 1965) measures 10 self-care activities.
- *The Functional Independence Measure* (FIM) (Hamilton et al. 1987) assesses 7 areas of independence and includes other documentation (e.g., diagnosis).
- *The Functional Status Index* (Jette 1980a, 1980b) measures functional abilities of individuals at home. It is a self-report measure.
- *The Katz Index of ADL* (Katz et al. 1963) measures independence in self-care activities.
- *The Modified Bartel Index* (Granger et al. 1975) adds other activities to the self-care activities.

(adapted from Bayles and Tomoeda 1997)

Although the functional abilities of the person with AD are important to know when planning activities, it is also important to consider the activity itself. Zgola (1987) suggests that activities must be analyzed and graded. Grading the activity means planning for more or less participation by the person with AD.



Zgola, J. M. *Doing Things: A Guide to Programming Activities for Persons with Alzheimer's Disease and Related Disorders*, page. 35. Baltimore: Johns Hopkins University Press, 1987.

Activities can be graded from the most involvement (e.g., planning, initiating, and completing an activity independently) to the least involvement (e.g., passively watching the activity). In between, some people can participate if given a verbal prompt, a physical prompt, or a structured setting to complete the activity in. To analyze an activity, consider the physical, sensory, and cognitive demands, and the value of the activity to the participant. Repetitive activities (e.g., folding towels, sanding wood) are usually successful.

In addition, environmental demands need to be considered. (See Chapter Five, pages 43-50.) Certain areas can be designated for certain activities to support comprehension. The environment should not be too stimulating. All the safety concerns of both the environment and the activity need to be noted. For example, conduct cooking activities in the kitchen rather than mixing and assembling in an activity room.

Scheduling activities to occur at the same time every day helps make the activities predictable. (See External Memory Aids, pages 60-62.) Consider when the person with AD has high or low energy periods when planning certain activities. How long should activities last? One assisted living facility found that 30-minute activities followed by a period of unstructured activity of about the same length was well tolerated by most of the participants. This same type of schedule could be used at home.

Included here are suggestions of activities that are routinely completed in most homes. Most of them can be modified for use in facilities. Make a step-by-step analysis of what must be done to complete the activity. Hand-over-hand guidance, visual cueing, and verbal cueing may also be needed for successful completion of the activity. Activities for people with AD should be familiar and allow them to feel successful (Dowling 1995).

Music

- Listen to music through headphones.
- Play music for resting.
- Sing favorite songs together.
- Watch videos of musicals.
- Use music for each part of the day (e.g., "Goodnight Ladies" at night).

Exercise

- Take a daily walk.
- Dance.
- Squeeze a small rubber ball.

- Use an exercise tape.
- Ride an exercise bike.
- Rake leaves.
- Pick up litter while walking.
- Sweep the porch, the patio, the sidewalk, the kitchen, etc.
- Vacuum.
- Pull weeds.
- Do range of motion exercises.
- Do the "Hokey Pokey."

Activities of Daily Living

Housekeeping

- Clip coupons.
- Fold laundry or towels.
- Match socks.
- Dust furniture.
- Help with laundry (e.g., gather dirty clothes, sort light and dark).
- Empty wastebaskets.
- Polish silver.
- Wipe off tables/patio furniture.
- Stack newspapers for recycling.
- Sort bottles and plastics for recycling.
- Water/mist plants.
- Feed the pet.
- Sort and wrap coins.
- Roll yarn into a ball or string onto a spool.
- Help make the bed.
- Polish shoes.

Meal Preparation/Clean-up

- Wash vegetables.
- Set the table (e.g., put out placemats, plates, etc.).
- Sort and put away silverware.
- Fill salt and pepper shakers.
- Put dishes away.
- Put groceries away.
- Organize cans of food.
- Scrub the sink.
- Chop soft fruits and vegetables for salads.
- Cut soft cheeses.
- Wash and dry non-breakable cups, dishes, and cooking utensils.
- Put ice in glasses.
- Butter bread.
- Wipe off the table.
- Fold napkins or place them in napkin rings.
- Mix juices and dressings.
- Complete steps of simple recipes with help (e.g., caregiver measures and person with AD pours and stirs).

Table Activities

- Cut and paste collages using items like magazine pictures and pieces of ribbon or other trim.
- Draw or paint using watercolors, chalk, markers, and colored pencils.
- Work simple puzzles.
- Make clay figures.
- Sort decks of cards by color.
- Sort or arrange dominoes.
- Wrap gifts.
- Write letters (even if you don't mail them).
- Sort mail.
- Sort small objects in a purse.
- Count tickets.
- Plant seeds.
- Look at family photographs.
- Make birdfeeders, fill feeders, or string Cheerios for the birds to eat.
- Sand wood.
- Use rubber stamps to make a design on paper.
- Sort items (e.g., nuts and bolts, colored pom-poms, textured cloth squares, pipe cleaners)
- Use adult coloring books[1].

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[1] Ruth Heller's *Designs for Coloring series,* Price Stern Sloan Publishers.
Dover Publications also offers a wide variety of topics to color (e.g., *Butterflies, Ancient Rome, African Designs, Stained Glass).*

Self-Care

Caregivers report that the loss of a person's ability to complete self-care activities is often distressing both to the person with AD and the caregiver. As we have seen in the discussion of external memory aids, pages 60-62, visual reminders can often help in the early stages of AD. Morning and evening routine schedules, pages 96-100, serve as an example of how to use visuals to help a person get through a routine self-care time. The self-care steps can be read or posted near the self-care activity area. The self-care steps may be reproduced if appropriate, or you may want to write your own.

Conclusion

"What can I do?" is a common question from caregivers, but what is the real question?

- "What can I do to make AD go away?"
- "What can I do to make my loved one healthy again?"
- "What can I do to keep my loved one busy and active?"
- "What can I do to keep my loved one safe?"
- "What can I do to keep from going crazy myself?"

Some of the techniques, strategies, and information in this chapter and in the next chapter (Caregiver Support Group Agenda) will answer a few questions, but AD is a disease that will not go away. Caregivers will find some comfort in trying another approach which I call "joyful sharing." Joyful sharing is a process in which the person with AD and the caregiver join together in a time of communication which both find enjoyable. Joyful sharing requires that you live in the moment, in the world, in the reality of the person with AD.

Batiuk and Ayers in the "Crankshaft" cartoon use their characters, the McKenzie sisters, to explore the experience of living with AD. One of the sisters has the disease, the other is the caregiver. In the cartoon below, the sisters are enjoying a shared reminiscence from long ago, not concerned about acting in an odd or strange way. It is a perfect illustration of joyful sharing!

CRANKSHAFT ©1999 Mediagraphics, Inc.
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Caregiver Support Group Agenda

The agenda in this section is intended as a guideline for a caregiver support group. These sessions provide information on a wide range of issues that can affect family caregivers. Presenting all the information listed here in one setting may be overwhelming to families. Use discretion in tailoring the outlines to your support group by selecting portions that are suitable to their specific needs and training.

The reproducible handouts, pages 79-93, contain useful information to share with families at the meetings and can also be used in conjunction with family consultations. Suggestions for reference books and brochures are made with each topic.

Goals:

- To provide patients with AD and their caregivers with basic information about financial, legal, health, and safety issues; and caregiver stress

- To suggest techniques caregivers may use to improve communication with the person with AD

Unit One: Legal and Financial Issues

This topic is presented first to emphasize the importance of decision-making while the person with AD is still able to take part in the planning. You many want to invite a local legal or financial expert on estate planning and elder issues to give a presentation during this unit.

I. The importance of planning for the future for families facing Alzheimer’s disease
   A. Families will need to meet to plan for future needs.
   B. Meetings and discussions are best held early in the disease.
      1. The person with AD may show where important papers are.
      2. The person with AD may explain financial assets and obligations.
      3. These important decisions are made as a partnership between family members.
   C. All family members should be invited. (Handout 1, page 79)
      1. Be open to compromise.
      2. Make decisions by consensus. Even though everyone may not agree, they should still follow the decisions.

    3. Do not bring up issues from the past.
    4. Be thoughtful of others' feelings; do not attack each other.

  D. If the primary caregiver works, he or she should investigate the Family and Medical Leave Act.

    1. Employers with 50 or more employees must grant up to 12 weeks of unpaid leave a year for the care of a parent, spouse, or child with a serious health condition. (AD is a serious health condition.)
    2. The leave can be taken all at once or used intermittently.

II. The importance of completing legal paperwork as soon as possible

  A. The person with AD needs someone trustworthy to act in his/her behalf sometime in the future.

  B. The person with AD should be able to choose that person for him/herself.

  C. The person with AD should state his/her preferences on legal issues to the designated person.

  D. The family should find a lawyer with experience in geriatric and estate planning issues to help them make decisions and complete the paperwork. The National Academy of Elder Law Attorneys, (520) 881-4005, will make referrals. (Handout 2, page 80)

    1. Durable Power of Attorney for financial decisions
    2. Durable Power of Attorney for health care
    3. Living Will
    4. Will
    5. Living Trust
    6. Conservators, Guardians, and Trustees

III. The importance of reviewing financial affairs

  A. Review assets and financial documents.

    1. Location and account numbers of checking and savings accounts
    2. Stocks, bonds, insurance policies, retirement accounts
    3. Social security and/or retirement payments
    4. Home, rental property, valuable personal collections

  B. Consider current expenses

    1. Expenses for shelter, food, and medicine
    2. Home mortgage or other debts

  C. Consider potential expenses

    1. Medical treatment
    2. Prescription drugs

3. Adult day supervision
4. In-home care
5. Full-time residential care
6. Nursing home care vs. assisted living care

D. Consider resources to help cover costs. (Handout 3, pages 81-82, for more information)

1. Personal resources
    a. Personal savings and investments
    b. Personal property/Reverse mortgages
2. Insurance
    a. Private health insurance or employee group insurance
    b. COBRA (Consolidate Omnibus Budget Reconciliation Act of 1985)
    c. Disability insurance (according to policy in place)
    d. Long-term care insurance
    e. Life insurance policies
3. Government programs
    a. Medicare
    b. Medicaid
    c. Social Security Disability Income
    d. Social Security Income (SSI)
    e. Veterans benefits
    f. Tax benefits

E. Use protective measures. (Handout 4, page 83)

1. Monitor all bills and checks. Have mail sent to caregiver or other family member at a different address or P.O. Box.
2. Use electronic transference of social security checks and other sources of income.
3. Cut down on junk mail.
4. Cut down on telephone solicitations.

Unit One Resources
Handouts

- *Family Planning: Can We Talk?*, page 79
- *Legal Decisions*, page 80
- *Possible Financial Resources,* pages 81-82
- *Protect Yourself from Fraud!*, page 83

Publications available from the Alzheimer's Association (1-800-272-3900; 919 N. Michigan Avenue, Suite 1100, Chicago, IL 60611 or a local chapter)

- *Taxes and Alzheimer's Disease*
- *Private Long-term Care Insurance: To Buy or Not to Buy*
- *Understanding Medicaid Long-term Care: A Primer for Alzheimer's Disease*
- *Steps to Understanding Financial Issues: Resources for Caregivers*
- *Steps to Understanding Legal Issues: Planning for the Future*

Other Publications

- Carlin, V. F. and Greenberg, V. E. *Should Mom Live with Us? And Is Happiness Possible If She Does?* NY: Free Press, 1992.
- *National Handbook on Laws and Programs Affecting Senior Citizens*. Chicago: American Bar Association, 1998.
- Strauss, P. J. and Lederman, N. M. *The Elder Law Handbook: A Legal and Financial Survival Guide for Caregivers and Seniors*. NY: Facts on File, 1996.

Unit Two: Health and Safety Issues

People with AD experience changes in their ability to remember and reason which can lead to potentially dangerous situations. This unit will first target safety issues and then review possible health issues. Use Handouts 6-9 to prompt discussions about safety. A listing of the safety hazards pictured in the handouts is on pages 89-90. You may want to invite a nutrition expert as a guest speaker on health topics.

I. The importance of safety issues
  A. The need for an emergency contact sheet (Handout 5, page 84)
    1. Important phone numbers: police, fire, ambulance, poison control center, primary physician, neighbors, nearby relative, and where to contact primary care-giver if needed
    2. Special instructions: medications, allergic reactions, hearing/vision loss, etc.
  B. The need to learn basic emergency procedures
    1. CPR, Heimlich maneuver, seizure response, other first-aid skills
    2. Make a first-aid kit.
  C. Evaluating the home for safety (Handouts 6, 7, and 8, pages 85-87)
    1. Kitchen
      a. Put sharp knives and cleaning products out of sight.
      b. Remove knobs from stoves and ovens.
      c. Supervise food preparation activities.
    2. Bathroom
      a. Adjust the hot water temperature to a safe temperature.
      b. Install safety seat and grab bars in bathtub and toilet areas.
      c. Be sure area is well lit.
      d. Lock medicines in a safe place.
      e. Avoid any tripping hazard (e.g., bathmat).
    3. Living room
      a. Remove clutter on floors and stairs.
      b. Light room to eliminate dark corners.

        c. Remove area rugs which might cause falls.
        d. Add hand rail to stairs.
        e. Remove large potted plants on the floor which might cause falls.
        f. Remove mirrors which can cause confusion.
    4. Fire safety
        a. Install smoke alarms.
        b. Install fire extinguishers.
        c. Supervise smoking.
        d. Keep matches out of reach.
        e. Place an ID sticker on bedroom window.
    5. Remove guns and firearms from home.

D. Evaluating the outdoors for safety (Handout 9, page 88)

1. Lock all cars.
2. Lock gates.
3. Keep equipment and tools in a locked garage or tool shed.
4. Keep garden hoses off walkways.
5. Remove plants with berries or nuts that might be poisonous and tempting to eat.

E. Driving

1. Point of disagreement even among professionals — there is a lack of medical and legal guidance on when to terminate driving.
2. Only California requires retesting of driving skills if AD diagnosed
3. Restrict from dangerous driving conditions (e.g., rush hour, bad weather, night driving).
4. Use Social Reminder "Driving," page 159.
5. Ask "Am I comfortable letting my children or grandchildren ride with this person?" If "no," end driving.
6. Enlist physician's prescription: "Do not drive car due to medical condition."
7. Ask physician to revoke license.
8. Make car unavailable or inaccessible.

F. Wandering (Handout 10, page 91)

1. The need for identification such as a medical ID bracelet or necklace (Sources include: Bodyguard Medical ID tags, 1-800-383-7790; or Custom ID Products: Medic ID, 1-800-439-8899). Inscribe with:
    a. Name
    b. Phone number
    c. Words "memory impaired"
2. Sew name and phone tags into clothing.
3. Alzheimer's Association's Safe Return Program (Scholarships available)
   P.O. Box A-3956, Chicago, IL 60690. For a one time registration fee, Safe Return provides:
    a. Identification products including bracelet or necklace, clothing labels, and wallet ID card

b. 24-hour, toll-free 800 number
c. Registration in a national database
d. Access to 17,000 law enforcement agencies
e. Connection to more than 200 community based Alzheimer's Association chapters around the country

II. The importance of health concerns

A. Medications

1. Observe the person with AD taking medication to insure proper dosage, etc.
2. Caregiver could administer the medication, if needed.
3. Use other reminders
   a. Weekly pill organizer
   b. Written reminder notes
   c. Clock that beeps to remind of dosage

B. Proper nutrition

1. Meal time
   a. Prepare foods that are easy to swallow.
   b. Verbally prompt to "swallow" if needed.
   c. Reduce noise, confusion, and other distractions.
   d. Several small meals may be preferred to three big meals.
   e. Consider formal swallowing evaluation if problems are occurring.
2. Dehydration can be a problem with inadequate fluid intake.
   a. Signs include dry skin, worsening mental function, low fluid output during urination, and skin "tenting" (pinch the skin gently; if it stays "tented," the person is dehydrated)
   b. Coffee and tea (diuretics) also reduce body fluids.
3. Consider home-delivered meals or "Meals on Wheels."
4. Use the Golden Diners program or another senior citizen meal program.

Unit Two Resources
Handouts

- *Information Sheet*, page 84
- *Safety Pictures*, pages 85-88
- *Wandering*, page 91

Publications available from the Alzheimer's Association (1-800-272-3900)

- *Just the Facts: Driving*
- *Just the Facts: Nutrition*
- *Just the Facts: Safety*
- *Safe Return brochure and fact sheet*
- *Steps to Enhancing Your Home: Modifying the Environment*

Unit Three: Joyful Sharing

There is no doubt that caring for a person with AD is one of the most stressful things a person can experience. This unit provides suggestions for improved communication (often the central cause of caregiver stress) and where to find hope and happiness—a search I call "joyful sharing." Some caregivers will need more help and support than this support group can provide. Guidelines are suggested to help caregivers determine if and when they need help dealing with grief, guilt, and anger.

I. Caregiver stress management (Handout 11, page 92)
  A. Care of the body
    1. Routine medical and dental checkups
    2. Healthy food (the Food Pyramid)
    3. Exercise
  B. Grief as a normal human reaction
    1. Stages
      a. Denial
      b. Anger and depression
      c. Letting go
      d. Acceptance
    2. Ups and downs
    3. Physical signs
      a. Insomnia
      b. Loss of appetite
  C. Individual or family counseling
  D. Keep a sense of humor
  E. Play
  F. Sleep
    1. Establish a restful routine.
    2. Limit intake of alcohol and caffeine if having sleep problems.
    3. Consult a physician if problems continue.
  G. Ask for help.
    1. Specific requests to family members
    2. Specific requests to friends and neighbors

II. Communication tips
  A. Improve communication (Handout 12, page 93, and information in Chapter 5)
  B. Communication breakdowns (information in Chapter 6)

III. Finding happiness and hope in AD (Gray-Davidson 1999)

  A. Happiness

    1. Learn to enjoy reminiscing with your loved one. Short-term memory may be damaged, but long-term memory often remains.
    2. Recognize the special abilities that often remain and enjoy them (e.g., playing a musical instrument, drawing, playing a particular game).
    3. All people (with and without AD) enjoy the same things (e.g., a good meal, animals, babies, a beautiful view, the feel of warm dirt in a spring garden).
    4. People with AD still enjoy hugs and other forms of affection. Sit close and look at pictures together.
    5. Learn to enjoy the present moment together. What is past is in the past and what is in the future is not yet here.

  B. Hope (Hodgson, 1995)

    1. Hope in research
    2. Hope in friendship
    3. Hope in living the moment

Unit Three Resources

Handouts

- *Caregiver: Take Good Care of Yourself*, page 92
- *Communication Tips*, page 93

Other Publications and Materials

- Richmond, M. *Caring for the Caregiver*. Journeyman Publishing, 1993. P.O. Box 2720, Santa Cruz, CA, 95063. Request title #5009, ISBN 1-56995-009-3.

Publications available from the Alzheimer's Association (1-800-272-3900)

- *Caregiver Stress Signs to Watch for, Steps to Take*
- *Respite Care Guide: How to Find What's Right for You*
- *Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease*
- *Steps to Planning Activities: Structuring the Day at Home*
- *Steps to Understanding Challenging Behaviors: Responding to Persons with Alzheimer's Disease*

Other Resources

These publications on caregiving are recommended to include in a "lending library" for the group. In addition, you might want to include the books marked with an asterisk in the reference section, pages 191-199. Allow time for the people in attendance to browse and look through the books.

Coughlan, P. B. *Facing Alzheimer's: Family Caregivers Speak*. NY: Ballentine Books, 1993.

Dass, R. and Gorman, P. *How Can I Help? Stories and Reflections on Service*. New York: Knopf, 1986.

Davidson, A. *Alzheimer's: A Love Story: One Year in My Husband's Journey*. Seacaucus, NJ: Carol Publishing Group, 1997.

Dyer, J. *In a Tangled Wood: An Alzheimer's Journey*. Dallas: Southern Methodist University Press, 1996.

Gillick, M. R. *Tangled Minds: Understanding Alzheimer's Disease and Other Dementias*. NY: Penguin Putnam, Inc., 1999.

Grant, L. *Remind Me Who I Am, Again*. London: Granta Books, 2000.

Hanh, T. N. *Being Peace*. Berkeley: Parallex Press, 1987.

Kushner, H. *When Bad Things Happen to Good People*. NY: Avon Books, 1981.

Mother Teresa. *Life in the Spirit*. San Francisco: Harper, 1982.

McKay, M., Rogers, P. D., and McKay, J. *When Anger Hurts: Quieting the Storm Within*. Oakland, CA: New Harbinger Publications, 1989.

Sogyal, R. *Tibetan Book of Living and Dying*. San Francisco: Harper, 1993.

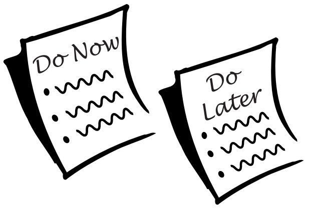
Veniga, R. *A Gift of Hope*. Boston: Little, Brown and Co., 1985.

Family Planning: Can We Talk?

Families should plan to meet more than once to discuss the care of the person with AD. The goal of the meeting should be to make a plan. This is not the time to discuss other family issues. Here is a list of things to accomplish:

❍ Make a list of the greatest needs.

❍ Decide which needs require immediate action and which can wait for future action.



❍ List the needs according to urgency.

❍ Discuss what time or money is needed to act on the "needs" list.

❍ Determine who will do what. The results may not always seem fair, but the goal is care of the loved one with AD.

❍ Close the meeting with positive comments about what has been accomplished.

(adapted from Gray-Davidson 1999)

Legal Decisions

If the person with AD is able, he/she should be the one to make as many of these decisions as possible.

Power of Attorney: This is a written document which must be witnessed and notarized that gives one person the authority to act on another's behalf. This permission can be limited to a specific time period (e.g., during recovery from brain surgery) or it can be for an unlimited time period (e.g., in the case of dementia). The unlimited power of attorney is called *durable power of attorney*.

> **Durable Power of Attorney for financial decisions** (also called *Durable Power of Attorney for property*): This type of power of attorney allows the designated representative or agent to manage property and finances. This person can make financial decisions about future costs of care.
>
> **Durable Power of Attorney for health care**: This type of power of attorney designates a person to make all health care decisions and end-of-life decisions for the person granting the authority. It can also include the person's specific directives and wishes.

Living Will: This document gives another person the authority to make end-of-life health care decisions only.

Will: The person with AD should have an up-to-date will.

Living Trust: This is a written agreement where the person affected (the grantor) gives a person or a bank (trustee) permission to control financial assets according to certain directions. It also gives directives on how assets are to be distributed after death. This must be set up with the help of an attorney.

Sometimes the disease is so advanced that the person with AD will be unable to take the protective steps listed above. In that case, courts may appoint a guardian, conservator, or trustee (called "fiduciaries") to act in behalf of the person affected. This can only be done through the court system and can be a lengthy and costly procedure. It is important to make these decisions as soon as possible with the help of the person with AD.

Guardian or Conservator: This person has the power to take care of the person and manage the property of the person unable to care for him/herself.

Trustee: This is a person appointed to manage a trust for the care and benefit of the beneficiary.

Possible Financial Resources

Personal Resources

- Personal savings and investments
- Personal property
  A reverse mortgage is available to a person over 62. A person is allowed to convert some of the equity of his/her home into cash and still retain ownership.

Insurance

If the person with AD is under 65:

- Private health insurance or employee group insurance may be in effect. Investigate how health expenses from AD will be covered.

- COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985) may be needed if the person leaves work or loses health care due to reduced hours due to AD. Under COBRA, the employee may continue with the health plan coverage for 18, 29, or 36 months (depending on circumstances). The insured person pays the full cost of the coverage. This may be useful until the person becomes eligible for Medicare at age 65 or other private health insurance becomes available.

- Disability insurance pays income (according to the policy in place) for an employee who is no longer able to work because of illness or injury.

- Long-term care insurance pays some money (according to the policy in place) for long-term care. These policies all differ, so examine them carefully.

- Life insurance policies will sometimes allow you to borrow from the cash value or pay "accelerated death benefits." Check the policy to see if these are available.

Government Programs

- Medicare is the primary source of health coverage for people over 65. It does not cover long-term nursing home care. For information about Medicare coverage, Medicare HMOs, PPOs, and POS plans and Medigap supplemental insurance, call 1-800-638-6833 or visit Medicare's Web site at <www.medicare.gov>.

- Medicaid pays for medical coverage for people with very low income or people in long-term care who have used up personal resources. Laws govern a person giving away financial resources to qualify for Medicaid. As Medicaid is funded by the federal and state governments, information on Medicaid in each state can be found by contacting that state's human or social services departments. Other information can be found at <www.hcfa.gov/medicaid/mcaicnsm.htm> or <www.familiesusa.org/medicaid/>

- Social Security Disability Income (SSDI) is for workers under age 65 who meet the Social Security Administration's definition of disability. Call 1-800-772-1213 or visit <www.ssa.gov> for information.

- Supplemental Security Income (SSI) is for people 65 or older who are disabled or blind and have very limited income and assets. Call 1-800-772-1213 or visit <www.ssa.gov> for information.

- Veterans benefits may be available to veterans. Call 1-800-733-8387 for information.

- Tax benefits may be available (e.g., deductions or credits on income tax). For tax information, consult your tax advisor or the IRS. Call 1-800-829-1040 or visit <www.irs.ustreas.gov> for information.

Protect Yourself from Fraud!

Junk mail

- Write:
  Mail Preferences Service
  Direct Marketing Association
  P.O. Box 9008
  Farmingdale, NY 11732

  Include the person's full name, address, and any spelling variations of name.

- Ask your local post office to stop delivering third-class mail.

Telephone solicitations

- Write:
  Telephone Preference Service
  P.O. Box 9014
  Farmingdale, NY 11735

- Call Opt Out Request Line (1-888-567-8688) to reduce credit card solicitations.

Fraud

Report suspected fraud attempts to:

- National Fraud Information Center: 1-800-876-7060

- State Agency on Aging: 1-800-677-1116 (to get local number)

(adapted from Kuhn 1999)

Information Sheet

Name: ______________________________

Phone: ______________________________

Address: ______________________________

____

General Information

Medications: ______________________________

____

Enjoys doing: ______________________________

Dislikes: ______________________________

May: ______________________________

____

Important Phone Numbers

Primary caregiver: ______________________________

Primary physician: ______________________________

Poison Control Center: ______________________________

Neighbor: ______________________________

Relative: ______________________________

Emergency: **911**

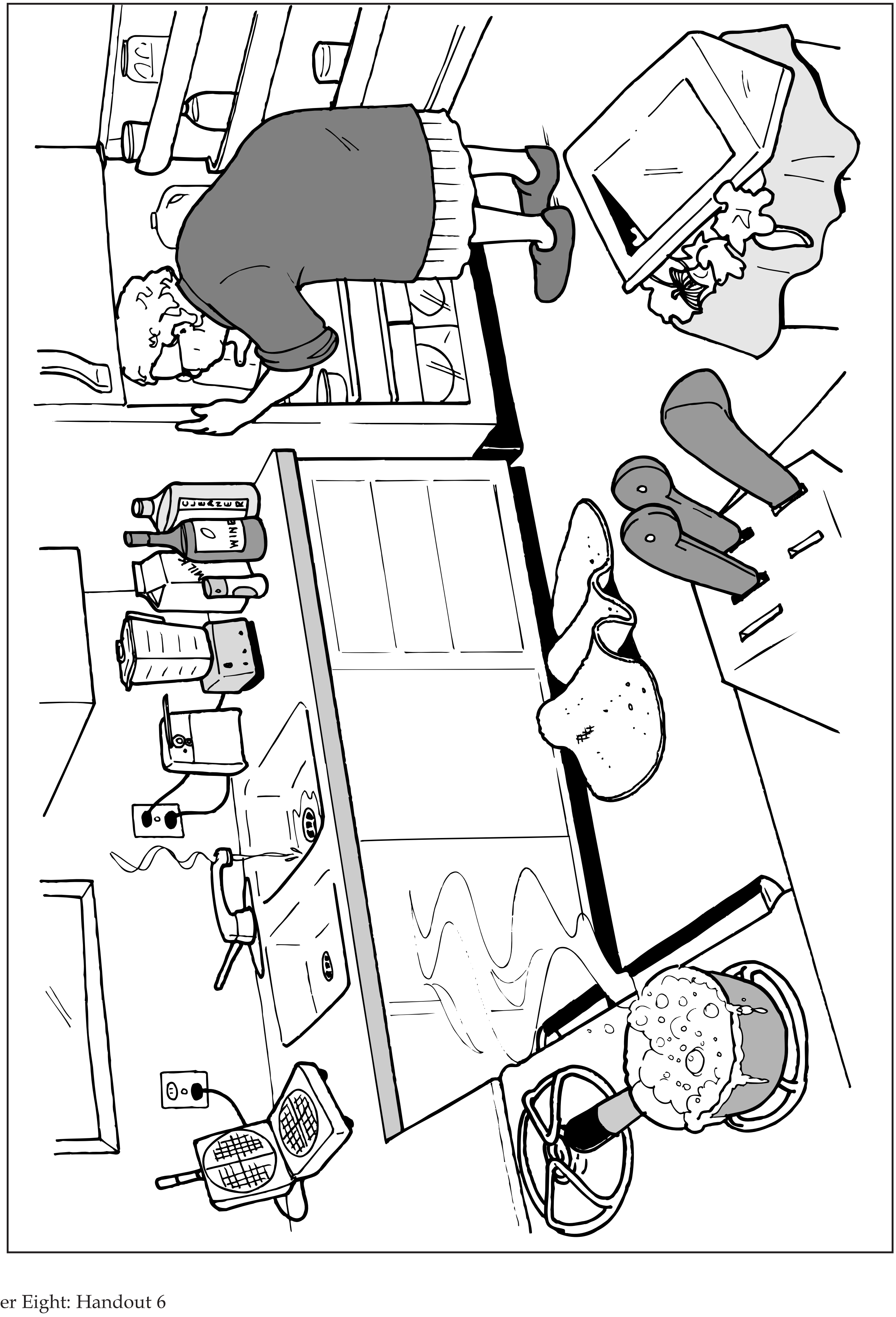
Other Emergency Numbers: ______________________________

Special Instructions: ______________________________

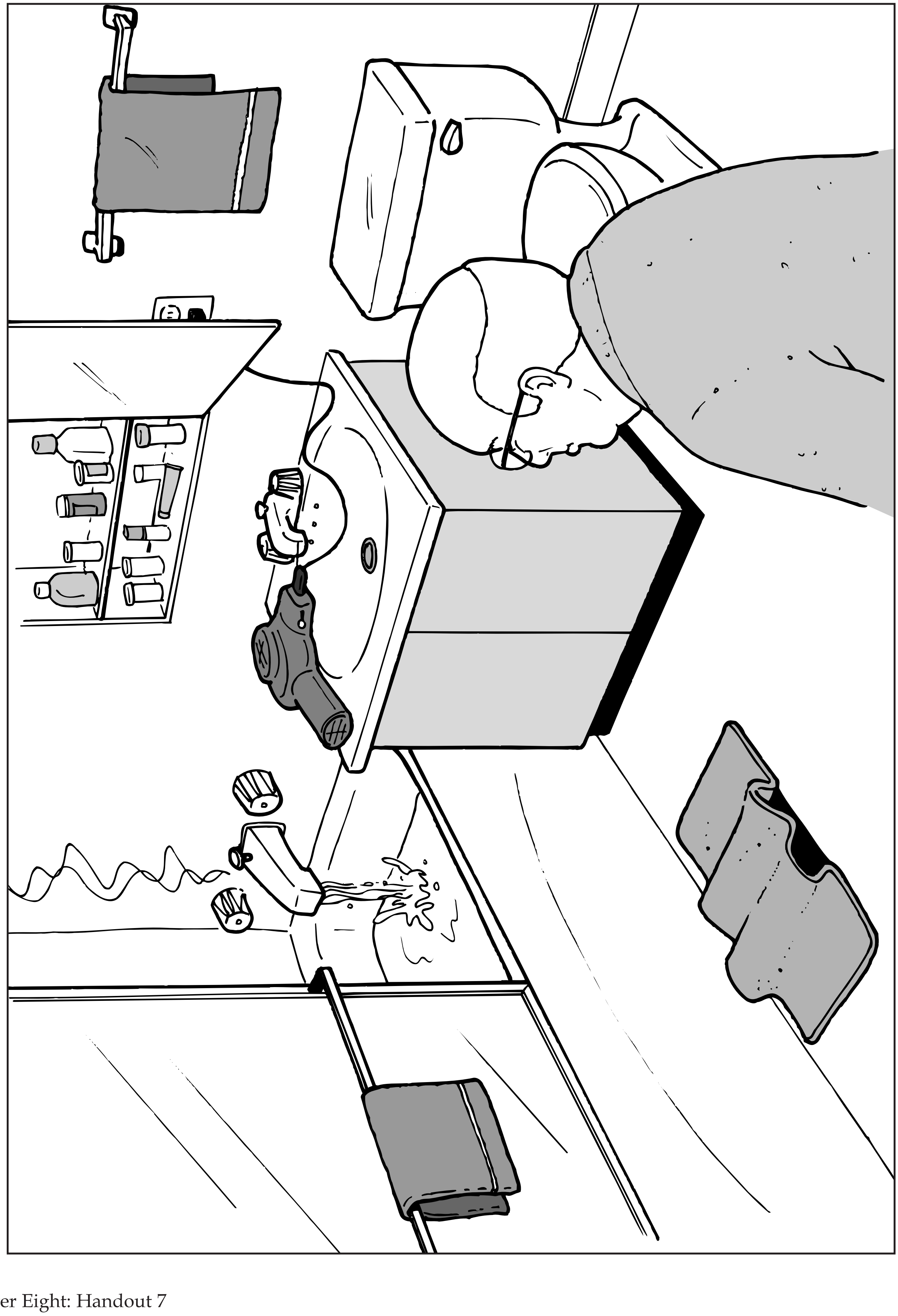
____

____

Kitchen

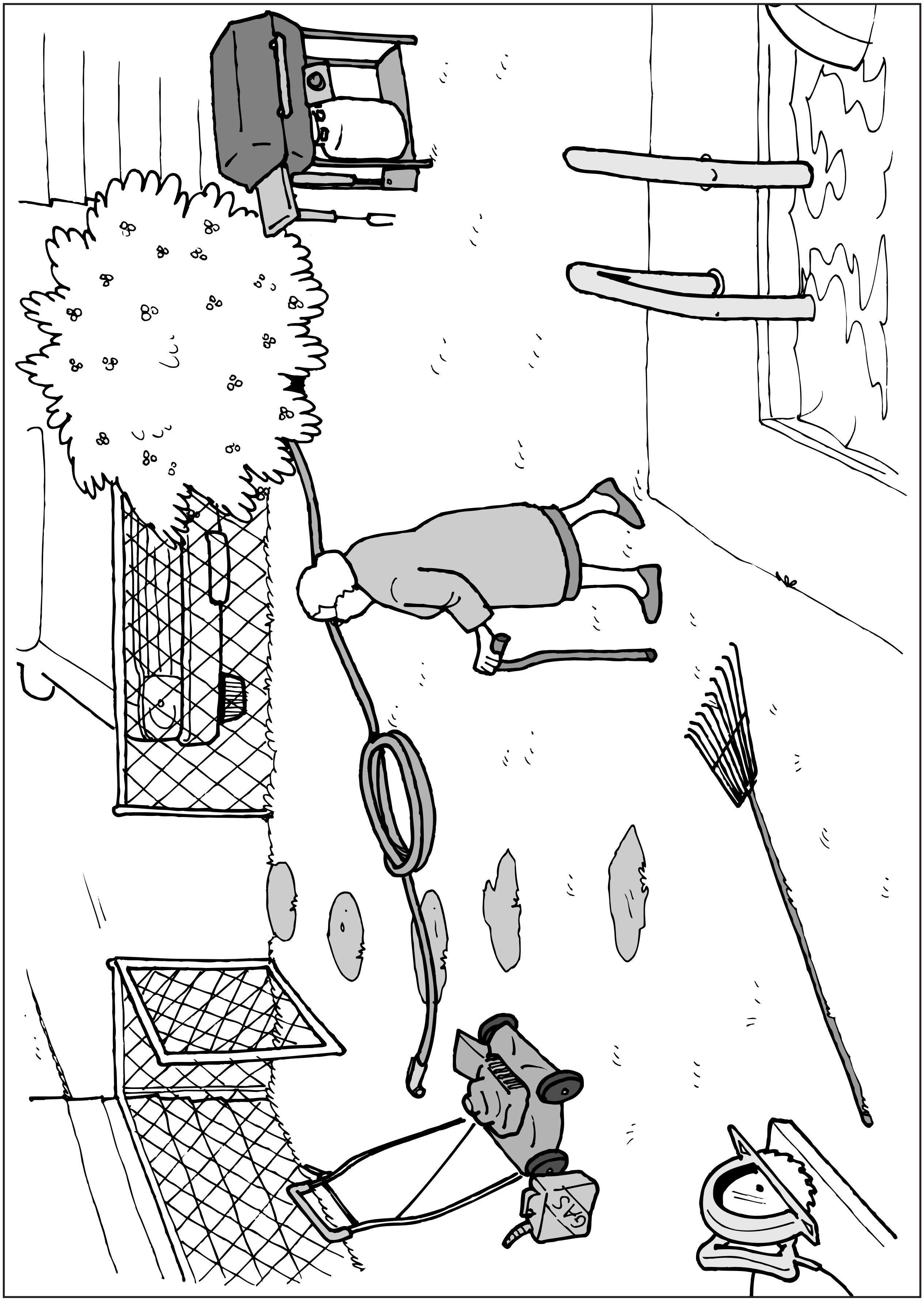


Bathroom



Living Room

Outside



Summary of Safety Hazards

(pictured in Handouts 6-9, pages 85-88)

Kitchen (Handout 6, page 85)

Stove: Open flames or hot heating elements can cause burns. Removing the knobs from the stove and oven can eliminate the temptation to turn them on. If the person with AD is still cooking, careful supervision is needed to prevent burns.

Kitchen counter: Knives, cleaning products, electric appliances, and alcohol should be stored out of sight and in a secure area.

Small rug: Small area rugs are a tripping hazard.

Water temperature: Check the temperature setting on the hot water heater. It should not be set high enough for the water to scald.

Overflowing garbage: Garbage should be covered or out of sight.

Fire extinguishers and smoke alarms: Fire extinguishers and smoke alarms should be installed.

Supervision during all cooking activities is recommended.

Bathroom (Handout 7, page 86)

Medicine cabinet: Medicines should be stored in a locked cabinet or box.

Safety devices: Safety devices such as grab bars, non-slip safety mats, and shower chairs can be used in the tub area.

Glass shower doors: Glass shower doors can be dangerous if someone falls.

Water temperature: Check the temperature setting on the hot water heater. It should not be set high enough for the water to scald.

Toilet: The toilet can be made safer with the addition of grab bars near the toilet and elevated toilet seats. Battery operated fluorescent lights over the toilet add more lighting.

Electric appliances: Electric appliances should be stored in a secure area. Their use should be supervised.

Bath mat: Bath mats create a tripping hazard.

Living Room (Handout 8, page 87)

Staircase: The stairs need a hand rail for support. Secure carpeting on the stairs to prevent tripping. Remove objects on the stairs which could cause tripping.

Windows (glare): Large, uncurtained windows create glare in a room. Draw curtains if glare is a problem.

Rugs: Small rugs create a tripping hazard.

Clutter: Clutter on table tops can cause confusion. Clutter on the floor is a tripping hazard.

Light sources: One central light source can cause shadows in corners of rooms. Lamps can eliminate the shadows, but be careful that cords don't present a tripping hazard.

Smoking: Smoking is a health and fire hazard. If the person with AD smokes, he or she must be supervised. Remove cigarettes and matches and keep them in a secure location.

Small stool: Placement of small pieces of furniture can cause tripping.

Potted plants: Large plants on the floor create tripping hazards and poisonous berries may be dangerous if eaten.

Mirror: Cover or remove mirrors if they cause confusion and disorientation.

Outside (Handout 9, page 88)

Car: Driving can be a problem (Social Reminder, page 159). Cars should always be locked.

Power tools: Store power tools and gasoline in a secure area. Supervise their use.

BBQ equipment: Matches and lighter fluid are fire hazards; a hot grill can cause burns. Always store matches and lighter fluid in secure areas and supervise grilling.

Swimming pool: Area around swimming pool should be locked. Access to pool area should be limited to supervised times.

Access to wandering: Gates should be locked to prevent wandering.

Bushes with berries: Check to see if berries are poisonous. Remove plants and replace with plants that don't tempt eating.

Hose on walk: Hoses, tools, toys, and other objects left lying about can cause tripping.

Wandering

What?

Wandering is the name of a behavior or communication breakdown that happens when a person with AD tries (often repeatedly) to leave the place where he or she is. This can happen at a nursing home or a home.

Who?

Person with AD:
- Wears an ID bracelet or necklace.
- Wears clothing with name and phone number written inside.
- Carries another ID in wallet or purse.
- Carries phone number for AA's Safe Return Program — 1-800-272-3900.

Caregiver:
- Make taking a walk together part of daily routine.
- Use communication tips from Chapter 5.

Neighbors:
- Keep names and phone numbers at hand. (Handout 5, page 84)

Police:
- May keep photo and fingerprints of person with AD on file.
- Keep information available (e.g., age, hair color, eye color, blood type, medical condition, allergies, any identifiable jewelry or body markings).

When?

Wandering is typically seen in the middle stages of the disease. It can occur at any time and caregivers need to be prepared.

Where?

Safety precautions to take inside your home:
- Put locks high or low on doors and out of normal line of vision.
- Place signs and nightlights in home to guide walking.
- Use special doorknob covers that need pressure to turn.
- Put chimes or bells on doors to alert you to the door opening.

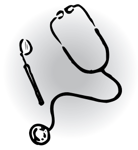
Safety precautions to take outside your home:
- Secure access to swimming pools or other water.
- Lock gates.
- Identify unsafe areas (e.g., steep stairs, busy streets, high balconies). Secure access to these areas.

Why?

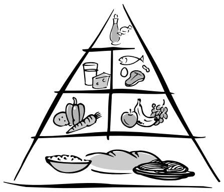
There are many different reasons: disorientation, fear, anxiety, desire to "go home," attempt to escape an environment that may seem unsafe or unpleasant. (See Chapter 5, page 56, for more information on wandering.)

Caregiver: Take Good Care of Yourself

Routine medical and dental checkups



Healthy food



Exercise

Social activities

Sense of humor

Play

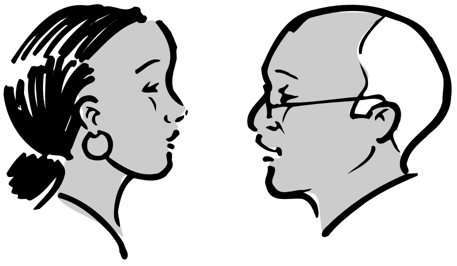
Sleep

Limit alcohol and caffeine

Ask for help

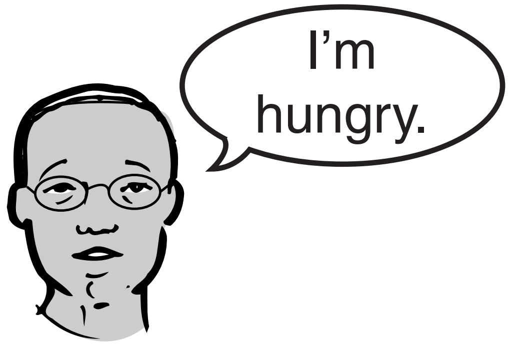
Communication Tips

Who



It takes two people to communicate.

What

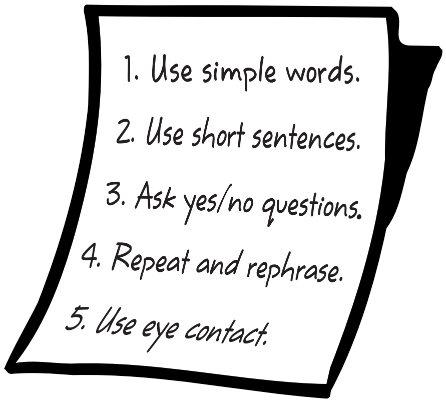


Someone has a message.

Where

Consider the environment. Try to reduce noise and distractions.

How



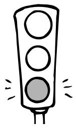
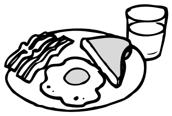
1. Use simple words.
2. Use short sentences.
3. Ask yes/no questions.
4. Repeat and rephrase.
5. Use eye contact.

Appendix One

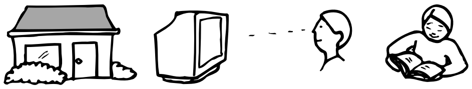
Therapy Materials

Schedules

Today (long schedule)

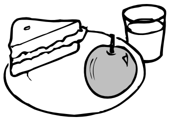




7:30 Go with ____________ to breakfast.

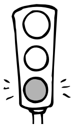



9:30 Home. Watch TV or read.


10:30 Fold laundry.

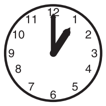
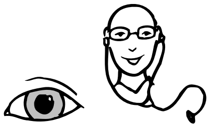
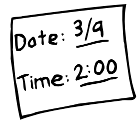



11:00 Lunch.

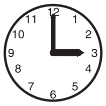




11:30 Go for a walk with ____________.

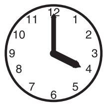
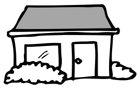
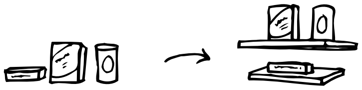

12:00 Rest.

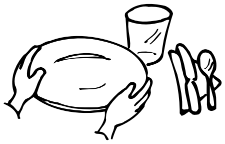
1:00 Eye doctor appointment.



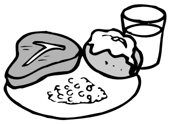

3:00 Grocery store.

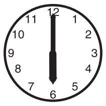
4:00 Home. Put groceries in pantry.

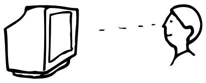
5:00 Set table.

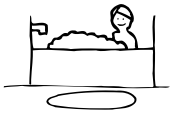
5:30 Dinner.



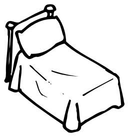

6:00 Pull weeds.

7:00 Watch TV.

9:00 Bathe.

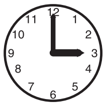



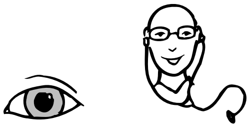
10:00 Bedtime.

Today (short schedule)

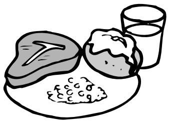
Sunday	[✓ Monday]	Tuesday	Wednesday	Thursday	Friday	Saturday

Today is Monday.





3:00 Eye doctor.



Tonight Sue and the kids are here for dinner.

Use the Bathroom

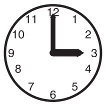
Put a check in the blank for each visit.


7:00 ______________ bathroom


9:00 ______________ bathroom


11:00 ______________ bathroom


1:00 ______________ bathroom



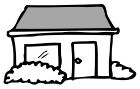

3:00 ______________ bathroom

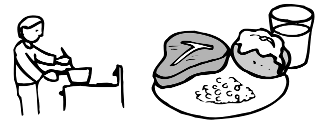

5:00 ______________ bathroom


7:00 ______________ bathroom


9:00 ______________ bathroom

Evening

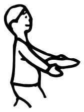

5:00

______________ will come home.


5:30

______________ will cook dinner.


I help ______________.


6:30

We eat dinner.


7:30


Take plate to the sink.


Dry dishes.

Therapy Conversation Topics

Daily Life

Entertainment

Time Line

Cooking

Cooking

Memory Prompts: wooden spoon, wooden rolling pin, measuring spoons and cups, pie pan, bowl, muffin tin, cookbooks, recipe cards, apron, assorted extracts (to smell)

Music: "Someone's in the Kitchen with Dinah," "Billy Boy," "Yes, We Have No Bananas," "That's Amoré"

Context Setting:

Level 1: I love to cook. I cook meatloaf — ground meat, egg, and ground crackers mixed together. I cook fried okra. Slice the okra and mix it with egg and cornmeal. Then fry it. I love to barbecue ribs too. What do you like to cook?

Level 2: I love to cook meatloaf, always a different way. Squishing the cold ground meat together with yellow, runny eggs and crushed crackers, it feels slippery and scratchy at the same time. Then I put the mixture in the pan to bake. Mmmmm, it smells good!

I love to cook fried okra. You cut the okra into little sections and then moisten it with eggs and then dump the little okra segments in yellow cornmeal. Then you fry the okra until it is crisp.

And I love to barbecue over charcoal, cooking baby back ribs slowly, very slowly, always basting on a special barbecue sauce until the ribs are tender and just a little crunchy along the edges. I love to eat them with corn on the cob that just oozes with butter and has salt all over it.

That's what I love to cook. How about you?

Yes/No Questions

Do you use eggs and flour to make a cake? (yes)

Does maple syrup taste good on a hamburger? (no)

Does the refrigerator keep food hot? (no)

Do you use a frying pan to scramble eggs? (yes)

Do you use a rolling pin to make a pie crust? (yes)

Forced-Choice Questions

Is an apple or a carrot a fruit? (apple)

Do people eat pancakes or hot dogs for breakfast? (pancakes)

Are fruit or vegetables in a cobbler? (fruit)

Do you bake cookies or ice cream in an oven? (cookies)

Do you make salad with lettuce or French fries? (lettuce)

Sewing

Sewing

Memory Prompts: different textures and types of cloth, buttons, zipper, thimble, sewing patterns, pincushion, measuring tape, other sewing notions (e.g., rickrack)

Music/Poetry: "The needle's eye that doth supply
The thread that runs so true.
Many a beau have I let go
Because I wanted you."

Context Setting:

Level 1: My mom taught me how to sew. She showed me how to thread a needle. She always made me use a thimble. I still stuck my fingers — Ow! I learned to make an apron and then a dress. I loved to sew, but I hated putting in zippers!

Level 2: The first thing I ever made by sewing was an apron. I was 8 years old. My mother showed me how to thread the needle. I hated trying to put that little tiny thread through the little tiny needle hole. I cut a piece of cloth the right size for an apron and one for the sash. The material was covered with little blue flowers. I made two rows of large, loose stitches across the top of the rectangle of cloth. Then my mom showed me how to pull the threads to draw up the cloth into little pleats. I attached the sash to the top and hemmed the bottom of the cloth. It was the first piece of clothing I sewed, but it wasn't my last!

Yes/No Questions:

Do shirts have buttons? (most)

Is a thimble used on a toe? (no)

Are pins kept in a pincushion? (yes)

Do patterns help you make clothes? (yes)

Does a sewing machine use electricity? (modern ones do)

Forced-Choice Questions:

Do you use scissors or a knife to cut cloth? (scissors)

Does thread go in a needle or a spoon? (needle)

Would you use satin or denim for a pair of pants? (denim)

Do pins or staples keep pieces of cloth together while you sew? (pins)

Would you put rickrack on a little girl's dress or a man's shirt? (little girl's dress)

Wood Working

Wood Working

Memory Prompts: toolbox; hammer; wrench; screwdrivers (Phillips and flathead); sandpaper; sawdust; turpentine (to smell); safety goggles; assortment of nuts, bolts, and washers

Music: "Pop Goes the Weasel"

Context Setting:

Level 1: I remember the first time my dad let me into his workshop. We sanded pieces of wood. "Measure twice and cut once" my dad always said. He even let me use his sharp tools that day to cut the wood. We worked all afternoon. When we finished, my mom had a new birdhouse for her birthday.

Level 2: I'll never forget the smells in my dad's workshop: turpentine and sawdust. My dad never let me handle his tools.

"They're not toys, Son," he would say.

I remember my surprise one day when my dad told me we had a job to do together. I must have been 5 or 6 years old. He had some old scraps of wood that he showed me how to sand. Ouch, I got a splinter! He showed me the plan we were going to use. We used an old tape measure to measure the lengths of wood. My dad always said, "Measure twice, cut once."

We penciled the marks on the wood and he helped me use the saw. Back and forth, until the lengths were right. He held the pieces together and showed me where to put the nail. My dad had to start the nail, but then I got to finish. We drilled a big hole in one side and then we were finished. My mom had a new birdhouse for her birthday!

Yes/No Questions:

Do you use a hammer with nails? (yes)

Do you use sandpaper to make wood rough? (no)

Do you use a hammer to cut wood? (no)

Do you use a wrench to tighten and loosen bolts? (yes)

Should you "measure twice and cut once"? (yes)

Forced-Choice Questions:

Do you use a hammer or a screwdriver with nails? (hammer)

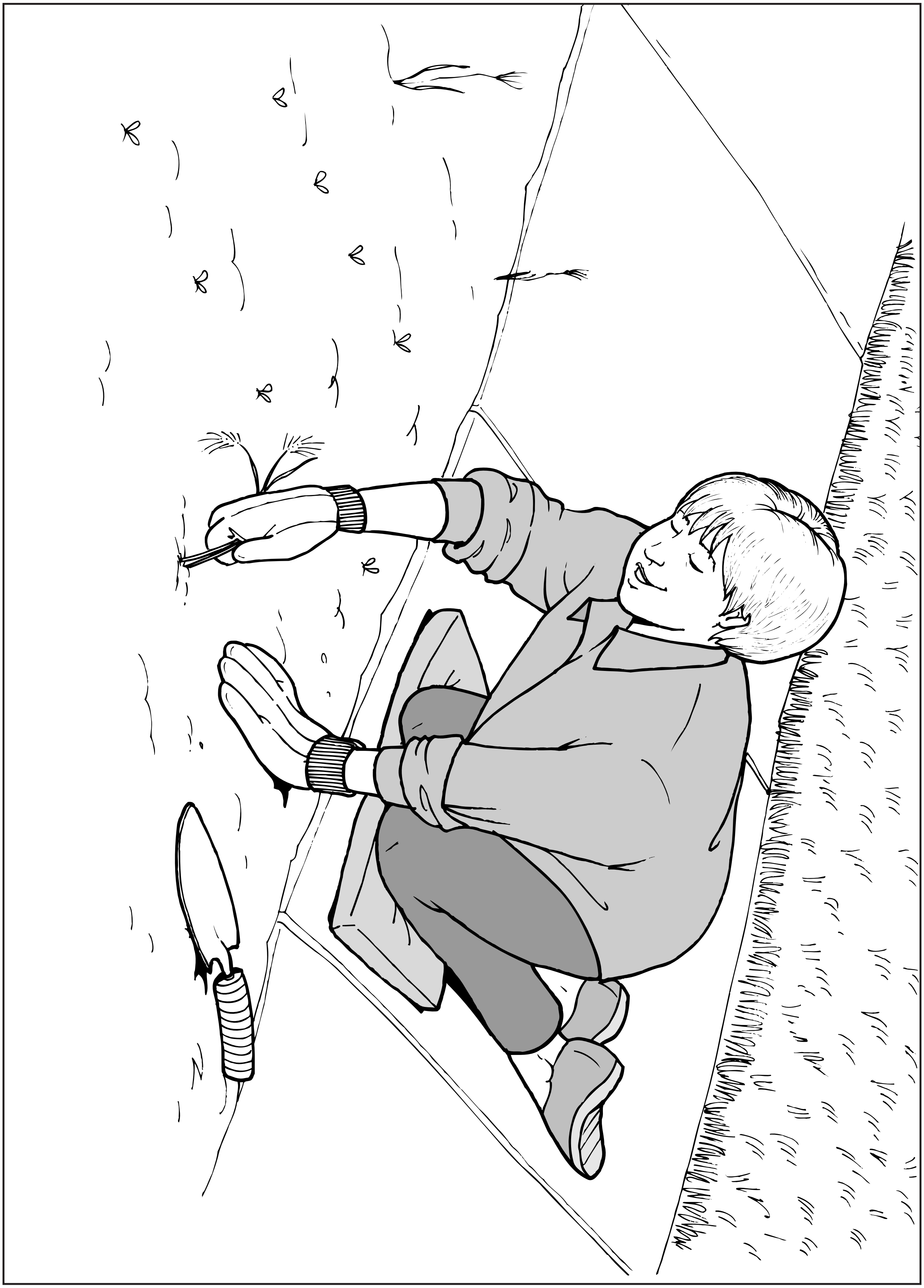
Does a carpenter or a mechanic work with wood? (carpenter)

Does a saw or a hammer cut wood? (saw)

Do nails go in wood or paper? (wood)

Do you store tools in a basket or a toolbox? (toolbox)

Gardening



Gardening

Memory Prompts: seed packets, bulbs, gardening tools (e.g., small shovel, trowel, clippers), small tubs of gardening soil (to feel), gardening gloves, watering can, mister

Music: "White Coral Bells," "An English Country Garden"

Context Setting:

Level 1: I like getting the garden ready in the spring. First you till the soil. Break up the clods. Then rake the soil smooth. Use your hands to make the rows and drop the seeds in. Then it's time to wait for the seeds to grow. Little plants in straight, green rows.

Level 2: The best part of gardening was the first green shoots. Getting the soil ready was not bad because you would burrow your hands in it after you had tilled and it was always warm. If you had worked hard, there were no clods, the good rich-smelling loam just powder falling through your fingers. And you could rake it, carefully and smooth, making sure it was a perfectly even bed to make rows in. But the best was still that morning a week or so later when, whether you had planted corn or beans or okra or whatever—that morning when you came down and a perfectly straight row of little green tips were shining at you from out of the soil. It was your garden and it smelled like the soil. The little buds had just escaped the ground, getting ready to spring up straight and be plants.

Yes/No Questions:

Is a measure of land an acre? (yes)

Do plants need water to grow? (yes)

Do you plant seeds to grow radishes? (yes)

Can you use a hoe to weed? (yes)

Does a hard freeze help young plants? (no)

Forced-Choice Questions:

Does an apple grow on a tree or a vine? (tree)

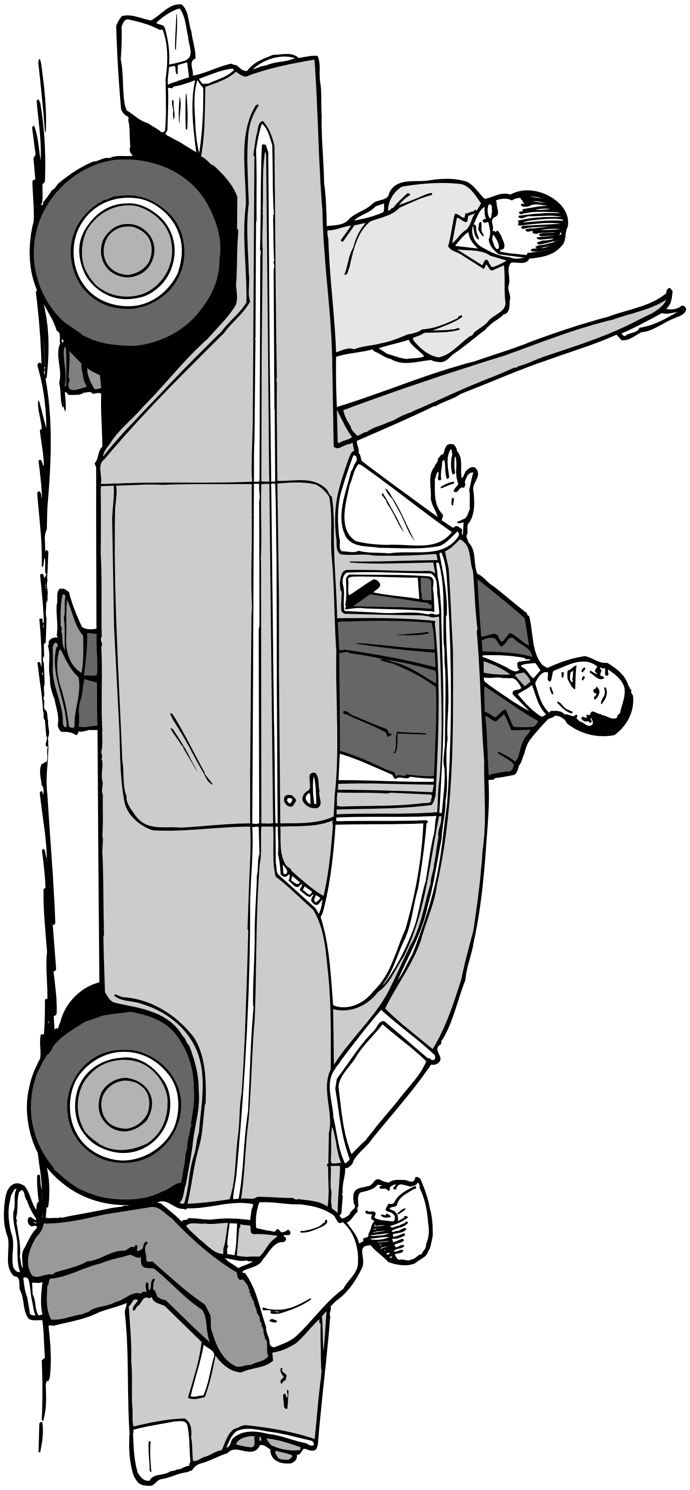
Is it easier to grow a tomato from a seed or a plant? (plant)

Do farmers use tractors or trains? (tractors)

Does John Deere or John Smith make tractors? (John Deere)

Is dirt or rocks better in a garden? (dirt)

A New Car



A New Car

Memory Prompts: empty oil containers, auto repair tools (e.g., wrench), chamois cloths (to feel)

Music: "Merry Oldsmobile," "Little Blue Coupe," "Little Old Lady from Pasadena"

Context Setting:

Level 1: We went to look at cars. We were not going to buy one. We saw a Chevrolet Bel Air. It was beautiful and red. It had fins. It smelled like a new car. I had to climb in the back. My dad looked under the hood. How could we ever resist? We just had to buy that car!

Level 2: We were not going to buy a new car. Not today. We were just looking.
"Folks, this is a 1956 Chevrolet Bel Air. It's the finest car made."
"We can't buy today. We just want to look."
"That's quite all right. Why don't you get in here? Get behind the wheel."
"Oooohh, look at those fins!"
"They're horizontal stabilizers. They keep the car on the road."
"Look at that one!"
"Oh, we don't want a red one. Do we?"
"Look at the way it shines!"
"Come here, young man. Why don't you climb in the back?"
And you would climb in the back. And there would be the smell of the new car. No one can ever describe how a new car—a brand new car sitting in the showroom— how it smells.

And your father would be walking around the car, looking at the engine, then talking about trade-ins and interest and other things.

And you would know, running your hand over the beautiful, spotless seat covers, that you were all going to drive home in the 1956 red Chevrolet Bel Air.

Yes/No Questions:

Do you ever need to change the oil in a car? (yes)

Do you sometimes need to add air to the tires? (yes)

Can you use jumper cables to start the radio? (no)

Do you push in the clutch to shift gears? (yes)

Did Henry Ford make the first Oldsmobile? (no)

Forced-Choice Questions:

If the car doesn't start, is it because of the battery or a flat tire? (battery)

Does a mechanic or a doctor repair a car? (mechanic)

Do you need a jack or a fork to change a tire? (jack)

Do you need to add antifreeze in the winter or the summer? (winter)

Is the battery charged by the generator or the spare tire? (generator)

Wedding

Wedding

Memory Prompts: bridal veil, garter, bride and groom cake top, wedding photos

Music: "Froggie Went A-Courtin'," "Let Me Call You Sweetheart," "Wedding March"

Context Setting:

Level 1: At the wedding, everything was going wrong. The best man lost the ring. The bridesmaid ripped her dress. The air conditioning wasn't working. Everything cost too much. Then the wedding started. The best man was there with the ring. The music started. The bride was beautiful. Everything was okay.

Level 2: Because it is a wedding, everything has gone wrong. One of the bridesmaids ripped her dress. The best man left the ring in the motel room. He has taken a car to get it, but he is stuck in a traffic jam. He can't be late because there's another wedding at four o'clock. The air conditioning is not working.

Because it is a wedding, everything has gone wrong. Now it is time to start. The bride's family is seated on one side. The groom's family is seated on the other side. The organ music starts. THE BEST MAN IS BACK! THE RING IS HERE!

And now, everyone is filing in—the groom, the best man, the groomsmen, the bridesmaids, the maid-of-honor.

There is a hush. The "Wedding March" starts . . . Tum tum ta ta, Tum tum ta ta . . . Everyone turns. The bride enters, holding the arm of her father. She looks up and smiles. The groom, far down at the altar, smiles back at her.

And because it is a wedding, everything is all right.

Yes/No Questions:

Is a woman getting married called a bride? (yes)

Is a man getting married called a groom? (yes)

Does a flower girl carry toys? (no)

Does a bride have bridesmaids? (usually)

When you sneak away to be married, is it called eloping? (yes)

Forced-Choice Questions:

Do brides and grooms say, "I do" or "I won't"? ("I do.")

Is the party after a wedding called a reception or a disco? (reception)

Does the bride wear a wedding ring or a wedding belt? (wedding ring)

Are the first words of the wedding march, "Here comes the bride" or "I like the bride"?
("Here comes the bride")

Is the groom's helper the best man or a baseball player? (best man)

Baby

Baby

Memory Prompts: rattles, cloth diapers, baby clothes, baby powder (to smell), bottles

Music: lullabies (e.g., "Rock-A-Bye Baby," "Hush, Little Baby," "Irish Lullaby")

Context Setting:

Level 1: It is late at night. The baby is crying. You wonder, "Is the baby wet? Is the baby hungry? Is the baby lonely?" You change the diaper and pick the baby up. Walk, walk, walk the baby. Rock the baby. Sing a quiet song. The baby goes to sleep again. The house is quiet.

Level 2: It is two AM, very dark and very quiet, except for the baby crying in the other room, and it is your turn. The hardwood floor is cold against your bare feet. You lean over the crib and you instantly smell why the baby is crying. You reach for a clean cloth diaper, just beside the crib.

You carefully remove the safety pins, big safety pins, and lay them on the table. Then you hold the baby's feet together and lift his legs so that his little bottom comes up off the crib sheet. You slide the dirty diaper out and carefully put it on the table because it must be washed out.

Then you wash the baby with a warm, wet washcloth. The crying is softer now. You put a new, dry diaper on, and fasten it snug with the pins. Then you pick the baby up and hold the little body, firm and warm against your shoulder. Your hand is behind his head.

Walk, walk, walk.

The baby is asleep again—and the house is quiet.

Yes/No Questions:

Do babies cry a lot? (yes)

Do babies drink from bottles? (many do)

Do babies sometimes need to be changed? (yes)

Do you pat a baby's head to burp it? (no)

Do most babies like to be rocked? (yes)

Forced-Choice Questions:

Do babies wear diapers or blue jeans? (diapers)

Do little babies crawl or jump? (crawl)

Do babies drink milk or coffee? (milk)

Do babies sleep in cribs or chairs? (cribs)

Do you sing lullabies or marches to babies? (lullabies)

Elementary School

Elementary School

Memory Prompts: laptop chalkboards and chalk, school photographs, apples

Music: "America the Beautiful," "School Days," "You're a Grand, Old Flag"

Context Setting:

Level 1: The school day passed slowly. We had fun at recess, but then it was time to work. I would write on a tablet of paper. There was an Indian chief on the cover. Sometimes I wrote on the blackboard. I'd always look at the clock. I wanted it to be three o'clock and time to go home. But it would only be ten o'clock in the morning.

Level 2: We would come in from recess where we had been playing softball. I remember it being very hot and, of course, we were sweating. The line was long behind the water fountain. Thomas Owens always stood behind me, and when it was finally my turn, he would poke me in the ribs to make me stop drinking.

"Quit!"

"What?"

"Quit!"

"I'm not doing anything!"

There were always several wads of chewed-up bubble gum in the bottom of the fountain and the little stream of water was always warm.

Our classroom was on the second floor. We would have to write things on tablets of coarse paper. On the tablet's cover was the head of an Indian chief in full headdress. I can remember seeing tiny flakes of wood in the paper, and my arm, still sweating from recess, made dark, wet stains on whatever I had written.

I would look up at George Washington's picture and at the clock beside it. I was hoping it would be three o'clock and time for the final bell so that we could go home. But it was just after recess, only ten o'clock in the morning.

Yes/No Questions:

Is elementary school for two years? (no)

Does a teacher use a blackboard? (yes)

Do children go to school in the summer? (not usually)

Do children play on the roof at recess? (no)

Do children learn to read at school? (yes)

Forced-Choice Questions:

Do children ride a bus or an airplane to school? (bus)

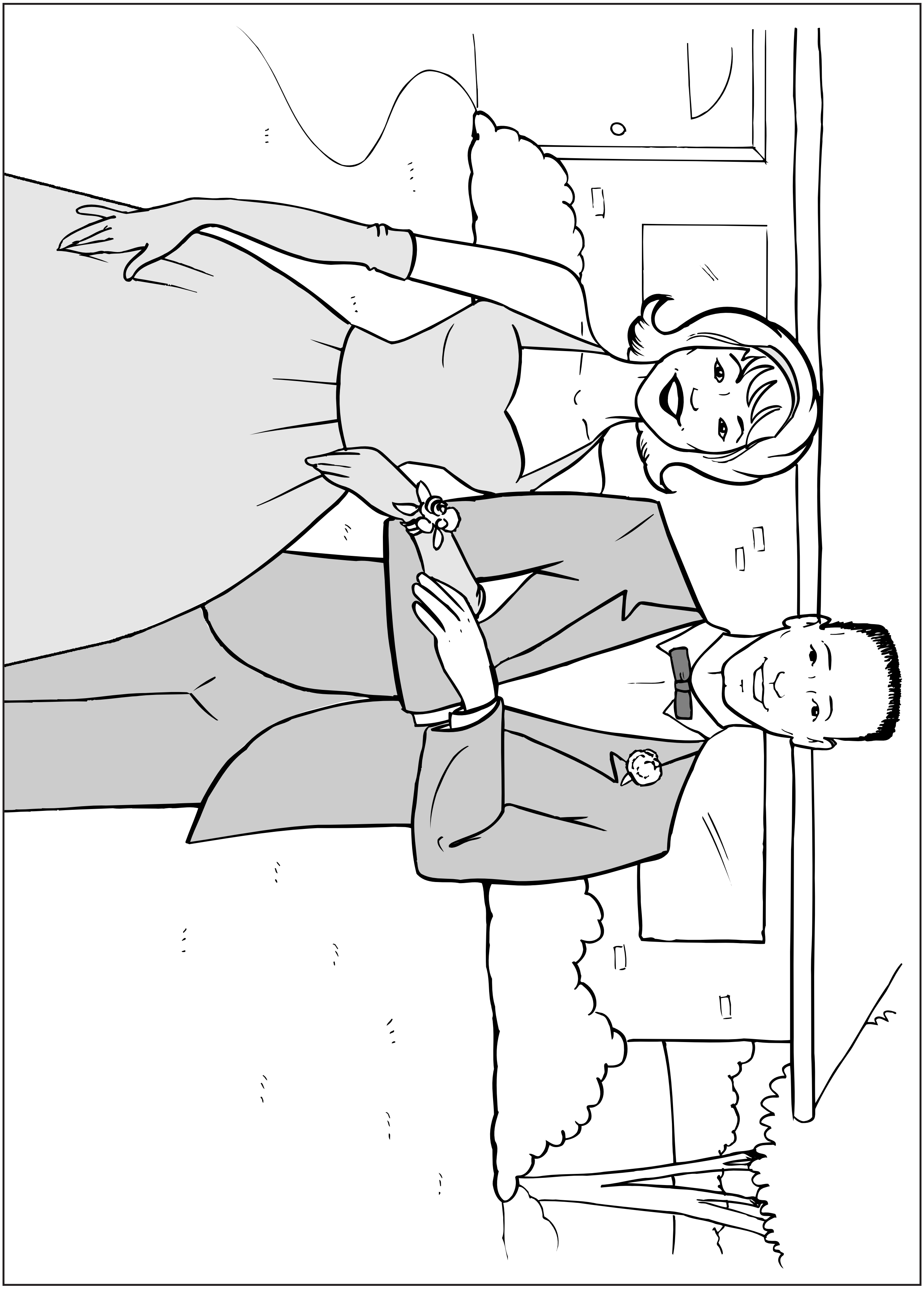
Do children need pencils or yo-yo's at school? (pencils)

Can children eat lunch or supper at school? (lunch)

Do children sit at desks or on sofas at school? (at desks)

Do children who misbehave have to sit in the corner or in the sink? (in the corner)

High School Prom



High School Prom

Memory Prompts: class ring, prom photos, yearbooks, corsage (to smell)

Music: “That’ll Be the Day,” “Last Dance,” “The Band Played On,” “The Tennessee Waltz”

Context Setting:

Level 1: It is time for the prom. The theme is Night in Paris. Some girls made a giant Eiffel tower out of wire and paper. Fast songs by Buddy Holly are played. Everyone likes the slower songs best. Couples dance slowly. It is the Senior Prom, 1965.

Level 2: This is my favorite high school memory. It was the night of the prom. The theme of the prom was Night in Paris, so the town Civic Center was decorated to look like Paris, France. The juniors made an Eiffel Tower out of baling wire and a lot of papier-mâché. Along the walls of the Civic Center were little tables with red checkered tablecloths and on them there were candles.

The lights went down and the music started. It was 1965. Buddy Holly was singing, “That’ll be the day—uhoh—that’ll be the day—uhoh.”

But the song was too fast. Some couples danced. But many of the girls stood by one wall talking and giggling.

Another song started. This song was played over and over. It was the song you could dance to in 1965. Floyd Cramer. “Last Dance.” It was simple and slow.

Above the Eiffel Tower a silver ball turned slowly. Light glittered around the walls as the ball turned. The boys crossed the floor to the girls, took their hands, and led them onto the dance floor. They rocked back and forth, all the couples, moving slowly around the huge, papier-mâché Eiffel Tower.

Yes/No Questions:

Can high school graduates go to college? (yes)

Do sophomores go to high school? (yes)

Do students go to high school for four years? (yes and no)

Do students have more than one teacher? (yes and no)

Can students play football and basketball at school? (yes)

Forced-Choice Questions:

Is the prom a dance or a test? (dance)

Are seniors or freshmen ready to graduate? (seniors)

When you graduate from high school, do you get a magazine or a diploma? (diploma)

Is the high school run by a principal or a doctor? (principal)

In your last year of high school, are you a senior or a mechanic? (senior)

Pets

Memory Prompts: stuffed animals, feeding bowl, catnip mouse, dog bone, bird cage

Music: “How Much Is that Doggie in the Window?” “B-I-N-G-O”

Context Setting:

Level 1: This is my favorite pet story. I had a beagle named Smokey. He loved to chase squirrels. One day he chased a squirrel into the pasture. “Bayooooo! Bayoooo!” He chased that squirrel right up into the tree. The squirrel climbed to the top and Smokey was right behind him. That beagle had somehow climbed the tree. When Smokey saw where he was, he started to yelp and cry. I helped him down. He licked me all over. He was my favorite dog.

Level 2: Everyone has a favorite pet story. Here is mine. It was a cold day. My brothers and my father and I were in the north pasture, gathering wood for the fireplace. Smokey, our beagle, was digging in the clumps of brush. Suddenly he went tearing away after a red squirrel. “Bayoooo! Bayoooo!”
“He’s gonna get that squirrel!”
“No! Squirrel’s in the tree!”
And it was true—the squirrel had reached a huge hackberry tree, bare of limbs. He leapt into it, claws scratching, and disappeared into a hole in the trunk. We went back to work. Some minutes later my brother said, “Look!”

I turned my head and will never forget what I saw. At the top of the tree was the squirrel. And in the middle of the tree, working his way up, thirty feet off the ground, was our dog Smokey. The beagle had climbed the tree!

Just then Smokey realized how far off the ground he was. He started yelping and crying. I’ve forgotten how I climbed high enough to get my arms around him. But I remember him licking my face as I climbed down with him. He was my favorite dog ever.

Yes/No Questions:

Are dogs good pets? (most)

Do cats drink milk? (some)

Does a pet bird live in a cage? (yes)

Do dogs sometimes get fleas? (yes)

Do fish live in the sink? (no)

Forced-Choice Questions:

Do dogs bark or sing? (bark)

Do dogs wear collars or hats? (collars)

Do cats purr or growl? (purr)

Do dogs have kittens or puppies? (puppies)

Do cats scratch or clap? (scratch)

Baseball

Baseball

Memory Prompts: baseball, glove, pennant, baseball cards

Music: "Take Me Out to the Ball Game"

Context Setting:

Level 1: I always liked a new baseball glove. I was a catcher. I always got a catcher's mitt. I bought it at the store with my dad. We rubbed oil on the glove. It had a special smell.

Level 2: What I remember most about baseball is the new glove. The glove was always special. It could be a Wilson or a Rawlings glove. But you would go buy it with your dad. It might be a mitt if you were a first baseman or a catcher. The two of you would bring it home, and the weather would be very hot. In the garage was always a can of neat's-foot oil. The two of you slathered the oil all over the glove. I can still remember the smell of the oil in the dark, hot garage. Then you would put a baseball in the glove, fold the oiled glove tight around the ball, and tie it with strong cord. The next morning the glove had a pocket; it was ready.

Yes/No Questions:

Are there 12 players on a baseball team? (no)

Are three strikes an out? (yes)

Does the pitcher throw the ball to the catcher? (yes)

Does the batter try to catch the ball? (no)

Did Babe Ruth play baseball? (yes)

Forced Choice Questions:

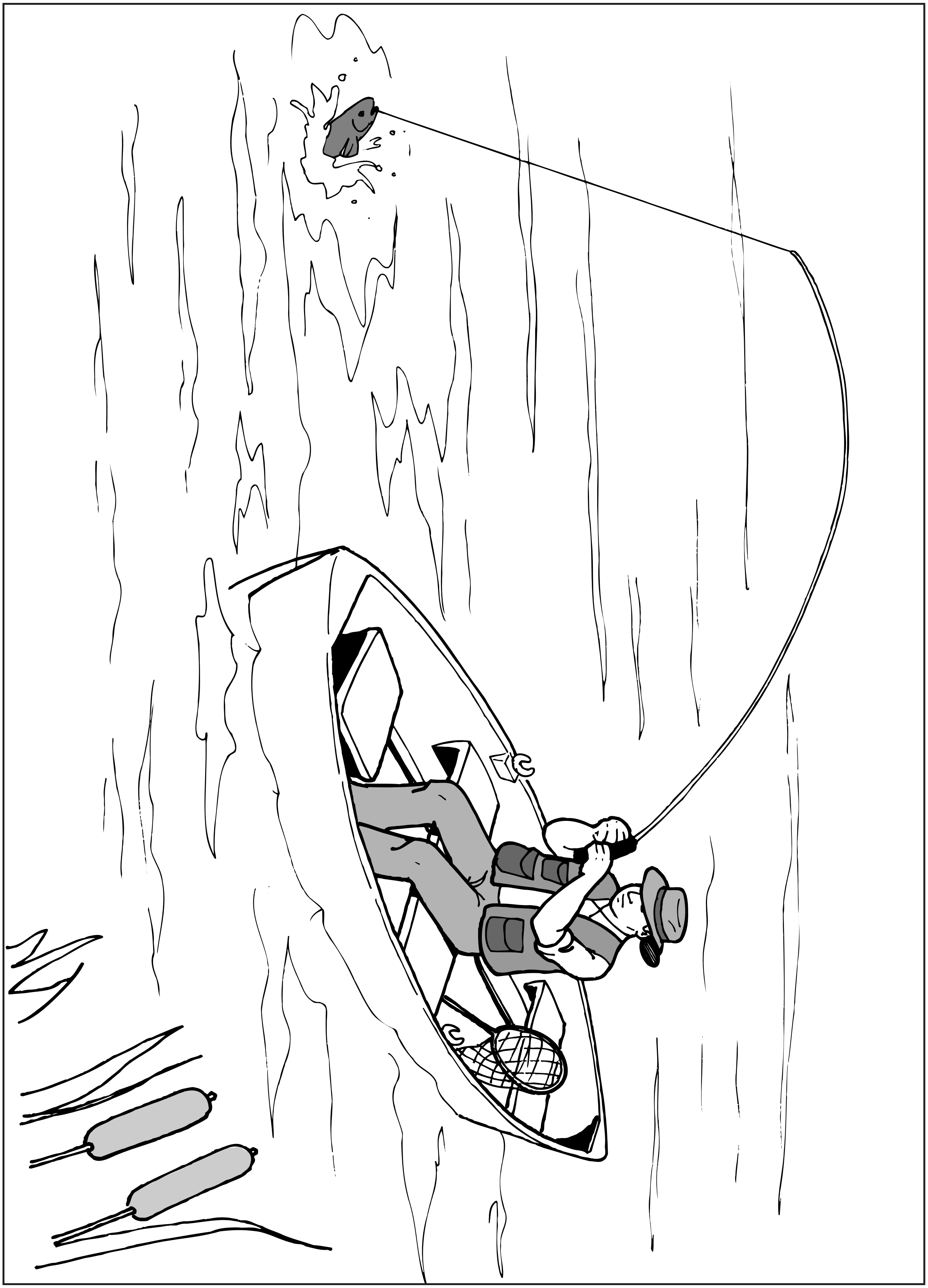
Are there five or nine players on a baseball team? (nine)

Are two or three strikes an out? (three)

Are four or five balls called a walk? (four)

Was Ty Cobb or Lou Gehrig called "The Georgia Peach"? (Ty Cobb)

Is the baseball championship called the City Series or the World Series? (World Series)



Fishing

Fishing

Memory Prompts: tackle box, fishing rod, assortment of lures (Be careful to remove hooks for safety.)

Music: "Gone Fishing"

Context Setting:

Level 1: I remember fishing with my dad. It was summer. We went to the creek near our house. We took drinks and crackers. We always used worms for bait. I would feel a nibble, then another. The bobber would go under the water.

"Now, yank!" said my dad.

Usually the fish got away. But we didn't care. My dad and I had fun fishing.

Level 2: I remember going fishing with my dad on the creek near our farm. We would dig up worms from our garden. Then we would go to a filling station, early in the morning, and get RC colas and some Vienna sausages with crackers. The fishing hole was a couple of miles from the farm and it would take us over half an hour to make our way to it, walking through tangles and briars. The sun would just be up and the summer air getting warmer when we would cast out into the middle of the creek and watch the red plastic bobbers, sitting upright in the water, just waiting for something to take the bait. After awhile, there would be a nibble, and then another, and finally the bobber would disappear.

"Now! Yank now!"

Sometimes the fish would get away, and even if we caught it, it would never be much more than a perch or sunfish. But that wouldn't matter. What was fun was that it was my dad and me, fishing on the creek.

Yes/No Questions:

Do you put a worm on a hook? (yes)

Can you fish in an ocean? (yes)

Is a marlin a saltwater fish? (yes)

Can you fish from an airplane? (no)

Can you fish in the winter? (yes)

Forced-Choice Questions:

Is a bass a fish or a lizard? (fish)

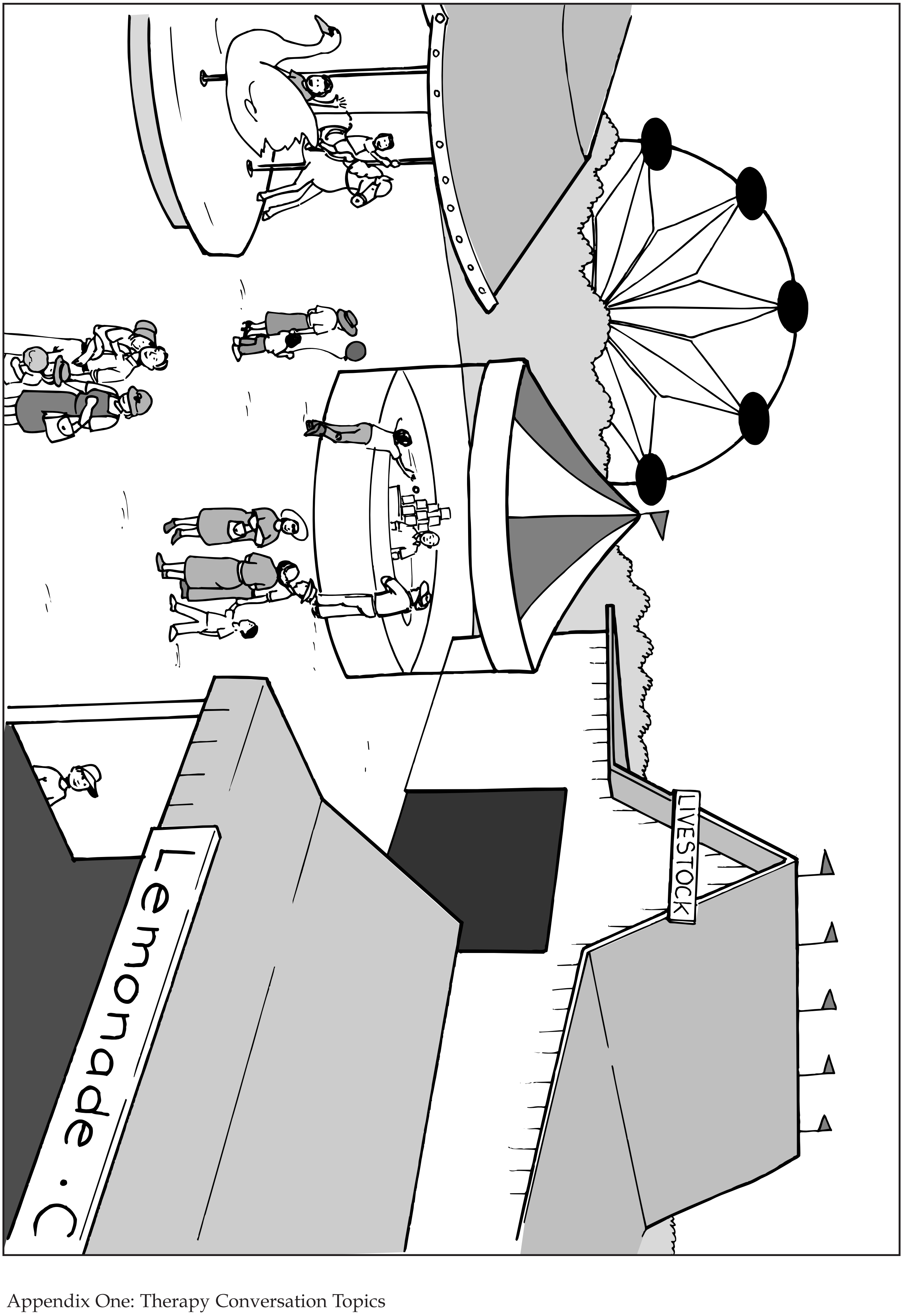
Do most people fish in the winter or the summer? (summer)

Can you fish in a swimming pool or a river? (river)

Does an outboard motor or an eggbeater power a boat? (outboard motor)

Would a bass strike at a lure or a spare tire? (lure)

Fairs



Fairs

Memory Prompts: fair ribbons, midway prizes (e.g., small stuffed animals)

Music: "Meet Me in St. Louis," "Our State Fair"

Context Setting:

Level 1: We loved the State Fair! Mom always took canned preserves. One year she won a red ribbon. My dad liked the stock barns. He would look at the red Hereford bulls. My brother and I loved the Automobile Building with all the new cars. We all went to the midway at night. We ate corn dogs. We rode the giant roller coaster.

Level 2: There was nothing like the State Fair for us. My brother and I would look forward to it all year, and when the cool crisp days of October came around, we knew it was near. Mom would have canned her preserves, every year thinking to win a blue ribbon and never doing much better than a red. Dad would be anxious to go to the stock barns, to look at the prize-winning sheep or the fat, red Hereford bulls, all standing in the stalls with FFA boys currycombing them. Those places would be our first stop, but then we would head for the Automobile Building to see the new model Fords or Chevrolets. I liked the shiny red ones that they would let you sit in, the upholstery smelling the way that only new cars do.

And after that, of course, the midway. "KNOCK DOWN TWO MILK BOTTLES! JUST TWO MILK BOTTLES WINS YOU A . . ."

We never won. And it looked so easy. But it wasn't important. Because you could always smell the corn dogs. And you always knew that you were going to ride The Lightning Roller Coaster, way up high over the fairground, watching the lights come on and the city glittering in the cold October night.

Yes/No Questions:

Can a cow win a ribbon at a state fair? (yes)

Can a pie win a ribbon at a state fair? (yes)

Does the cattle barn at a fair have carnival rides? (no)

Is a Ferris wheel at a state fair? (yes)

Can you get cotton candy at a state fair? (yes)

Forced-Choice Questions:

Are pigs or motorcycles at fairs? (both)

Are state fairs in the fall or spring? (fall)

Is cotton candy pink or blue? (both)

Does the best animal get a blue or yellow ribbon? (blue)

Would you win stuffed animals in the midway or the animal barn? (midway)

Camping

Camping

Memory Prompts: map, camping gear (e.g., flashlight or lantern, canteen, binoculars)

Music: "Home on the Range," "Green Grass Grew All Around," "Shine On, Harvest Moon"

Context Setting:

Level 1: I like to go camping when it is cold. Put up the tent before it gets dark. Then build the campfire. You need lots of kindling and little sticks to start it. Then build the fire bigger. At night you can look at the stars. You can tell stories around the campfire. Bacon frying for supper smells good.

Level 2: You do the best camping when it is cold, I think, and you can get down in a draw or ravine, out of the north wind that's whistling over you. You get there in the late afternoon, knowing that in winter the sun will be a gray disk low in the sky, and that it will get dark quickly. Then one of you stakes the tent, while the other gathers wood. You have to start with tiny little splinters of kindling, good and dry. Then you need a lot of branches that are about as thick as your finger and bigger ones maybe wrist size. Arrange them like a tepee and you can watch the air drafts sucking the young, bright orange fire up through the top of the tepee, while you gradually drag bigger logs around the campfire. Then you fry the bacon in an old skillet and get the coffee going.

You might tell stories later on when the wind is howling in the trees above, or you might wander up into a clearing to watch the stars late at night; but somehow I think nothing is ever better than that first smell of bacon on the campfire you've made.

Yes/No Questions:

Do you need a sleeping bag when you camp? (sometimes)

Do you cook over a fire when you camp? (sometimes)

Can you camp in national and state parks? (yes)

Can you take electrical appliances when you camp? (only if your campsite is equipped)

Do binoculars help you see things far away? (yes)

Forced-Choice Questions:

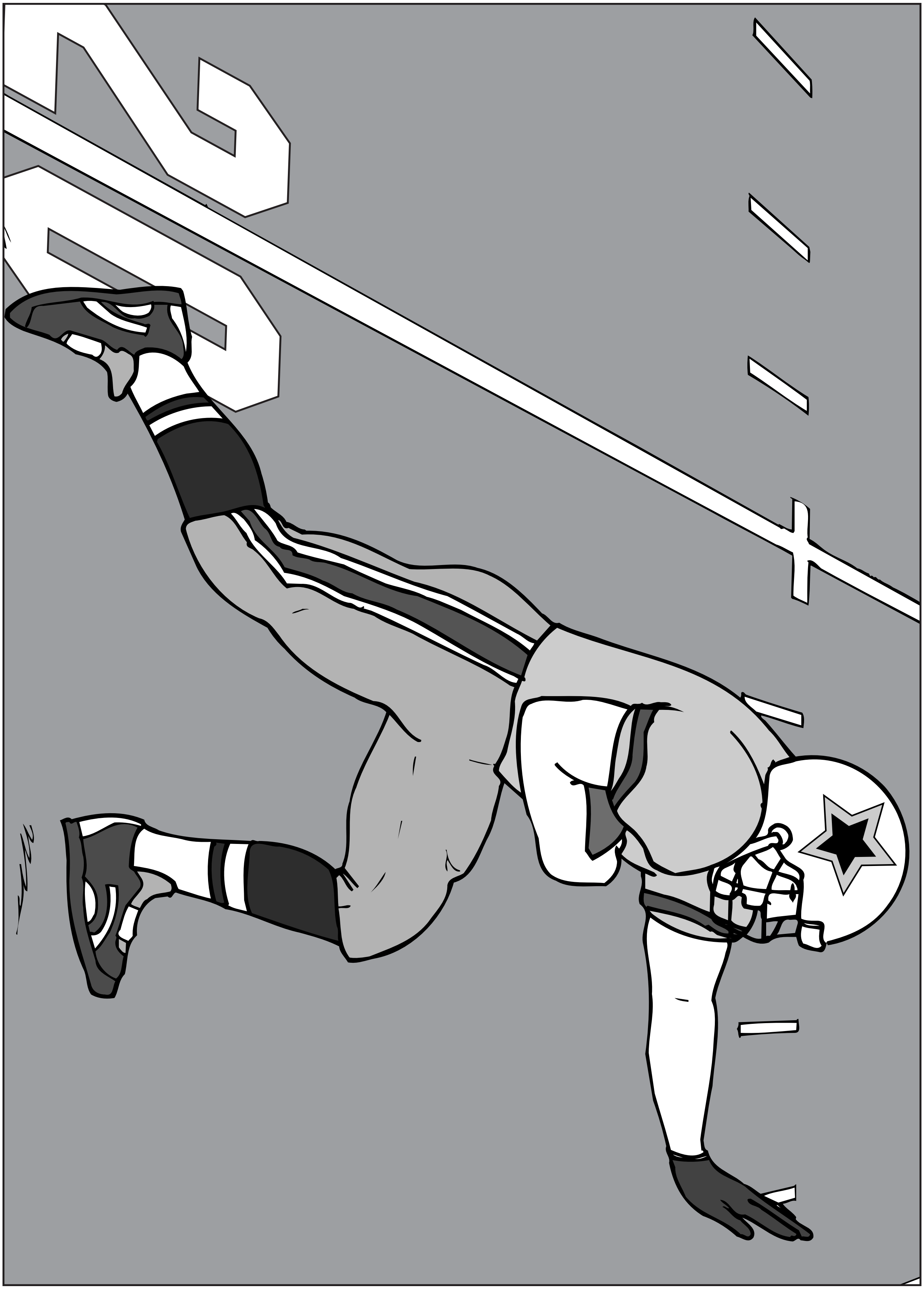
Do you camp in a tent or a house? (tent)

Do you fish or go to the movies when you camp? (fish)

Do you sleep in a sleeping bag or a bed when you camp? (sleeping bag)

Is it quiet or noisy when you camp? (usually quiet)

Could you see a deer or a traffic light when you camp? (deer)



Football

Football

Memory Prompts: football, pennants, cheerleader pom-poms, football helmet

Music: "On Wisconsin" or the Notre Dame fight song

Context Setting:

Level 1: Everyone in my family loved the Dallas Cowboys football team. We watched every game. Were the Redskins better this year? No, Tom Landry would always have some tricks. The great players were Jethro Pugh, Roger Staubach, and Bill Bates. Different people were on the team each year, but we still loved the Dallas Cowboys!

Level 2: All of the women in the family—even my grandmother after years and years of protest—had learned that the Dallas Cowboys went with Thanksgiving. The family would all have gathered by ten that morning, uncles and granddads and new young dads standing out on the lawn, women busy in the kitchen. And there would be huge kettles, boiling water, all kinds of dressing, turkey, spinach, and beans, fresh green beans, cooking down while the smells got richer and richer. The meal was always over by three o'clock because that's when the Cowboys were on.

"Bill, I believe the Redskins are a little better this year."

"Yeah, they won that first game. But this one counts, and old Tom Landry's got a few tricks he's gonna play on them."

Then all of the men and boys would go to the living room where it would be peaceful and quiet. And the game would start. Don Meredith. Bob Lilly. Lee Roy Jordan and Jethro Pugh. Later Roger Staubach and Drew Pearson and Bill Bates and . . . .

The names always changed . . . But they were always the Cowboys.

Yes/No Questions:

Are five people on a football team? (no)

Does the quarterback sometimes throw the ball? (yes)

Is the championship game called the Super Bowl? (yes)

Is a field goal four points? (no)

Is a touchdown six points? (yes)

Forced-Choice Questions:

Do football players need a football or a golf tee? (football)

Do football players wear a helmet or a cap? (helmet)

Do players try to tackle or tap other players? (tackle)

Is the National Football League the NFL or the AFC? (NFL)

Does a cheerleader say cheers or speeches? (cheers)

The Movies

The Movies

Memory Prompts: picture of movie stills, photos of movie actors (e.g., Cary Grant, Katharine Hepburn, Jimmy Stewart, John Wayne, Humphey Bogart), popcorn, movie tickets

Music: theme songs from memorable musical movies (e.g., My Fair Lady, The Music Man, The Sound of Music, Oklahoma, Gone with the Wind)

Context Setting:

Level 1: My favorite time to go to a movie is in the afternoon. The theater is empty. I get popcorn, candy, and a hot dog. The popcorn is salty and buttery. I like to watch all the previews. I love going to the movie in the afternoon. I like musicals best.

Level 2: People have different ways to see movies. Some people like to go to the big night when the movie opens. They like the crowds. They like to stand in line and watch a new release in a jam-packed movie house.

I like to go to the movies in the afternoon, on a weekday if I can, when almost no one else is there. A big part of it is the concession stand.

"Can I get you something, Sir?"

"I'd like a large popcorn, buttered. I want a hot dog with a little mustard on it. I want a large Coke. And I want a package of Milk Duds."

You can just barely carry all of this into the darkened theater. It's very cool in the theater and it's almost impossible to see as the door closes behind you. Your eyes have to adjust. You sit down, put your Coke safely on the floor, and cram a few big handsful of popcorn into your mouth. It's very salty and the butter is oily on your fingers. You take a slurp of Coke through a straw. Then you set the box of popcorn beneath the seat and eat the hot dog.

Now the previews are showing. The feature movie will start soon. Anything will be good because it's a summer afternoon and you're at the movies.

Yes/No Questions:

Was Humphrey Bogart in *Casablanca*? (yes)

Did Katharine Hepburn and Spencer Tracy make movies together? (yes)

Did movies always have sound? (no)

Did John Wayne make westerns? (yes)

Did Katharine Hepburn play Scarlett O'Hara? (no)

Forced-Choice Questions:

Was Judy Garland in *The Wizard of Oz* or *The Wizard of Menlo Park*? (*The Wizard of Oz*)

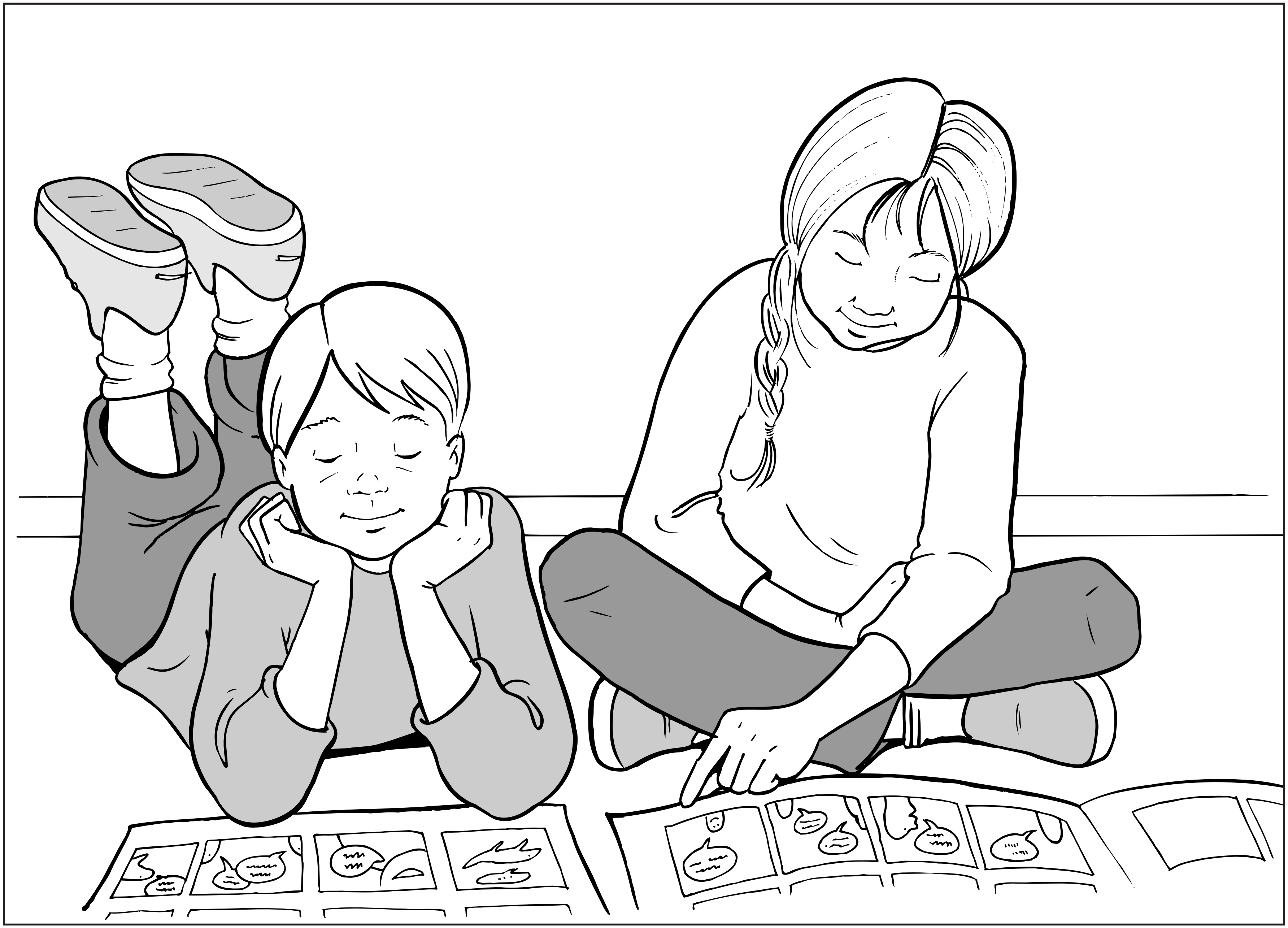
Was Harvey a giant rabbit or a giant cow in the Jimmy Stewart movie *Harvey*? (a giant rabbit)

Was Gregory Peck or Cary Grant in *To Kill a Mockingbird*? (Gregory Peck)

Did Abbot and Costello make comedies or tragedies? (comedies)

Do people usually eat popcorn or spaghetti at the movies? (popcorn)

The Funny Papers



The Funny Papers

Memory Prompts: comic strips (e.g., “Blondie,” “Dick Tracy,” “Felix the Cat,” “Li’l Abner,” “Flash Gordon,” “Superman,” “Batman,” “Peanuts”)

Music: none

Context Setting:

Level 1: We loved to read the funny papers. On Sunday they were always in color. “Peanuts” was our favorite. Lucy always fooled Charlie Brown. He tried to kick the football and “Whump.” He always landed on his back. Good grief!

Level 2: We read them every morning and so they become a part of our lives. They are like the holidays. Fall comes and the colors change and it smells like burning leaves. Lucy holds the football on a kicking tee and says, “I’ll hold the football, Charlie Brown, and you run up and kick it.” For the first few years, he would always do it, and she would always pull it away, and he would fly up in the air and come down—WHUMP!—on his back. Then she would stand over him and give some advice like, “Never believe everything that people tell you.”

In later years, he would not try to kick the football until she had assured him that this time he was actually going to get to kick it. And he would always believe her. I guess life is like that. Good grief!

Yes/No Questions:

Can Superman fly? (yes)

Is Batman a super hero? (yes)

Does Dagwood always eat giant hamburgers? (no)

Does Snoopy sleep on his doghouse? (yes)

Are the funnies on TV? (no)

Forced-Choice Questions:

Is Clark Kent Superman or Flash Gordon? (Superman)

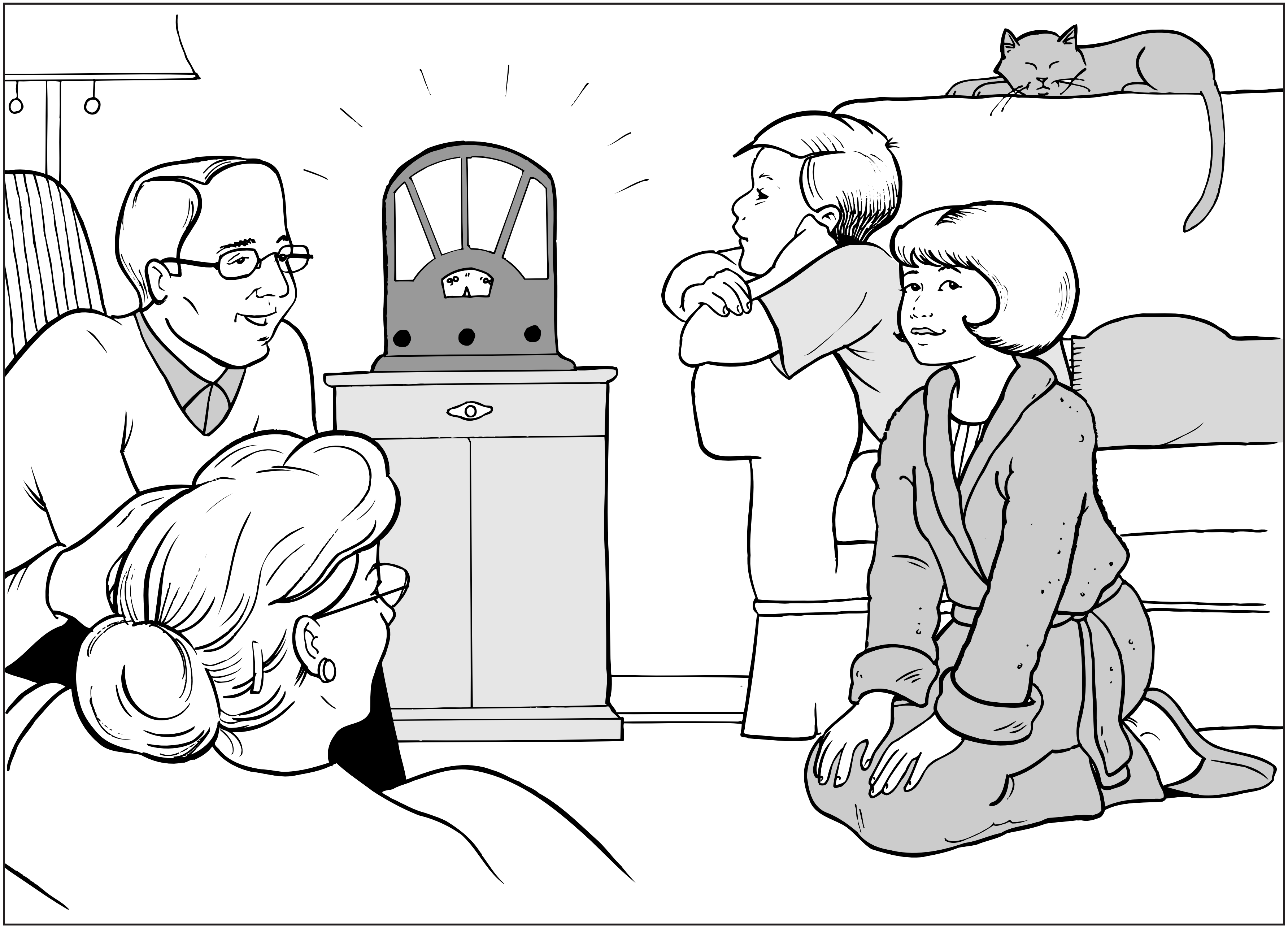
Does Batman drive a Batmobile or an Oldsmobile? (Batmobile)

Does Li’l Abner live in the hills or in the city? (in the hills)

Is Snoopy a dog or a cat? (dog)

Is Dick Tracy a police officer or a firefighter? (police officer)

The Golden Age of Radio



The Golden Age of Radio

Memory Prompts: audiotapes of radio programs from the 30s, 40s and 50s; photos of vintage radios

Music: "William Tell Overture" (from *The Lone Ranger*), "When You Wish Upon a Star," "That Ain't Right," "Don't Fence Me In," "I'm Making Make-Believe"

Context Setting:

Level 1: Every Thursday night we listened to the radio. All the people in the city listened to the same programs. Our favorites were *Burns and Allen*, *The Lone Ranger*, and *Bob and Ray*. Sometimes we heard important news on the radio. One time we heard President Roosevelt talk about the bombing of Pearl Harbor as "a day that would live in infamy."

Level 2: On Thursday nights at 6:30, the town was deserted. It seemed that no one was on the roads or sidewalks. It was like a ghost town. But all along the streets, there were lights in open windows. You could walk along the sidewalks and the same voices would be coming from each house. The voices were louder as you went by. Then they became fainter, but they were replaced by the same voices, getting louder now, at the next house down the street.

Freeman Gosden and Charles Correl. Arthur Godfrey. Or it might be Jack Benny. "Put up your hands, Benny! Your money or your life!" Long silence. "Well?" "I'm thinking!" All along the street, laughter.

And now all of us are gathered around the big wooden radio, listening as the static crackled . . . "We have nothing to fear . . . but fear itself." And, some years later . . . "December 7, 1941. A day that will live in infamy."

Are those voices still out there somewhere, floating in space? That golden age of radio.

Yes/No Questions:

Was Milton Berle a comedian? (yes)

Did Orson Welles write *War of the Worlds*? (yes)

Did the Lone Ranger ride a horse named "Buddy"? (no)

Were Fibber McGee and Molly on the radio? (yes)

Did Lowell Thomas have a news program? (yes)

Forced-Choice Questions:

Was *Gunsmoke* a western or a comedy? (western)

Was Kate Smith a singer or a gossip columnist? (singer)

Do radio stations have call letters or call numbers? (call letters)

Was Jack Benny generous or stingy with his money? (stingy)

Did Jack Benny play a violin or a trumpet? (violin)

Westerns

Westerns

Memory Prompts: photos of TV westerns and movie personalities (e.g., Gene Autry, Hopalong Cassidy, Roy Rogers, Tom Mix, James Arness)

Music: theme music from television or movie westerns (e.g., *Gunsmoke*), "I Walk the Line," "Your Cheatin' Heart," "Do Not Forsake Me," "Yellow Rose of Texas"

Context Setting:

Level 1: My favorite television western was *Gunsmoke*. James Arness was the marshall, Matt Dillon. He and Festus and Doc and Miss Kitty lived in Dodge City. There were new adventures every week. Marshall Dillon kept law and order in the town.

Level 2: There are, of course, the great Western heroes of the old movies. There was Roy Rogers. Gene Autry. Hopalong Cassidy. There was John Wayne and there was Tom Mix. All of them were great heroes.

The best Westerns came in the 1950s on Saturday or Sunday nights. Our family would wait all week for *Gunsmoke*. The best *Gunsmoke* shows were the earlier ones that only lasted half an hour. It would be eight o'clock and Marshall Dillon would step out into that long street in Dodge City. Someone would have called him out. You could only see his back while the theme music played.

Then POW POW! Two shots and the other guy would always fall down dead at the other end of the street. Marshall Dillon never lost.

Yes/No Questions:

Were westerns popular TV shows in the 50s? (yes)

Was *Wagon Train* a TV western? (yes)

Was James Garner in *Maverick*? (yes)

Were Ben Cartwright's sons named Adam, Hoss, and Little Jeffrey? (no)

Did James Arness play Festus? (no)

Forced-Choice Questions:

Was Gary Cooper or Cary Grant in *High Noon*? (Gary Cooper)

Did a sheriff or a mayor keep law and order in the west? (sheriff)

Did people travel west in wagon trains or airplanes? (wagon trains)

Did towns in the Old West have sidewalks or boardwalks? (boardwalks)

Was there a famous gunfight at the OK Bank or the OK Corral? (OK Corral)

Elvis

Elvis

Memory Prompts: photos of Elvis (young or old)

Music: any Elvis songs

Context Setting:

Level 1: I remember the first time I saw Elvis. He was on the Ed Sullivan show. He carried his guitar. His eyes were black. His hair was a little long. When he sang, he moved his hips in a way I never saw before. The girls all screamed. That was the day music changed forever.

Level 2: I remember it very well. We were all sitting in front of the television because it was Sunday night and Ed Sullivan was about to come on. He was going to have The Flying Wallendas and a new comedian named Johnny Carson.

We had just finished watching Lucky Strikes' Hit Parade. That was a music show in which Snooky Lanson, Giselle McKensie, or someone else like that would sing the top ten songs of the day. This particular Saturday, Snooky Lanson had sung his arrangements of two of my favorites, "The Ballad of Davy Crockett" and "How Much Is that Doggie in the Window?"

We were enjoying Ed Sullivan. But about halfway through the show, a young southern man came on. We thought he might be a magician or a comedy act. He had the strangest name—and he was stock still, staring out at the audience with coal black eyes under hair much too long. And sideburns! The music started very suddenly, "Youaintanuthinbutahoundogga—Cryinallthetime!" And he was twisting and gyrating and moving and dancing and then he stopped suddenly. And all the teen-aged girls in the audience screamed!

My father shook his head in disbeleif. Then he left the room. But I just watched as all the girls kept screaming. And the world, even though I didn't know it, had changed forever.

Yes/No Questions:

Was Elvis' last name Presley? (yes)

Did Elvis sing "You Ain't Nothing but a Hound Dog"? (yes)

Was Elvis from New York? (no)

Was Elvis drafted into the Navy? (no)

Was Elvis' home in Memphis called Graceland? (yes)

Forced-Choice Questions:

Was Elvis' home in Memphis or Nashville? (Memphis)

Was Elvis old or young when he died? (young)

Did Elvis marry Priscilla or Penelope? (Priscilla)

Did Elvis wiggle or stand still when he sang? (wiggle)

Was one Elvis song "Love You Lots" or "Love Me Tender"? ("Love Me Tender")

The Roaring Twenties

The Roaring Twenties

Memory Prompts: pictures of Model Ts, flappers, people dancing the Charleston

Music: "Ain't We Got Fun?," "The Sheik of Araby," "I'm Nobody's Baby," "Yes, Sir, That's My Baby," "Five Foot Two, Eyes of Blue," "Yes, We Have No Bananas"

Context Setting:

Level 1: Do you remember these things from the Roaring Twenties: Prohibition, Al Capone, Gangland War in Chicago, flappers, speakeasies, the Charleston?

I remember one time. We drove our car to the old railroad track. We waited. The Red Ball Express roared by. Inside were the New York Yankees. They were going back to New York from spring training. Babe Ruth was inside that train.

Level 2: Do you remember the Roaring Twenties? My memories are vague because I was just a boy, on the farm, hearing stories, seeing things in the paper. Al Capone. Gangland war in Chicago! The flappers. Charleston! Charleston! Mansions on Long Island, wherever that was. Great touring cars pulling up circular driveways, men with tall hats and women with short skirts, getting out to go into huge estates and dance the Charleston. Will Rogers.

And one night in late March, 1927, we cranked the old car up and drove half way between Lancaster and Waxahachie. We sat beside the old InterUrban Railroad track for two hours. Then it came. The Red Ball Express. It was coming up from Florida, heading north. It roared by as we watched. The bright windows of the train were just golden blurs. Then it was gone. We weren't able to see anyone inside, but it didn't matter. Inside that train were The New York Yankees, returning from spring training. Between Lancaster and Waxahachie, Texas, on a March night in 1927, I had been that close to Babe Ruth.

Yes/No Questions:

Did women get to vote in the 20s? (yes)

Was alcohol legal during Prohibition? (no)

Was Louis Armstrong called "Satchmo"? (yes)

Was a flapper a girl with a short skirt? (yes)

Did the stock market crash in 1949? (no)

Forced-Choice Questions:

Was the Charleston a dance or a bridge? (dance)

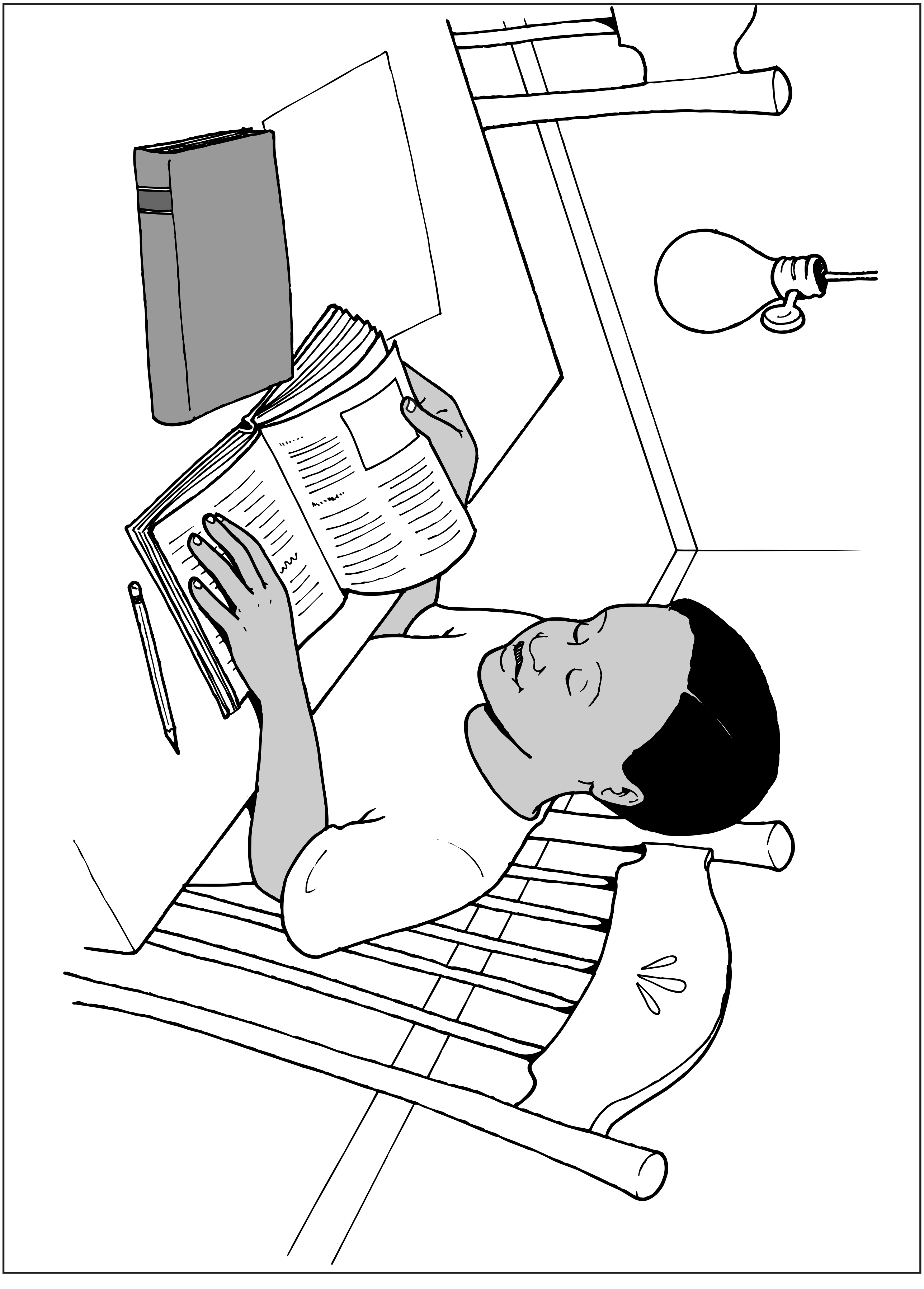
Was Rudolph Valentino an actor or a president? (actor)

Is jazz a type of music or a type of ice cream? (music)

Is "Little Orphan Annie" a real child or a comic strip? (comic strip)

Did Prohibition make liquor or beef illegal? (liquor)

Electricity



Electricity

Memory Prompts: lightbulbs or flashlights, pictures of people working by lantern or candle light, candles and candlesticks (light the candle)

Music: none

Context Setting:

Level 1: We were the first farm in the county to get electricity. Huge towers and poles went up. No more oil lamps. Soon we also had radios and phonographs. My grandmother didn't trust electricity. She always plugged up the electric outlets at night so the electricity wouldn't leak out!

Level 2: My father was on the Board of Directors of the REA, the Rural Electric Association. One Tuesday every month we would sit in the car in the nearby town while he and the board met. I got to know Mr. Farrow, the director of the REA, and I got to know many of the linemen who fixed the lines when storms blew them down. I even remember a picture taken in our home when I was around one year old. We were one of the first farms in the county to get electricity, and the picture was taken for publicity.

Still, it is impossible for me to imagine what changes in the life of my parents and grandparents those lines brought about. They eliminated the coal oil lamp. The huge towers and poles, striding across the farmland like so many invaders from Mars, and the lines singing in the wind. I wonder what it must have been like to see an electric lightbulb for the first time?

Soon thereafter came phonographs and radios. What would it have been like to hear them for the first time? I only remember a story about one grandmother who insisted that the electric outlets be plugged up every night. The electricity, she feared, would seep out into the room.

And still, I must admit, I don't understand why that doesn't happen.

Yes/No Questions:

Did Thomas Edison invent the lightbulb? (yes)

Were the first lights in peoples' homes often "drop lights"? (yes)

Did the REA bring electricity to farms? (yes)

Did people use flashlights for light before electricity? (no)

Does electricity make an iron cold? (no)

Forced-Choice Questions:

Did most people get electricity in the 1800s or 1900s? (1900s)

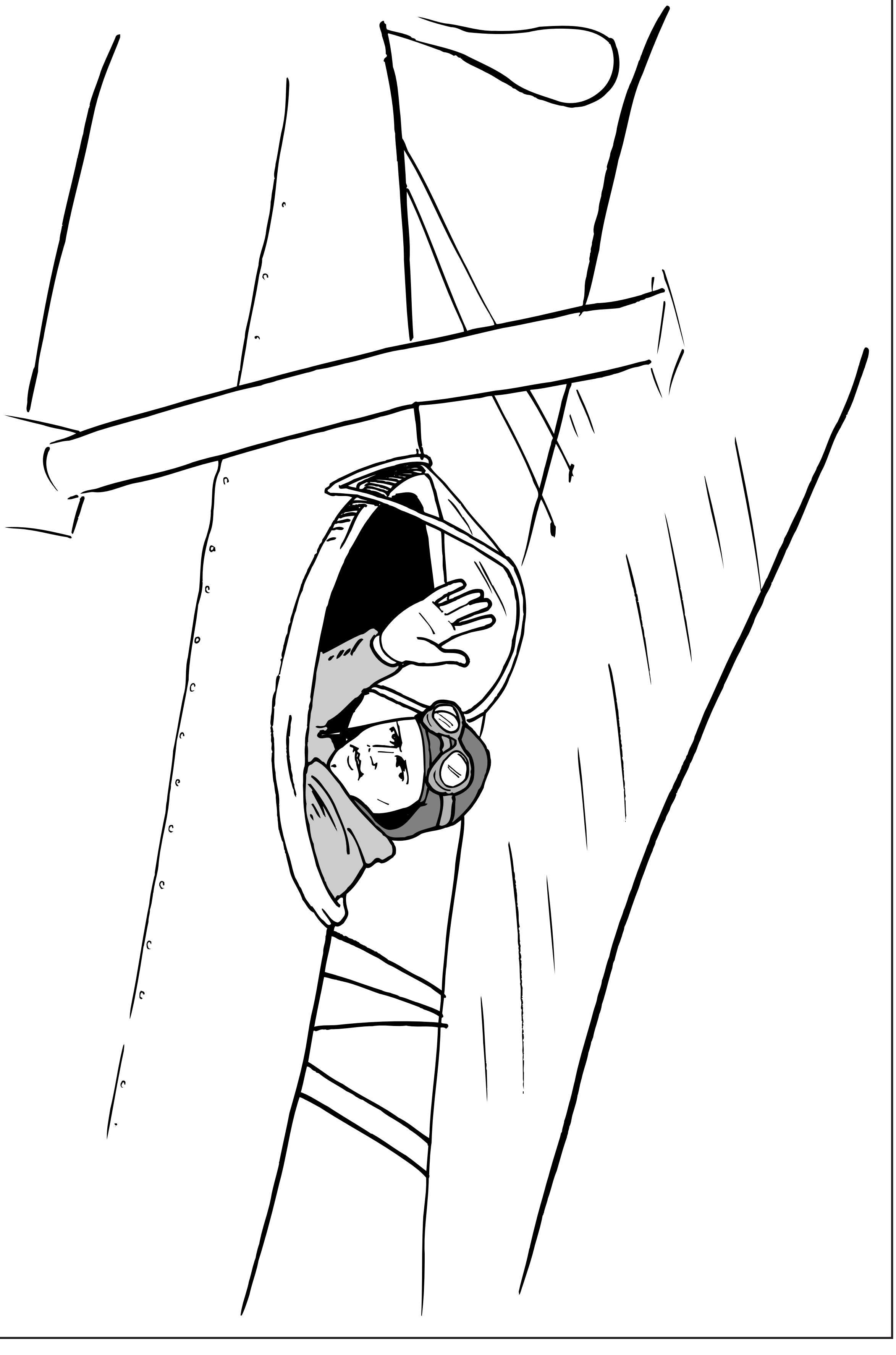
Did Thomas Edison or Benjamin Franklin invent the lightbulb? (Thomas Edison)

Can electricity shock you or shoot you? (shock you)

Did people use flashlights or oil lamps before electricity? (oil lamps)

Do more people heat their homes today with electricity or coal? (electricity)

Heroes in the Air



Heroes in the Air

Memory Prompts: model airplanes, aviator glasses and/or helmet, photos of old planes and pilots

Music: "Blue Skies," "Off We Go" (Air Force song), "Come Fly with Me"

Context Setting:

Level 1: I loved model airplanes when I was little. I made them out of balsa wood and plastic. I made models that looked like Flying Tigers. I made models that looked like British Spitfires. I wonder, did Charles Lindberg and Amelia Earhart make model airplanes when they were young?

Level 2: Airplanes are first for children. As a child, you would go into the five-and-dime store and buy a model and some Testor's glue. You started with balsa wood models bought for a quarter. Then you bought models for sixty-nine cents. They were made by Revell, and they were the most wonderful models. Exactly accurate. Plastic and in bright colors. They were The Flying Tiger, with the snarling teeth of a tiger on the decal to be applied just under the propeller. The Flying Tiger hung in your room, gray and ready for battle, circling in gentle air currents blowing through open windows beside the British Spitfire and the German Messerschmidt. And the next model (it would be a Japanese Zero I got just that morning at the store)—this model would be put together even more carefully, so that no glue smudges would be seen on the clear plastic canopy.

And years ago, other children played with other models, learning of the propeller, the struts, the wings, the flaps. Wally Post. Charles Lindberg. And the little girl—how strange, a little girl playing with airplanes! The little girl, who was, one foggy morning, to fly off into the sky, not to stop until she had flown around the world. The little girl that we never saw again. I wonder, what was Amelia Earhart's favorite model airplane?

Yes/No Questions:

Did Charles Lindbergh fly alone from New York to Moscow? (no)

Was the Spirit of St. Louis a boat? (no)

Did a movie called "Wings" win the first Oscar? (yes)

Was Amelia Earhart the first woman to fly across the Atlantic? (yes)

Was the Zeppelin a blimp that carried passengers? (yes)

Forced-Choice Questions:

Did Charles Lindbergh land in France or Spain? (France)

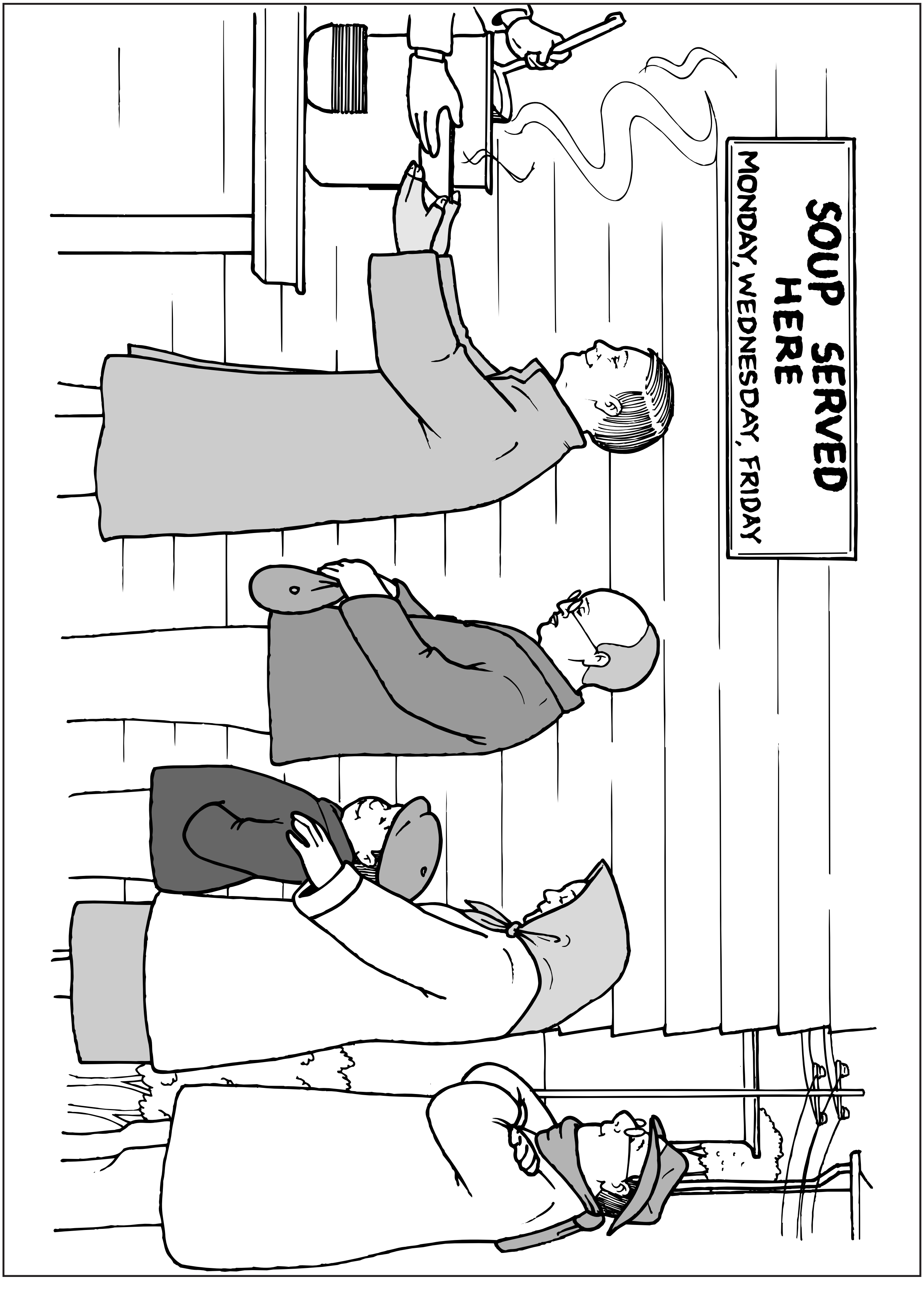
Did Lindbergh cross the Atlantic or the Pacific Ocean? (Atlantic)

Did Lindbergh cross the Atlantic alone or with a friend? (alone)

Was Amelia Earhart a woman who flew airplanes or drove cars? (flew airplanes)

Was the Spirit of St. Louis an airplane or a boat? (airplane)

The Thirties



The Thirties

Memory Prompts: photos from the Depression (e.g., soup lines, the Dust Bowl)

Music: "It Don't Mean a Thing (If It Ain't Got that Swing)," "I Wanna Be Loved," "Only a Paper Moon," "Blue Moon," "The Way You Look Tonight," "They Can't Take that Away from Me," "A-Tisket, A-Tasket," "Over the Rainbow"

Context Setting:

Level 1: No one had any money in the 1930s. But one night, in 1939, we had enough money for a movie. The movie theater was like a palace. It had huge chandeliers. We stood in line for the movie. Inside, it got dark. The movie started. It was *Gone with the Wind*, one of the greatest movies of all time.

Level 2: When you talk about the 1930s, Most people think of The Great Depression. The images are all there — clouds of dust rolling in on terrible West winds, driving farmers off their Oklahoma farms. Caravans of poor people driving out to California, trying to make a living picking lettuce. Farms foreclosed by the local bank. The Great Depression. No one had any money.

But at the end of the Thirties, I remember one year especially well. It was 1939 and there was a great theater on a downtown city street. The theater was like a palace. Huge chandeliers hung from the ceilings. There were three balconies. Three! The line to get into the theater snaked around the block. There was no money, but people had found enough to get in that night. And once in, finally, the great room grew dark. Everyone was breathless. Then came the music — "Tara's Theme." It was the first scene of the greatest movie of all time — *Gone with the Wind.*

Yes/No Questions:

Was the Great Depression in the 1950s? (no)

Did people lose their jobs in the Depression? (yes)

Did Franklin Roosevelt say, "The only thing we have to fear is fear itself"? (yes)

Was the Dust Bowl in the 1930s? (yes)

Were Bonnie and Clyde gangsters in the 1930s? (yes)

Forced-Choice Questions:

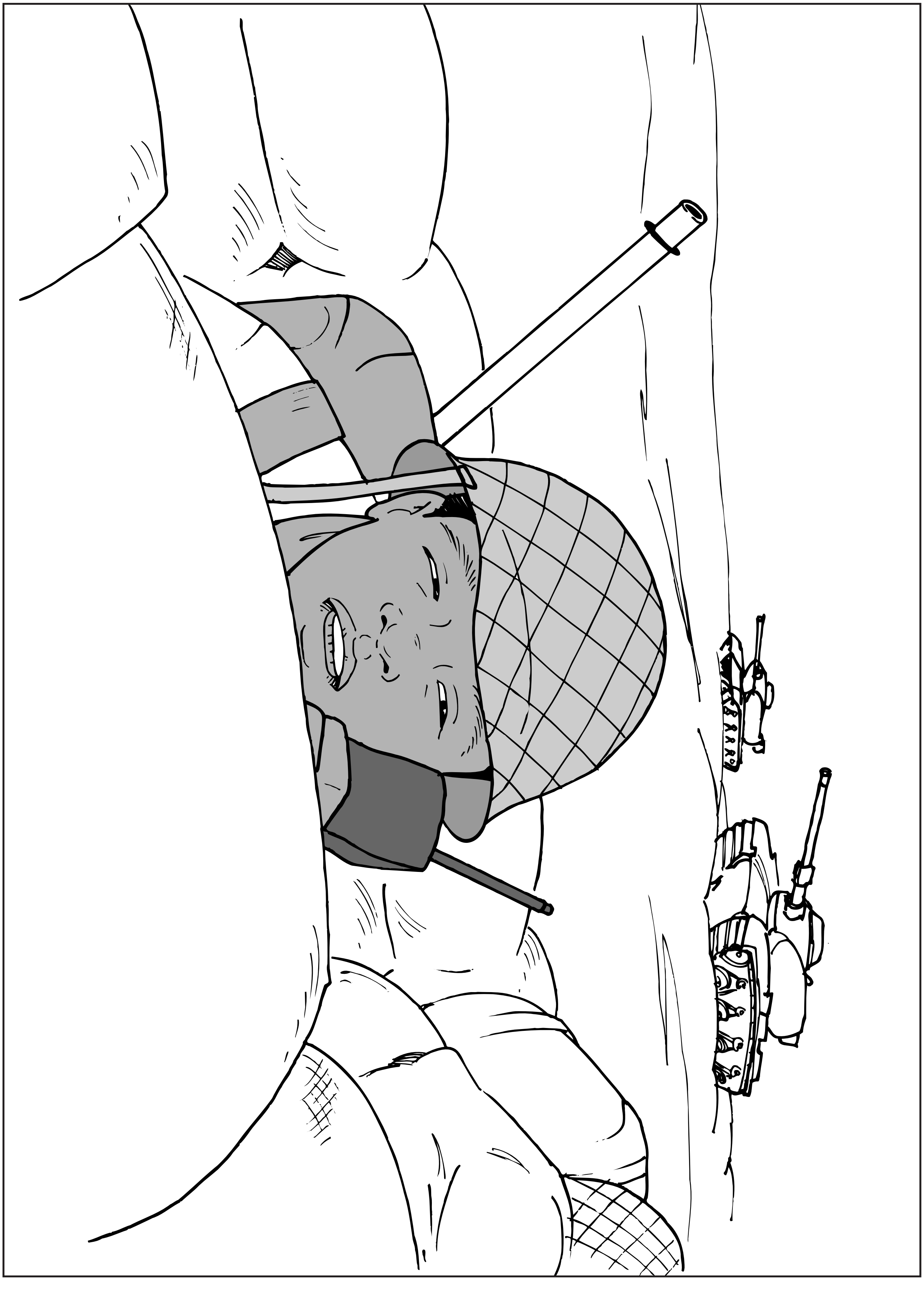
Was "Baby Face" Nelson a gangster or a doctor? (gangster)

Was the Dust Bowl or the Soup Bowl in Oklahoma? (Dust Bowl)

Was Clark Gable or Jimmy Stewart in *Gone with the Wind*? (Clark Gable)

Was Franklin Roosevelt or Dwight Eisenhower president in the Thirties? (Franklin Roosevelt)

Was Benny Goodman "The King of Swing" or "The King of Swat"? (The King of Swing)



World War II

World War II

Memory Prompts: pictures from World War II (e.g., the flag being raised at Iwo Jima) or of famous people (e.g., Eisenhower, Churchill, Roosevelt, Hitler, Mussolini)

Music: "When the Lights Go on Again (All Over the World)," "I'll Be Seeing You," "Sentimental Journey," "The Boogie-Woogie Bugle Boy"

Context Setting:

Level 1: This happened to my brother in World War II. He was in Patton's army. He was in the Battle of the Bulge in 1944. One day he was leaning on a tree to light a cigarette. When he woke up, he was in a hospital. A German sniper had shot him. The bullet went through his helmet, but did not kill him. After that he always walked with a limp, but he came home.

Level 2: We were sitting around the dinner table when FDR told us about the day that would live in infamy. The Japanese had attacked Pearl Harbor. Jack, my older brother, got up and walked over to the window. "I'll go," he said, "but I don't think I'll come back. I feel it. I won't come back."

We all went, all of the brothers. I spent four years overseas in the signal corp. I was in Palermo and Casablanca, and finally Naples. Living in tents the whole time, I never got warm. Four years, cold every day. And wet.

Jack became a lieutenant in the infantry. He was in Patton's army. His unit was retreating during the Battle of the Bulge, in 1944. They say—someone had seen it, I guess—that he leaned up against a tree to light a cigarette. The snipers always went for the officers.

He woke up in a hospital in Brussels. The bullet had gone through his helmet and creased his brain. It damaged a nerve. He would never again walk without a limp. But he was coming home. His feeling had been wrong.

Yes/No Questions:

Did the French attack Pearl Harbor? (no)

Did Germany invade France? (yes)

Did MacArthur say, "I shall return"? (yes)

Was D-Day on June 6, 1944? (yes)

Was the U.S. allied with Germany and England? (no)

Forced-Choice Questions:

Was Hitler the leader of Germany or England? (Germany)

Did the U.S. troops land in Normandy or Brittany on D-Day? (Normandy)

Did the Germans or the Japanese bomb Pearl Harbor? (Japanese)

Was Ernie Pyle a soldier or a reporter? (soldier)

Did Germany or Japan surrender on V-J day? (Japan)

Political Conventions

Political Conventions

Memory Prompts: photos of political conventions, campaign materials (e.g., political signs, political candidate's buttons)

Music: "Happy Days Are Here Again," "Hail to the Chief"

Context Setting:

Level 1: Political conventions were always in the summer. We would listen to them on the radio. In 1956, Eisenhower was the Republican nominee. Who would the Democrats nominate? The voting went on until late at night. There was a roll call of the states: "Mister Chairman, the Great State of Alabama casts its votes for the next President of the United States: Adlai E. Stevenson." And then we went to bed.

Level 2: Political conventions used to be fun. In the summer of 1956, there were wonderful conventions. Speech after speech after speech. Who would the Democrats nominate? Finally, the great roll call of the states:

"Mister Chairman, the Great State of Alabama wishes to take this opportunity to cast all thirteen votes for the next President of these United States . . ."

And the commentators: "Yes, Chet, it looks like it's getting closer and closer. It may go down to the last state."

Inconclusive. More haggling. One o'clock in the morning. "Wyoming will cast its votes for the next President of the United States—Adlai E. Stevenson!"

Then bands playing "Happy Days Are Here Again" and confetti and wild delirious people. And we would go to bed exhausted, believing in our hearts that Adlai E. Stevenson would be the next President of the United States.

Yes/No Questions:

Are Republicans a political party? (yes)

Are Democrats a political party? (yes)

Is a cat a symbol for the Democrats? (no)

Is the elephant a symbol for the Republicans? (yes)

Do presidential candidates sometimes have debates? (yes)

Forced-Choice Questions:

Do political conventions nominate presidents or governors? (presidents)

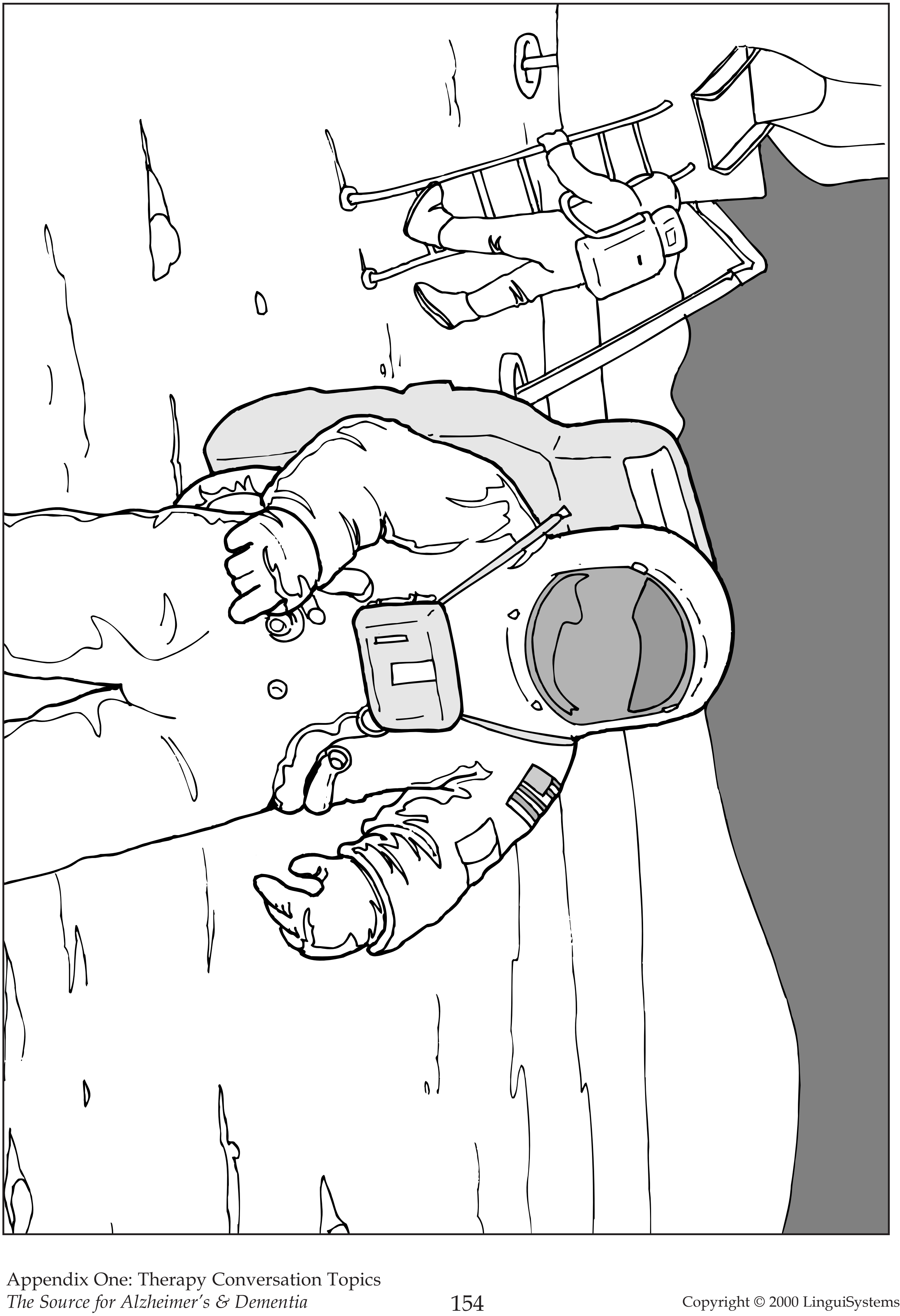
Is the donkey the symbol for Democrats or Republicans? (Democrats)

Is the elephant the symbol for Democrats or Republicans? (Republicans)

Do state delegates vote on candidates for governor or president? (president)

Are presidential political conventions held in the summer or the winter? (summer)

The Space Race



The Space Race

Memory Prompts: photos of rocket launches, familiar astronauts, Tang powdered drink mix

Music: "Fly Me to the Moon," theme from "2001: A Space Odyssey"

Context Setting:

Level 1: The Russians went into space first with Sputnik. We wanted to be first on the moon. In July, 1969, the whole world watched and listened. As Neil Armstrong stepped onto the moon, he said, "One small step for man, one giant leap for mankind!"

Level 2: It all began with Sputnik. The unthinkable had happened. The Russians had beaten us into space. As a little boy/girl, you dreamt that you would be the first to fly to the moon. And then the Russians went into space. Before us! All around the country, schools started teaching more science. More math. We had to beat the Russians! And we did.

Suddenly there was Cape Canaveral and pictures of huge rockets taking off in a burst of white fire so bright that people could see it for twenty, thirty miles away. Alan Shepard circling the Earth with all school children standing outside looking at the sky, knowing that once every so many minutes he would be passing above; going around the world.

Then in 1969, in July, the whole world was watching. The broadcast was gray and there was static. Walter Cronkite was the anchorman. We all remember his voice, Walter Cronkite's deep voice:
"We're getting the signal now. Here it is . . ."
Like an old Flash Gordon movie, the space figure made its way down the ladder and jumped.
"One small step for man, one giant leap for mankind."
And we were on the moon!

Yes/No Questions:

Was Sputnik a French satellite? (no)

Did we have a space race with the Russians? (yes)

Was Alan Shepard the first American in space? (yes)

Did Russia put the first man into space? (yes)

Was Gus Grissom the first man on the moon? (no)

Forced-Choice Questions:

Was our space race with Russia or Germany? (Russia)

Did Sputnik orbit the Earth or go to Mars? (orbited the Earth)

Were the moon missions called Apollo or Jupiter? (Apollo)

Was James Lovell or Neil Armstrong the first man on the moon? (Neil Armstrong)

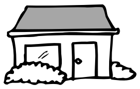
Did the astronauts on Apollo 13 die in space or make it safely home? (made it safely home)

Social Reminders

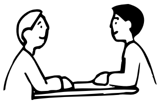
My Home

This is my home.

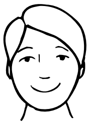
_____________ is here with me.
(person)



We have lived here for _____________ years.
(number)



We can _____________ together.
(activity to distract)



I am safe at home with _____________.
(person)

Driving

I should not drive.

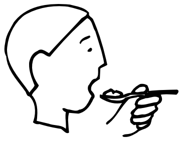
I might crash.

I might hurt someone.

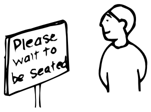
I might get lost.

It is not safe for me to drive.

Eating Out



I am going to eat at _________.
(place)



I might have to wait for a table.

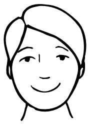
The waitress will take my drink order.

After she brings the drinks, she will take my food order.

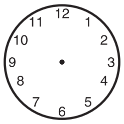
I will wait a short time for the food.

When everyone is finished eating, I will go home.

When Are We Going?

 →

Today I am going to ______________.
(place)

→ 

I will leave at ______________.
(time)

______________ will take me.
(person)

Talking on the Phone

Sometimes I have trouble understanding people on the phone.

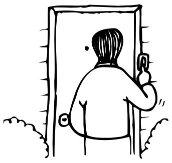
I can let the answering machine answer.

I can say, "Just a minute" and get ____________ to talk on the phone.
(person)

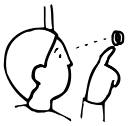
I do not have to answer the phone.

Answering the Door

The door stays locked for safety.



Someone might ring the bell.

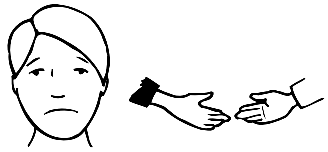


Wait. Do I know the person at the door?

I will not open the door if I do not know the person.

The door is locked for safety.

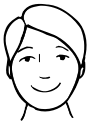
Getting Help



I might need help.

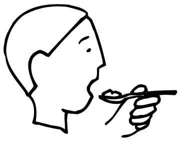
I can call ______________.
(person)

The phone number is ______________.
(phone number)



______________ will help me if I need it.
(person)

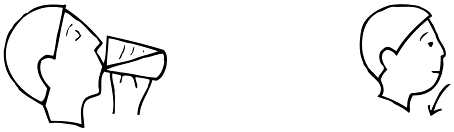
Enjoying Meal Time



I take a little bite of food.

I put my fork down.

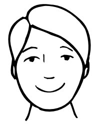
I chew slowly.



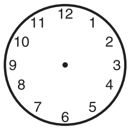
I take a sip of drink and swallow.

I eat slowly and enjoy my meal.

Social Club

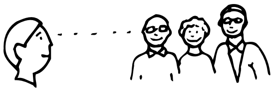
 →

Today I go to _____________.
(place)

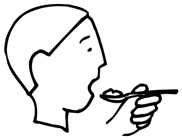
→ 

I leave at _____________.
(time)

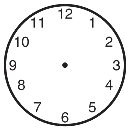
_____________ will take me.
(person)



I will see my friends.

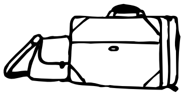


I will eat.

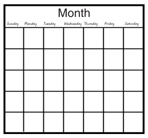
 

_____________ will pick me up at _____________.
(person) (time)

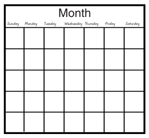
Going Away



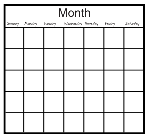
_____________ is going to _____________.
(person) (place)



_____________ will stay in _____________ for _____________ days.
(person) (place) (number)



The calendar shows when _____________ will come home.
(person)



I can check the calendar every day.

_____________ will come home in _____________ days.
(person) (number)

Self-Care Activities of Daily Living

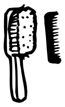
Morning Routine

Use the toilet.

Wash hands.

Wash face.

Brush teeth.

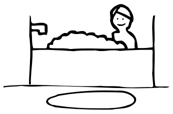


Brush hair.

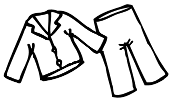
Evening Routine

Use the toilet.

Undress.



Take a bath.



Put on pajamas.

Brush teeth.

Brushing Teeth

Wet the toothbrush.

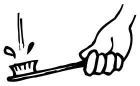
Remove the cap from the toothpaste.

Squeeze a little toothpaste onto the toothbrush.

Brush teeth.

Spit.

Rinse mouth and spit again.



Rinse toothbrush.

Washing Hair

I put water on my hair.

I pour a small amount of shampoo in my hand.

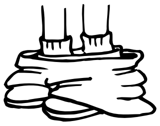
I rub my hands around on my hair.

I scrub my scalp with my fingers.

I put water on my hair. I rinse until the suds are gone.

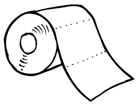
Using the Toilet

I tell ______________ when I need to go.
(person)



I pull down my pants.

I use the toilet.

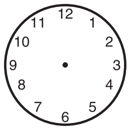


I wipe myself with toilet paper.

I flush the toilet.

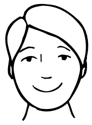
I wash my hands.

Bathing

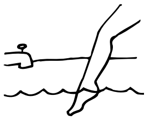


I will take a bath at ______________ o’clock.

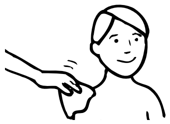
I will take off my clothes.



It is okay. I am safe.



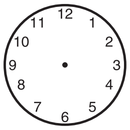
I will get in the water.



______________ will help me wash.
(person)

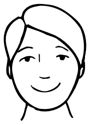
I like to be clean.

Taking a Shower



I will take a shower at _____________ o'clock.

I will take off my clothes.



It is okay. I am safe.

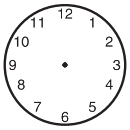
_____________ will help me.
(person)

The water will splash on my face.

I like to be clean.

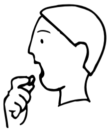
Taking Medicine

The doctor wants me to have medicine.

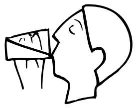


______________ will tell me when to take medicine.

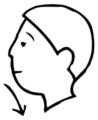
(person)



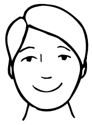
I will put the medicine in my mouth.



I will take a drink of water.

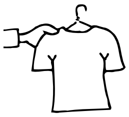


I will swallow.

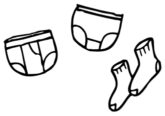


I will feel better.

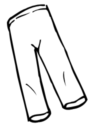
Getting Dressed



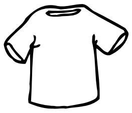
______________ helps me to choose clothes.
(person)



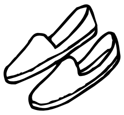
I will put on my underwear and socks.



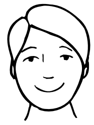
I will put on my pants.



I will put on my shirt.



I will put on my shoes.



I look nice.

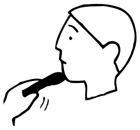
Shaving

(with electric razor for safety)

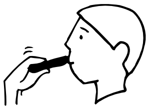
Turn on the electric razor.

Shave one cheek and jaw.

Shave the other cheek and jaw.



Shave my chin.



Shave my upper lip.

Is all the hair gone?

Other Forms of Dementia

Sometimes the diagnosis is not Alzheimer's disease. Remember that the diagnosis of AD is an exclusionary diagnosis. A doctor will look for many other things that could be causing the dementia, and only when those have been eliminated as possibilities will the doctor diagnose AD. (Types of dementia can be classified as degenerative, as caused by infection, or caused by inherited metabolic disorders.) Some, such as Parkinson's disease, are more familiar to families. Others, such as Lewy Body dementia, are less familiar and often puzzling to caregivers when used by professionals. This is a brief overview of some causes of irreversible dementia that are sometimes diagnosed instead of AD.

Degenerative Dementias

Lewy Body Syndrome
There are possibly two forms: Lewy Body Variant of Alzheimer's disease or Lewy Body Dementia. Lewy bodies are protein deposits found throughout the cortex. In the case of Lewy Body Variant, the Lewy bodies are found alongside the plaques and tangles of AD. In Lewy Body Dementia, the Lewy bodies may or may not be found with the plaques and tangles. Hallucinations, some Parkinson-like symptoms of gait disturbance, and a more rapid progression than AD characterize this form of dementia.

Pick's disease
In Pick's disease, there is degeneration of nerve cells particularly in the frontal and temporal lobes. This type of dementia is characterized by dramatic changes in personality and social behavior (giggling and silliness is sometimes reported) but memory is not affected until later in the disease.

Huntington's disease
Huntington's disease is an inherited, degenerative disease that affects the brain and the rest of the body. Intellectual decline, involuntary body movements, and emotional disturbance characterize it. This disease was called chorea in past times due to the uncontrolled body movements.

Parkinson's disease
Parkinson's disease is a disorder of the central nervous system. It is characterized by tremors, muscular rigidity, poor balance, and decreased muscular activity. It is slowly progressive and dementia often co-occurs. A severe shortage of the neurotransmitter dopamine is linked to the disease.

Progressive Supra nuclear Palsy
Progressive supra nuclear palsy is a rare, degenerative brain disorder. Symptoms can include vision problems (e.g., blurred or double vision),

dysphagia, motor or balance problems (e.g., falling, difficulty walking, slow movement), and personality changes in mood or behavior. Dementia is mild. The cause is unknown.

Irreversible Dementia Caused by Infection

Creutzfeldt-Jakob disease

Creutzfeldt-Jakob disease is a rapid, progressive dementia caused by an infectious disease of the brain. It is also sometimes called subacute spongiform encephalopathy (SSE). Microscopic vacuoles or holes appear in the brain, giving it a spongy appearance. The cause is currently thought to be a prion (short for proteinaceous infection particle). A prion is neither a virus nor other known infectious agent. It is thought to be an unconventional agent consisting of a protein.

Recommended Books About Alzheimer's Disease

Books for Children

Bahr, M. *The Memory Box*. Morton Grove, IL: A. Whitman & Co., 1992.

Baumann, K. & Conners, E. *Through Tara's Eyes: Helping Children Cope with Alzheimer's Disease*. Rockville, MD: American Health Assistance Foundation, 1995.

Cargill, K. *Nana's New Home: A Comforting Story Explaining Alzheimer's Disease to Children*. Abilene, TX: Krisper Publications, 1997.

Delton, J., Tucker, D., and Robinson, C. *My Grandma's in a Nursing Home*. Niles, IL: Albert Whitman and Co., 1986.

Guthrie, D. *Grandpa Doesn't Know It's Me*. New York: Human Sciences Press, 1986.

Karkowsky, N. *Grandma's Soup*. Rockville, MD: Kar-Ben Copies, Inc., 1989.

Kibbey, M. *My Granny*. Minneapolis, MN: Carolrhoda Books, 1988.

Potaracke, R. *Nanny's Special Gift*. New York: Paulist Press, 1993.

Rappaport, D. *But She's Still My Grandma!* New York: Human Sciences Press, 1982.

Sanford, D. and Evans, G. *Maria's Grandma Gets Mixed Up*. Portland, OR: Multnomah Press, 1989.

Schein, J. *Forget-me-not.* Toronto: Annick Press, 1988.

Whitelaw, N. *A Beautiful Pearl.* Morton Grove, IL: A. Whitman & Co., 1991.

Books for Teenagers

Nonfiction:

Frank, J. *The Silent Epidemic*. Minneapolis, MN: Lerner Publications Co., 1985.

Young, A. E. *What's Wrong with Daddy?* Worthington, OH: Willowisp Press, 1986.

Fiction:

Graber, R. *Doc.* New York: Harper and Row, 1986.

Kehret, P. *Night of Fear.* New York: Dutton, 1994.

Kelley, B. *Harpo's Horrible Secret.* Redfield, AR: Ozark Publishing, Inc., 1993.

Klein, N. *Going Backwards.* New York: Scholastic, 1986.

Smith, D. B. *Remember the Red-Shouldered Hawk*. New York: G.P. Putnam's Sons, 1994.

AD Support Organizations and Web Sites

(These are web sites that I have found helpful. There are of course many, many more that you may find. Be careful to investigate the sources of the information you find on the Internet. You will want to use reliable sources.)

The Alzheimer's Association
This organization's mission statement is to "provide leadership to eliminate Alzheimer's disease through advancement of research while enhancing care and support services for individuals and families. Information on the site includes: Medical Issues, Research, News Updates, The Facts, and Taking Care. Information available about contacting local chapters.

www.alz.org 800-272-3900

Alzheimer's Disease International
This international organization is based in London and is an umbrella organization of 50 national Alzheimer's Association groups. Its purpose is to improve the quality of life for people with dementia and their caregivers. It offers links to resources, publications, and the international groups.

www.alz.co.uk

Alzheimer's Society of Canada
This site offers information in English and French. Information includes Frequently Asked Questions, Guidelines for Care, News & Events, Physicians Corner, Forums, Resources, and Also of Interest. It's a voluntary organization that promotes policy changes and funds research.

www.alzheimer.ca 414-488-8722 (US) 800-616-8816 (Canada)

Alzheimer's Society of UK
This site covers England, Wales, and Northern Ireland. Information includes Dementia, Help for Carers (caregivers), News & Events, and 20 Common Questions.

www.alzheimers.org.uk

The Alzheimer's Disease Education and Referral Center (ADEAR)
This site is a service of the National Institute on Aging (NIA) under the auspices of the US Department of Health and Human Services. Information includes What's New, Information and Referral, NIA News, Alzheimer's Disease Publications (over 5,300 educational materials on AD), Clinical Trials Database, and links to other federal resources.

www.alzheimers.org 800-438-4380

Alzheimers.com
This site is dedicated to preventing and treating the cognitive decline of AD and providing current information. It is inspired by, but not affiliated with the Alzheimer's Association. Information includes The Basics, Risk Factors, Diagnosis, Treatments, and Coping & Resources. Material is written under the direction of a staff of professional medical writers and reviewed by an advisory board of professional and family caregivers.

www.alzheimers.com

Alzheimer Europe
This site serves European countries and has information in English, French, German, Spanish, Dutch, Portuguese, Swedish, Danish, and Finnish.

www.alzheimer-europe.org

Dementia Web
This site is based in London and is sponsored by the Dementia Research Group and CANDID (Counselling and Diagnosis in Dementia). Information is included on research findings, early onset AD, and drug guidelines. There is also a caregiver support chat room.

http://dementia.ion.ucl.ac.uk

Alzheimer Web
This site covers current information available about medical advances and information for caregivers. It is edited by a neurologist, Dr. David Small, and is based in Australia.

http://werple.mira.net.au/~dhs/ad.html

Agenet.com
This information and referral network is designed to "Bridge the Distance" between aging parents and adult children by providing "actionable" information on products and services. Topic areas include Geriatric Health, Geriatric Drugs, Legal, Insurance, Financial, and Caregiver Support. It has links to books on dementia.

www.agenet.com

Elderbooks.com
This is the site of a leading publisher of books about AD. Selected titles include "My Mother's Voice" by Sally Callahan, "Activity Ideas for the Budget Minded" by Debra Cassistre, and "Show Me the Way to Go Home" by Larry Rose. Many other books are available.

www.elderbooks.com

Amazon.com
Type in Alzheimer's or Dementia. Hit Search and watch out. Hundreds of related titles are available.

www.amazon.com

Universities and Hospitals:
(Some universities and hospitals offer AD sites. These include, but are not limited to:)

www.ohioalzcenter.org
This site is sponsored by the University Alzheimer Center, Cleveland, Ohio.

http://alzheimer.ucdavis.edu
This site is sponsored by the University of California at Davis Alzheimer Disease Center.

www.adrc.wustl.edu/ALZHEIMER
This site is sponsored by Washington University Alzheimer's Disease Research Center, St. Louis.

Site for Children:

www.angelfire.com/ma/alrac/kidsad.html
Contains "What's Wrong with My Grandma," "A Gift You Can Make," "Things You Can Do," and "Kid's Stories" (personal accounts of AD written by children).

Sites for Related Dementias:

Pick's Disease

www.pdsg.org.uk

http://dementia.ion.ucl.ac.uk/candid

Lewy Body Syndrome

www.ccc.nottingham.ac.uk/~mpzjlowe/lewy/lewyhome.html

Huntington's Disease

www.hdsa.org

www.had.org.uk

Creutzfeldt-Jakob Disease

www.cjdvoice.org

http://members.aol.com/crjakob/intro.html

Down Syndrome and AD

www.TheArc.org/misc/alzbk.html

Glossary

alpha-2 macroglobulin (A2M): a gene which may make a person at risk for developing AD

acetylcholine: a neurotransmitter in the brain that is greatly reduced in people with AD

ADL's (activities of daily living): activities or skills used for self-care (e.g., brushing teeth) and other more abstract tasks (e.g., paying bills)

apolipoprotein E (APOE): a gene associated with increased risk of developing AD

amyloid precursor protein (APP): a protein in the brain that supports growth of neurons and helps maintain them

anomia: difficulty remembering a specific word

anxiety: a state of uneasiness and/or distress about future uncertainties

axons: long, tube-like extensions on neurons

beta amyloid: a short, sticky piece of protein that has been clipped off the larger protein (APP) that is found in the neuritic placques (See **neuritic placques** on page 189.)

CAT or CT scan (computerized axial tomography)**:** a type of brain scan using X rays; sometimes used as part of the diagnostic battery for AD

catastrophic reaction: when a person with AD overreacts unexpectedly to a situation with angry outbursts

cdk5: a benign enzyme in the brain which is thought to be converted to an enzyme that causes tau to collapse and twist into the neurofibrillary tangles found in the brain in AD (See **tau** on page 190.)

dehydration: a condition in which a person is not getting enough fluids

delusion: an incorrect belief that cannot be changed

dementia: a group of symptoms including a loss of cognitive and linguistic skills in an adult. There are many causes of dementia including AD and multi-infarct dementia.

dendrites: small branches on the ends of neurons which increase the neuron's ability to receive information

DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition): publication of the American Psychiatric Association; contains criteria used to describe types of dementia including AD

durable power of attorney for financial decisions (also called *durable power of attorney for property):* a legal document that allows the designated representative to manage property and finances

durable power of attorney for health care: a document that designates a representative to make all health care decisions and end-of-life decisions for the person granting the authority

dysphagia: a swallowing disorder

echolalia: when a person repeats words or sentences said by others

episodic memory: memory of the events of a person's life

errorless learning: a technique first described by Baddely and Wilson (1994) in which mistakes made by people with memory problems are kept to a minimum as they learn new information

external memory aids: visual tools (e.g., calendars, memos, lists) that are used as memory reminders

guardian (or conservator): a person appointed by the courts who has the power to take care of someone who is unable to care for him/herself and manage that person's property

hallucinations: misinterpretations of sensory information (e.g., sight, sound, smell, touch)

lexical memory: memory of words

living trust: a written agreement where the person affected (the grantor) gives a person or a bank (trustee) permission to control financial assets according to certain directions. This must be set up with the help of an attorney.

living will: a document that gives another person the authority to make end-of-life health care decisions only

MCI (mild cognitive impairment): a memory impairment that does not include the additional cognitive problems of people with AD

MRI (magnetic resonance imaging): a test using large magnets which produces a three-dimensional image of the brain; sometimes used as part of the diagnostic test battery for AD

MID (multi-infarct dementia): a type of dementia caused by a series of small strokes

neuritic placques: clusters of beta amyloid seen in large numbers in the brains of people with AD

neurofibrillary tangles: twisted pieces of the tau protein found in large numbers in the brains of people with AD

neurotransmitters: chemicals (e.g., acetylcholine) in the brain that help nerve cells communicate with each other

palilalia: describes when a person repeats his or her own words over and over

paranoia: fear or suspiciousness that someone is trying to hurt you in some way

PET (positive emission tomography): an imaging technique which uses radioactive materials to measure glucose and oxygen metabolism in different areas of the brain; used predominately in research

perseveration: describes when a person does something repeatedly; can be verbal (saying something over and over) or physical (doing something over and over)

power of attorney: a written document (which must be witnessed and notarized) that gives one person the authority to act on another person's behalf. If it is written to last beyond the point of mental incapacity, it is called *durable power of attorney.*

procedural memory: memory of a learned motor task

secratases: enzymes in the brain

semantic memory: memory of facts or concepts about the world

spaced retrieval: the process of continually recalling information over increasingly longer periods of time; first described by Landauer and Bjork (1978)

SPECT (single photon emission computed tomography): a test which measures cerebral blood flow; sometimes used in place of PET scans

sundowning: restlessness and/or agitation in a person with AD which increases in the late afternoon or early evening

tau: a protein in the brain that is normally found in the internal structure of neurons. In AD, tau collapses and twists, forming neurofibrillary tangles.

trustee: a person appointed by the courts to manage a trust for the care and benefit of the beneficiary (e.g., a person with AD)

working memory: active memory that makes decisions and initiates actions

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*These publications are recomended to include in a "lending library" for caregivers support groups (page 78).