

Aphasia

Loneliness

Depression

Deja vu

medications

Support Groups

Exhaustion

Memory Loss

Understanding

Changes

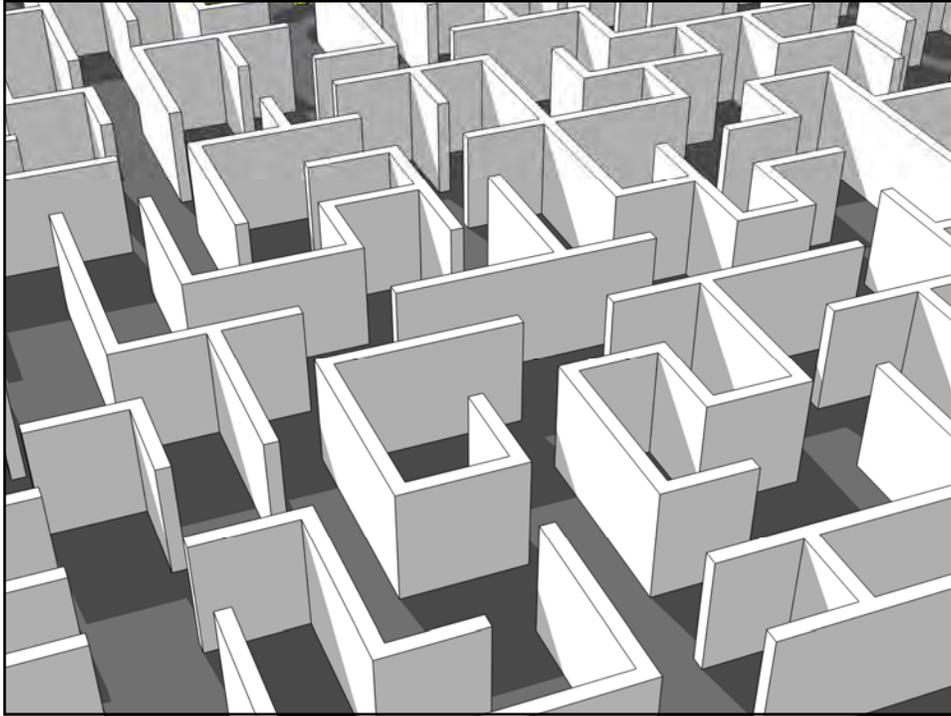
Acceptance

**Living in This Maze
of Alzheimer's** ©

Bill Smutny
May 07, 2020

© All rights reserved 2015
William Smutny

For Laura



Early Stage Symptoms

Symptoms:

- Minor memory problems
- Subtle Personality Changes / Obsessive behaviors
- Depression / Emotional Instability
- Modest decline in executive functions
- Sleep problems

The 4 Horsemen of Early Stage Dementia Frustration, Exhaustion, Confusion, Depression



Conquest, War,
Famine, Death

“Four Horsemen of Apocalypse” (1887) by the Russian artist Viktor Vasnetsov

The 4 Horsemen Represent:



Frustration:

- Anger or other emotional spikes or lows with no seeming justification



Exhaustion:

- Fatigue, sleep disorders – can't fall asleep or trouble staying asleep or excessive sleep



Confusion:

- Memory loss, cognitive impairment, speech impairment



Depression:

- Anxiety, apathy, general discontent, sadness, repetitious thoughts, paranoia, thoughts of suicide



ALZHEIMER'S vs. DEMENTIA

Are they the same thing?

Which is worse?

Is one the precursor to the other?

What does this have to do with sleep or emotions?

Each Breed Is a Dog Yet Each Has Different Characteristics



75+ Kinds of Dementia

Lewy Body

Vascular

Alzheimer's

Frontotemporal Lobe

Parkinson's

Syphilis (STD)

Multiple Sclerosis

Traumatic Brain Injury
(Normal pressure
hydrocephalus)

HIV-associated
neurocognitive disorder
(HAND)

Creutzfeldt-Jakob disease

And on and on...

Mixed Breeds: Two or More Breeds Represented



Dementia is More than Memory Loss

Memory Recall

Confabulation

Sensory Input

Vision Hearing

Taste Touch

Smell Temp

Acceptable Social Skills

Sequencing

Language Skills

Understanding, Using Words

Expressing Thoughts / Ideas

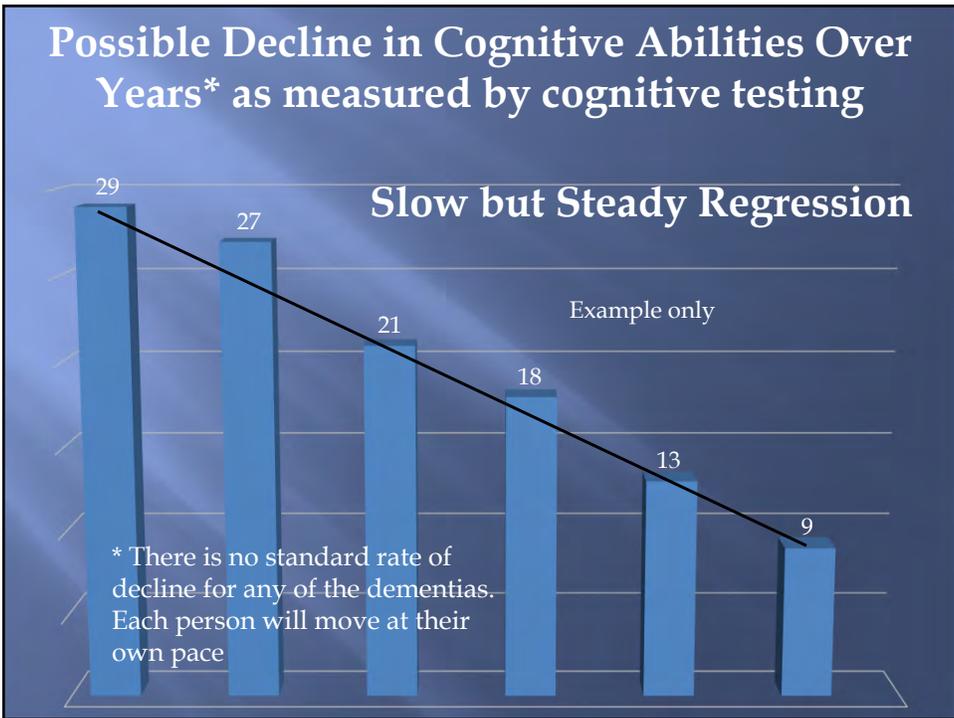
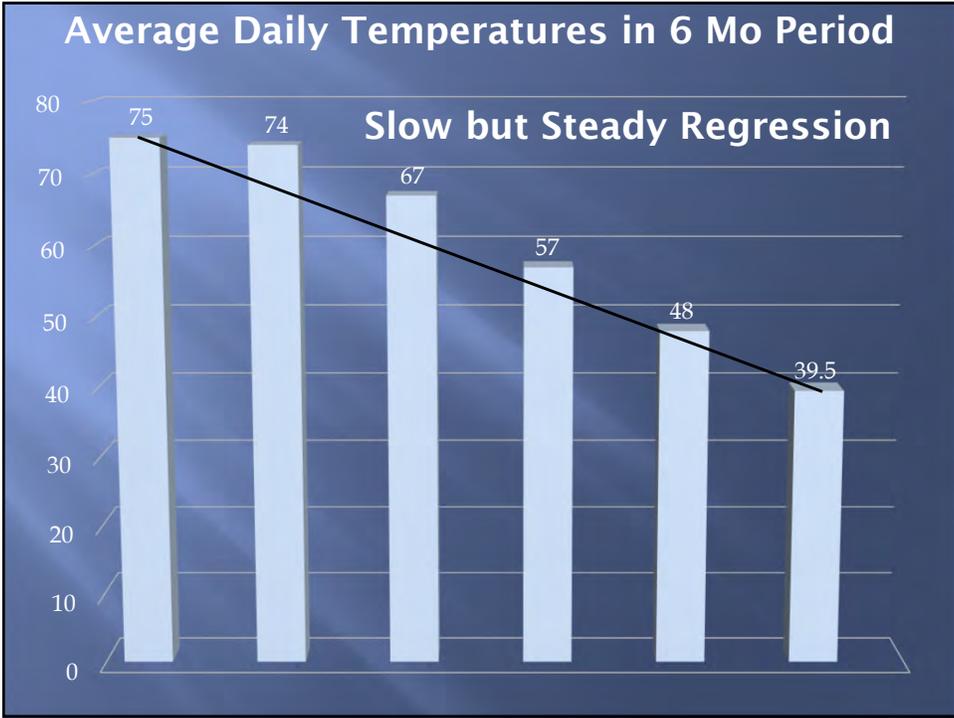
Time Skewed

Decision Making

Balance

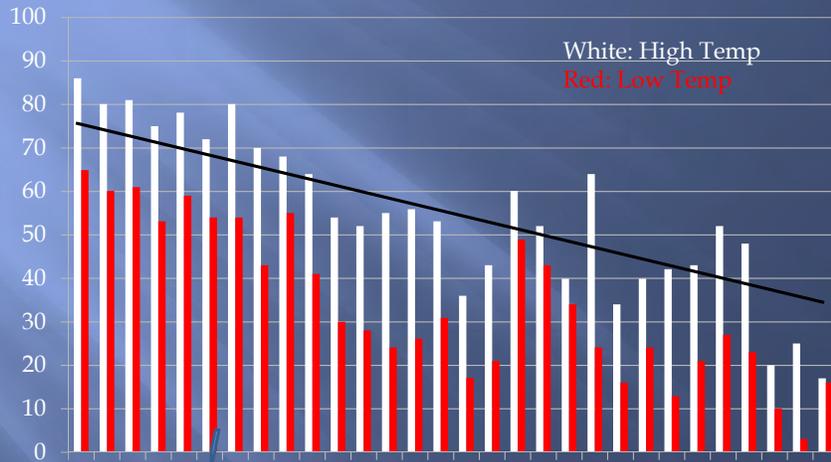
Sexual Behaviors / Attitudes

Hallucinations / Delusions



Daily Highs and Lows for Same Period

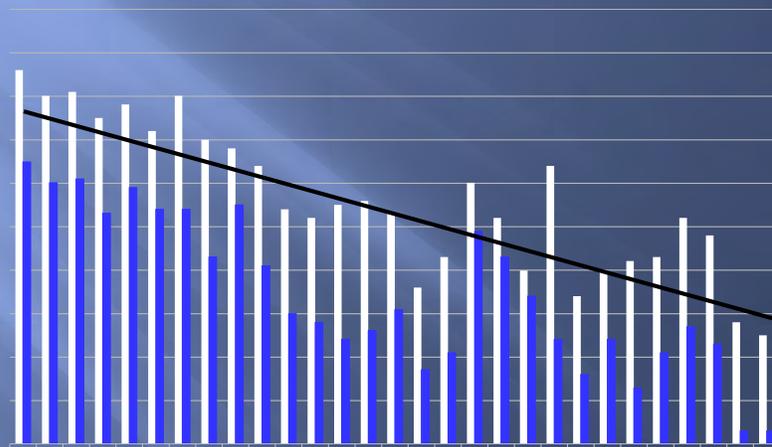
(every 6 days)



Every day is different. Every day is filled with its own highs and lows

With Dementia It's the Same

Example only



Every day is different and every day abilities can change

Our Primary Job as Care Partners

- ❑ Preserve Dignity
- ❑ Build Self Confidence
- ❑ Restore Self Worth
- ❑ Boost Morale

It makes everything fall into place

Serenity Prayer

*God, grant me the serenity to accept
the things I cannot change*

The courage to change the things I can

*And the wisdom and understanding to
know the difference*

Three Keys to Walking the Maze called Dementia:

1. Acceptance

- Without acceptance you can't move forward
 - You will remain a victim
- Allows you to find ways to deal with it

Three Keys to Walking the Maze called Dementia:

2. Understanding

- *Any fool can learn. The point is to UNDERSTAND*
-Albert Einstein
- To effectively initiate, facilitate, and maintain changes in your life you must understand *why* you are making them

Three Keys to Walking the Maze called Dementia:

3. Change

- For those with the diagnosis
 - Change is constant and inevitable. There is no choice.
 - Changes can
 - Appear quickly or slowly
 - Be short or long-lived
 - Vary in intensity - dramatic or subtle

Three Keys to Walking the Maze called Dementia:

- For the Caregiver
 - Change is a *choice and a decision to adjust your*
 - Expectations ○ Attitude
 - Thought Process ○ Speech
 - Behavior
- With dementia the only constant is change

Dementia Can Disguise Itself

The ability to rise to the occasion, hiding or masking her condition

Wearing the Mask of Normality...



The Mask Effectively Hides the Confusion and Other Symptoms

Wearing the Mask

- The mask is a facade to anyone, including themselves, that makes them appear normal. It can be a conscious or an unconscious effort.
- It can be easily worn and put on at a moment's notice
- Like anything there is a price, and the bigger the purchase the higher the cost. The price will be paid in any combination of the following world currencies:

\$ Frustration	€ Confusion
£ Depression	¥ Exhaustion

How Does 'The Mask' Work?

- Many peaks and valleys in any given day
 - Maybe it's just a 'good' period
- Extra effort required – mind is working feverishly
 - Shot of adrenaline or acetylcholine
- Social chit chat, muscle memory, and routines are embedded deep within our brain
- Shows she is fighting - not surrendering

Hardest Part of the Journey

In *my* opinion...

- The beginning period is the toughest part of this journey
 - Behaviors and symptoms are erratic
 - Roles are ill defined
 - Personalities are shifting
 - Emotional Rollercoaster
 - Neither partner has come to grips with what is happening
 - Little or No Acceptance, Understanding, or Change

Flickers: Flashes of unexpected behaviors

- ❑ a preview of things to come
- ❑ Not permanent
- ❑ Last for short periods of time - moments or minutes
- ❑ Usually unexpected
- ❑ Preview of things to come



Not to be confused with everyday slip ups - Hey, we're all human

Confabulation

- ❑ An intricate story that is woven around personal history, past experience, or just perception
 - Dig deep enough you will find a seed of truth
- ❑ Memory does play a role - They remember, just not correctly



Develop Mantra

“Does it really matter?”

- Work to overcome the urge to correct or be correct

Lying: To Deceive or To Comfort?

- In strictest sense, if you are saying something to convey a false impression...
- Is there harm in it? Are you deceiving to take advantage or to comfort?
- Are you presenting too much information?
- Are there ways around it?

*"Perspective is to life
as a rudder is to a ship
or a bridle to a horse."*

Leonardo da Vinci

A Matter of Perspective

- ▣ Am I focused on the completed task?
- ▣ Is Laura angry with me?
- ▣ Is it more important to finish quickly?
- ▣ Is she shadowing me?
- ▣ Do I see Laura trying as hard as she can?
- ▣ Is she frustrated with herself?
- ▣ Can she work at her own pace?
- ▣ Does she need a little reassurance?

Diagnosed: Mid Stage Symptoms

- The Four Horsemen of Alzheimer's
 - Frustration • Confusion
 - Depression • Exhaustion
- Executive Function / Memory Problem Decline
- Personality Changing
 - Controlling and obsessive behaviors
 - Paranoia
 - Emotional rollercoaster - Anxiety / Emotional Turmoil
 - Withdrawal
- Changes in libido
- Denial and some acceptance
- Begins to lose the concept of time
- Susceptible to marketing and scams

Care Giver: Mid Stage Symptoms

- **Bewilderment**
- **Denial**
- **Resentment / Anger**
- **Depression / Sadness**
- **Acceptance of Situation**
- **Recognition of the need for change**
- **Outside burdens / responsibilities seem heavier**
- **Skilled at 'Improv Thinking'**
- **Concern over own mental health**

Balancing Act

- **Helping**
 - Needs help, doesn't want it
 - Needs help, asks for it
 - Needs help but we don't see the urgency
 - Doesn't need help, gets it anyway
- **Struggle for independence**
- **The desire NEED to help, contribute and FIT IN**

Lesson Learned

INSTEAD OF

- ❑ NO, we don't need that...
- ❑ Don't do that...
- ❑ No, dinner isn't ready yet
- ❑ It's too hot to wear that sweater (implied 'no')

SAY THIS

- ❑ I think there is some in the pantry
- ❑ Here, try this instead
- ❑ Dinner will be ready at five, munch on this
- ❑ Let's wear some matching shirts... or...

Our words can often have as much affect as a pharmaceutical

Time is Irrelevant & Unperceivable

- ❑ The ability to perceive time is lost
- ❑ 5 minutes or 55 minutes can be the same
- ❑ “Hurry Up” means nothing
 - It can actually cause the reverse
- ❑ Clocks exist; time does not.



Shadowing explained In Six Little Words

Best and simplest explanation:

“Please come here. I need you.”

- ❑ Listen closely and read between the lines and your loved one will reveal his / her needs

Sundowners

Emotional turmoil or confusion late afternoon or near the end of the day

- ❑ Watch for trigger(s) to avoid future episodes
- ❑ Use Diversions
- ❑ Talk to MD



*The Birds and
the Bees!*

As with all things dementia, libido can change too

The desire to touch and be touched can be heightened

Desire, frequency, and/or curiosity can ebb or flow during the journey

When Facing the Giants There is No Denial Possible

- For everyone the giants are different
 - Driving – the most common
 - Power tools for carpenter
 - Shoes for Laura
- As a caregiver, be sensitive
 - Find something to be positive about
 - Use positive diversions
 - Use “Help Me”

Diagnosed: Late Middle Stage Symptoms

- Cognitive impairment declines
 - Amnesia • Apraxia
 - Agnosia • Aphasia
- Perception of Time and Space is skewed
- Greater deficits in Activities of Daily Living (ADLs)
- Logical reasoning lacking
- Incontinence
- Social Filter is ajar
- Behavior Problems
 - OCD • Stubbornness
- Personal history is in state of flux
 - Confabulation
- Interpretation through senses is diminished
 - Preferences subject to change
- Hallucinations / Delusions
- Wandering
- Appetite is affected +/-

Care Partner: Late Middle Stage Symptoms

- Sadness
- Denial
- Withdrawal
- Bewilderment
- Resentment / Anger
- Embarrassment
- Recognition of the need for change
- Emotional Drain
- Little “Me” Time
- Support Critical
- Develop a Thick Skin
- Marriage Vows
- Role of Servant
- Remember your loved one is still there

The Four A's of Alzheimer's



- ❑ **Amnesia:** Memory Issues
- ❑ **Apraxia:** Motor Coordination and Spatial Recognition
- ❑ **Agnosia:** Recognition of Common Articles and their Uses
- ❑ **Aphasia:** Speech and Language Skills Challenged

Living in the Moment

My definition has changed over time

- In my twenties it meant "Have a good time! Celebrate!"
- With the onset of the diagnosis it meant "Slow down, let each moment happen"
- As the disease progressed it meant, "In that particular moment - nothing else matters"



Living in the Moment

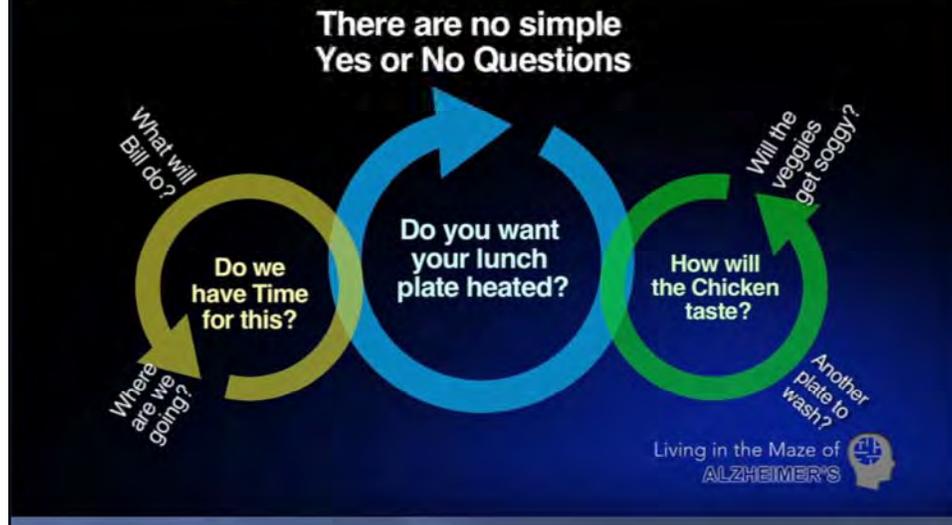
It's More Complicated than It Sounds...

- If things are not at hand, they are lost
- Creates a sense of urgency
- Causes panic and frustration
- Creates a need for attention
- Unable to channel energy to more productive pursuits



I calmed the storm of chaos that raged in Laura's mind

There are no 'Simple' Yes or No Questions
No Simple Questions - No Simple Answers



Decision Making Should Be Inclusive

Don't take away the opportunity to try or to be part of the solution

- ❑ Inclusion is based on how you frame it
 - Limit choices and lead
 - Don't give TMI (too much information)
- ❑ Tone is important
- ❑ Don't assume responsibility - work *with* your loved one
- ❑ Homework: Drop the word "No" from your vocabulary
- ❑ Be Creative

Diagnosed: Later Stage Symptoms

Symptoms Continue to Worsen

- Cognitive impairment declines
 - Amnesia
 - Apraxia
 - Agnosia
 - Aphasia
- Perception of Time and Space is skewed
- Greater deficits in Activities of Daily Living (ADLs)
- Logical reasoning lacking
- Incontinence
- Social filters are gone
- Behavior Problems
 - OCD
 - Stubbornness
- Personal history is in state of flux
 - Confabulation
- Interpretation through senses is diminished
 - Preferences subject to change
- Hallucinations / Delusions
- Wandering
- Appetite ebbs and flows

Rising to Meet the Challenge as a CarePartner

- Acceptance
- Role Reversal / adoption confusing or clumsy
 - Parent or Spouse
 - Helping in unfamiliar areas
- Overwhelmed / Stressed / Lonely
- Master the '*Art of Cueing*'
- Continued Withdrawal – imposed / self induced
- Faith increases
- Patience Continues to Grow

The Answer Was Irrelevant, But So Was the Question

- Logical reasoning is challenged
- Reacting to moment
- Behaviors may put safety at risk – need to be one step ahead
- They *never* do something until they do it for the first time



A Wall of Separation

- ❑ Social Isolations
 - Family and friends become distant by our choice or theirs
- ❑ Misunderstanding, Jealousy, Resentment, Miscommunication are basic ingredients for the mortar of the wall
- ❑ Our loved ones withdraw
 - Harder to express themselves
 - If we focus on the negatives
- ❑ Leads to further darkness despair and anger



Breaking the Silence

- The house becomes disturbingly quiet
- Laura needs mental AND social stimulation
 - Trips / Errands out to big box stores, grocery stores, malls
 - Lunch in QUIET restaurant
 - Read out loud to her
 - Speak my thoughts out loud
 - Found things that worked for us
 - Walks in mall
 - Limited electronics
 - Support Groups
 - Do what works for YOU!

Activities of Daily Living (ADLs) Slowly Regress



- Cues for everyday life
 - Bathing
 - Dressing
 - Eating / Drinking
 - Opening & Shutting Doors...

Perspective

What do you see?

“Let us try to see things from their better side. You complain about seeing thorny rose bushes; me, I rejoice and give thanks to the gods that thorns have roses.”

Anonymous French Writer

The Heart of the Maze The Final Stages



Complete loss of awareness of the world around her/him

Speech and language limited

Mobility Gone

Loss of the ability to use or complete basic survival functions

The Heart of the Maze Caregiver: Facing Reality



- ❑ Everyone will tell you what to do
 - ❑ Smile, say “thank you” and then assess your own situation
- ❑ Step back and think about resolving a situation
- ❑ Prayer

Two Figures in Undergrowth (1890)



“Normality is a paved road. It’s comfortable to walk, but no flowers grow on it.” van Gogh

Serenity Prayer

*God, grant me the serenity to accept
the things I cannot change*

The courage to change the things I can

*And the wisdom and understanding to
know the difference*

Thank You

(Notes) **As a Friend What Can You Do?**

- This is a personal journey – everyone is different and at different stages
- Don't say "I'll do anything" instead Do Something
- Be There – listen and ask; don't compare
- Be Patient – things may take more time; don't interrupt and don't prompt for an answer
- Consider group size, level of confusion, noise level, temperature, etc. when thinking of group events
- Always include but don't be hurt if turned down
- Remember, what's possible one day, may not be possible the next but okay again in

(Notes) **Parts of the Brain**

- **The Frontal Lobe**, controls responses to input from the rest of the central nervous system (brain and spinal cord). Responsible for voluntary movement, emotion, planning & execution of behavior, intellect, memory, speech, writing.
- The **Parietal Lobe** (above the ear) receives / interprets sensations of pain pressure, temperature, touch, size, shape, and body part awareness.
- The **Temporal Lobe** (behind the ear) understanding sounds and spoken words, as well as emotion and memory.
- The **Occipital Lobe**, back of the head, understanding visual images and the meaning of the written word.
- The **Hippocampus** crucial in learning and in processing various forms of information as long-term memory. Damage to the hippocampus produces global amnesia.