

Understanding Shifts in Mood

How to live successfully with memory loss

- Common reactions
- Why they occur
- What to do



Living Successfully with Memory Loss

Memory loss is not something that anyone expects or is prepared for. It causes problems in areas that were never a problem before. This can be extremely frustrating and discouraging to live with each day.

It is important to remember that these problems are a direct result of physical changes in the brain. It is like scar tissue. Messages are sometimes blocked from getting through. Our emotions can be on edge. New information becomes harder to hold on to.

All of this is very hard to accept. It takes time. It also takes an appreciation of all that is remains in your life - all that has not changed and continues to bring joy.

We are a lot more than memory machines!

Try to be especially kind to yourself as you grow in understanding and patience. Trust in yourself. You will be able to find the answers you are looking for and the resources you need to live with these changes – and to be happy.

Personal Perspectives on Living Well with Losses **by Thad Raushi, Ph.D.**

Dr. Raushi was diagnosed with Alzheimer's disease at age 57.

We may or may not be able to change our outer circumstances,
but with awareness we can always change our inner attitude,
and this is enough to transform our life.

Even in the worst external circumstances,
we can choose whether we meet life from fear and hatred
or with compassion and understanding.

from A Path with Heart by Jack Kornfield

What powerful words! What an empowering thought! For me, as someone diagnosed with early-onset Alzheimer's, this perspective has become an important part of my way of thinking about life, about my vision for high quality living with a low quality disease.

At the core of high quality living is the spiritual. I find rich meaning in the words attributed to an ancient sage: "Guard your inner spirit more than any treasure, for it is the source of life."

I think of "spiritual" as the way we experience our daily living and the "spirit" as that life within us that emerges in this experience.

So the inner spirit is the "source of life" within me, that vital force guiding how I see quality living, how I understand the Alzheimer's, and how I mold attitudes.

Acknowledging the circumstances of Alzheimer's and experiencing the accompanying feelings allows me to let go of what I don't want and to move on with living well. It's not always easy.

Some days I start out in the shower full of energy thinking I can tackle the world, denying the Alzheimer's. Then, later on in a conversation which I can't handle, or instructions I can't follow, or a problem I can't think through, I am brought back to reality.

Yet I move on. What helps me to move on is realizing that to be stuck in negative feelings is a miserable place to live. And I just don't like feeling miserable.

Living in the moment fully is to live not clinging to past realities or to future dreams, but living fully present in today.

Mindfulness meditation has helped me to learn the richness of the moment. I have grown close to the philosophy of always seeing myself as doing the best I can at any given time with what I have at that time.

Instead of wasting energy comparing myself to “the me” of the past and instead of bemoaning what I could have been in the future, I focus on the now. I can’t counsel or teach as I once could, but I can share my journey in talks and in writing.

About attitude: Adjusting my attitude is simply recognizing that while I may not be able to change the circumstances of my life, I do have the choice of how I will view these circumstances. While the cancer or brain tumor or Alzheimer’s will not disappear, though there may be such things as miracles, my attitude toward the diseases is my choices.

About openness and sharing: Both in the giving and the receiving of support, everyone benefits. Having early dementia does not preclude the person from giving support to others.

And being open to receive help can be a gift to the other person who desires to care and share their love.
--

I do draw a line, though, in the receiving. Imposed help and the funeral parlor attitude of “Oh I am so sorry for you”, just does not have a place in my life.

About relationships: At the heart of all of my relationships is the love and caring Sylvia and I share together. Sylvia is precious to me, a treasure in my life. There is also the love and caring of our grown children David and Deborah, our daughter-in-law Diana, and precious grandson, Derek. There is a long-distance brother who calls to check on me often and have some laughs. There is a long-time colleague and friend with whom I have lunch weekly. There are friendships, old and new. Family and friends are important, as is the nurturing of these relationships.

Some people feel friends fall away with a dementia diagnosis. No doubt sometimes this happens. But I know for myself and several others with the disease, that friends remain friends and continue to share hobbies and play tennis and volunteer together. It can happen.

About life outside Alzheimer's: I work at maintaining a life outside the disease. It is important to have hobbies and interests and activities. For me this includes volunteering, writing, enjoying family, gardening, genealogy, and other things.

Then there is adapting: Knowing I can't change the Alzheimer's, yet believing that I still have choices over how I see the disease in my life, I am able to work at making adaptations on how I will live.

To me this is rehabilitation. Some examples of adaptations are: learning to concentrate on one activity or thought at a time; carefully selecting daily activities; and concentrating extra hard in conversations.

What powerful words these are of Bob Dylan for those with Alzheimer's or a related dementia: "He who is not busy being born is busy dying." Early diagnosis does not have to be a death sentence, a time to be "busy dying".

Rather, early diagnosis can be an opportunity to take an outer circumstance one cannot change, and turn that circumstance into a new and meaningful life.

This life is "busy being born" every day into some new venture, some new thought, some new dimension in quality living, no matter how large or how small that experience may be.

Taken from *Perspectives: A Newsletter for Individuals with Alzheimer's Disease or a Related Disorder* by Lisa Snyder, LCSW, August-October, 2004. To subscribe, contact Lisa Snyder, UCSD Alzheimer's Disease Research Center, 9500 Gilman Dr - 0948, La Jolla, CA 92093, 858-622-5800, email: lsnyder@ucsd.edu

Top Ten Tips on Avoiding Frustration

1. Avoid scheduling too many things in one day.
2. Allow plenty of time to get ready.
3. Keep to your normal routine – even when traveling.
4. Rest when you are tired.
5. Drink plenty of fluids, especially in the afternoon.
6. Take a break when you become frustrated.
7. Limit noise and commotion.
8. Schedule regular visits with family and friends.
9. Share your feelings with those who love you.
10. Don't be afraid to ask for help!

If you have your sense of humor it is worth more than any medicine.

Brilliant Insights on Common Reactions From Persons Living with Memory Loss

1. Its hard to ask for help. I've always been so independent.
2. I'm losing words – but not cuss words!
3. There's a lot of pain to it – someone taking your privileges away.
4. I used to be the strong one. It's hard to accept when I can't do everything like I used to.
5. I'm angry! I can't accept all of this.
6. My daughter thinks she's the mother and I'm the daughter!
7. I can be trusted more than you think.
8. We must find ways to see areas of conflict as funny, instead of tragic.
9. I don't ask for too much help. I don't want to be a burden, or a bother.
10. Sometimes people look right through you.
11. My husband and I are getting on each other's nerves.
12. Its hard when you're there all the time. I need some leeway.
13. I get upset that I have to have my wife remind me of things. I'm not the man I used to be.

We seem to get bogged down in what we can no longer do.
I like to think about what I can still do – with no help.
In fact, I made a list!

14. The important thing is hanging in there when you can't change what's happening.
15. Sometimes I say to myself, tomorrow is another day.
16. I feel the anguish between my wife and me.
17. Sometimes I get so angry at forgetting, I want to smash the project I'm working on.
18. My problem is that I feel left out sometimes. I want to say, "Hello, I'm here!"
19. Half the time we don't know why we are acting the way we are – so how are they supposed to know?
20. We have to be honest with ourselves about our limitations.
21. I try to stay active and enthusiastic about doing things as much as I can.
22. I can do it myself; I want to do it myself.
23. I decided to have a "be good to Jane day".
24. He's not my caregiver – he's my husband
25. I'm convinced now that I have Alzheimer's disease; but I try to put it out of my head. I don't focus on what I forget; I just try to keep going.
26. I still feel very much a part of a loving family.
27. My dog understands every word I say; there would be a hole in our lives if she wasn't here.
28. Don't ever give up!

Stress-Busting Techniques From Persons Living with Memory Loss

- ✓ Go for a walk
- ✓ Pet the cat . . . dog's are good, too!!! 😊
- ✓ Go on the treadmill
- ✓ Call my friends and talk about something else
- ✓ Listen to music
- ✓ Read something inspiring



What do I do???

- ✓
- ✓
- ✓
- ✓

Where do I go?

- ✓ To my favorite chair
- ✓ In the kitchen for a cup of tea
- ✓ Outside on the porch
- ✓
- ✓
- ✓

What do I say to myself?

- ✓ I have a lot to be thankful for.
- ✓ Tomorrow's another day.
- ✓ I'm doing a pretty good job.
- ✓
- ✓
- ✓
- ✓
- ✓

What happens is not as important
as how you react to what happens.

Thaddeus Golas

Exercise Your Brain: Stretching Your Imagination

You will need one other person for this exercise. They can be any age – they just have to be fun! This can also be done with a small group.

Try acting out each of the following – one at a time – with no words:

Walk a tightrope

Thread a needle

Dance the Charleston

Dig a hole

Shave your beard

Do the Hula

Hang clothes on the line

Sweep the floor

Walk a dog

Flip a pancake

Iron a shirt

Drive a car

Use a slingshot

Rock a baby

Milk a cow

Hammer a nail

Paint a fence

Put on Nail Polish

Make a telephone call

Put curlers in your hair

Knit a sweater

Open an umbrella

Catch a fish

Play the piano

Pick apples

Wash clothes on a washboard

Swat a fly

Break three eggs and beat

Put on lipstick

Sew a hem

Saw a log

Brush your teeth

Burp a baby

Type a letter

Blow up a balloon

Musical Instruments:

Cello

Harp

Trumpet

Drums

Trombone

Flute

Bass

Xylophone

Harmonica

Eating Foods:

Very hot soup

A banana

Ice cream cone

Corn on the cob

Spaghetti

Sports:

Bowling

Golf

Archery

Tennis

Basketball

Baseball

Horseshoes

Fencing

Shot put

Boxing

Swimming

Diving

Horseback riding

Ping pong

Exercise Your Brain: Word Exercise



Welcome
Spring!

Write down any flowers or trees that begin with each of the letters in SPRING:

S _____

P _____

R _____

I _____

N _____

G _____

**Blessed are
the Flexible
for They
Shall Not Be
Bent out of
Shape**

Learning Together II Leaders Manual: Persons with Memory Loss

Focus: Understanding Shifts in Mood:

Supplies:

Flip chart

Marker

Feelings cards: large different colored cards to post or sets of small cards for each individual

Handouts for workbooks (3-hole-punched, paper clipped to take home)

Discussion handouts (copies at end)

1. *Brilliant Insights, p. 7-8*
2. *Blessed are the Flexible, p. 14*

1. Our topic this month is understanding moods or how to handle the ups and downs. Before we get into our discussion, though, I'd like to check in with each of you. As always I gave a fun question to add as well. May I start with you? _____, how is everything going? In checking in, respond to person's body language, e.g. you are quieter than usual, what is happening? After checking in, may ask each to share one favorite memory from the springtime (cue as needed, e.g. when you were child, gardening, flowers, religious, baseball).

If new individual, ask each person to introduce themselves. Note that everything we talk about here is confidential.

2. Now on to our topic. In these groups, we talk about how to live successfully with memory loss. An important piece is handling the ups and downs.
3. First of all why. Everybody experiences these feelings. However, they can be more sudden and intense for someone who has memory loss. This is due to the chemical changes in the brain. I had one man say that, "I have a roller coaster of emotions". Another woman

told me, "I no longer have much interest in going out with my friends." Another person said, "I have a really short fuse now".

4. These are some of the most common feelings we hear from individuals in these groups (note posted cards). Let's look at some of these, starting with common feelings on the not so good days: SAD, ANGRY, SCARED, FRUSTRATED, DISCOURAGED. Read cards; open for discussion, e.g. what do you think is the most common feeling of all? Why? Other feelings? How do you handle these feelings? What do you do when you become frustrated (can list on flip chart)?

OPTIONAL TECHNIQUE: pass out 5 feelings on a not so good day to each individual. Read cards; ask each person to pick one card that describes a feeling they have had; give plenty of time; assist as needed. Okay, are you ready? On the count of 3, hold up your cards. Notice similarities and differences; open for comments on why individuals chose this card; move on to second card choice. May open for feelings not on these cards. So how do we handle these feelings? What do you do when you become frustrated (can list on flip chart)?

5. Now let's look at the good days: HAPPY, SATISFIED, LOVED, COMPETENT, PEACEFUL. What do you think about these?
6. Brain exercise: Think Spring word game. Leader writes the word SPRING down left side of flip chart. Starting with "S", opens to group to think of a flower or tree that begin with this letter; writing answers on flipchart; continues with rest of letters.
7. Brain exercise: Stretching Your Imagination activity (note exercise in handouts).

One way to stretch our imaginations is to act out a few things. I have a selection of cards with activities on them. These are all ones we can do sitting right here at the table. I'll go first. Leader acts out activity and asks them to guess; then opens to group, passing a card to anyone willing to act something out. If person is hesitant, pass second card for them to choose from. Leader moves on to activities

that need to be acted out standing up; can cue group with comments such as, who likes outdoor sports?

8. If time allows, hand out *Brilliant Insights*, p. 7-8. Open to group for anyone who would like to read the first few. Move on to others who are interested in reading, pausing often for comments.
9. End on *Blessed are the Flexible*, p. 14.

Sad

Angry

Scared

Discouraged

Frustrated

Happy

Satisfied

Loved

Competent

Peaceful

Play the piano

**Thread a
needle**

Swat a fly

**Make a phone
call**

Knit a sweater

Eat hot soup

Flip a pancake

Drive a car

**Use a
slingshot**

Rock a baby

Hammer a nail

**Break 3 eggs
and beat**

**Brush your
teeth**

Burp a baby

Type a letter

**Blow up a
balloon**

Play a flute

Play a guitar

Play a trumpet

Eat a banana

**Eat an
ice cream cone**

**Eat corn
on the cob**

Paint a fence

Dig a hole

**Walk a
tightrope**

Do the hula

Saw a log

**Dance the
Charleston**

Play tennis

Iron a shirt

**Sweep the
floor**

Walk a dog

Milk a cow

**Open an
umbrella**

Bowl

Throw a ball

**Swing a golf
club**

Box

Swim

**Shoot an
arrow**

**Play
basketball**

**Swing a
baseball bat**

Catch a fish

Brilliant Insights on Common Reactions From Persons Living with Memory Loss

1. Its hard to ask for help. I've always been so independent.
2. I'm losing words – but not cuss words!
3. There's a lot of pain to it – someone taking your privileges away.
4. I used to be the strong one. It's hard to accept when I can't do everything like I used to.
5. I'm angry! I can't accept all of this.
6. My daughter thinks she's the mother and I'm the daughter!
7. I can be trusted more than you think.
8. We must find ways to see areas of conflict as funny, instead of tragic.
9. I don't ask for too much help. I don't want to be a burden, or a bother.
10. Sometimes people look right through you.
11. My husband and I are getting on each other's nerves.
12. Its hard when you're there all the time. I need some leeway.
13. I get upset that I have to have my wife remind me of things. I'm not the man I used to be.

We seem to get bogged down in what we can no longer do.
I like to think about what I can still do – with no help.
In fact, I made a list!

14. The important thing is hanging in there when you can't change what's happening.
15. Sometimes I say to myself, tomorrow is another day.
16. I feel the anguish between my wife and me.
17. Sometimes I get so angry at forgetting, I want to smash the project I'm working on.
18. My problem is that I feel left out sometimes. I want to say, "Hello, I'm here!"
19. Half the time we don't know why we are acting the way we are – so how are they supposed to know?
20. We have to be honest with ourselves about our limitations.
21. I try to stay active and enthusiastic about doing things as much as I can.
22. I can do it myself; I want to do it myself.
23. I decided to have a "be good to Jane day".
24. He's not my caregiver – he's my husband
25. I'm convinced now that I have Alzheimer's disease; but I try to put it out of my head. I don't focus on what I forget; I just try to keep going.
26. I still feel very much a part of a loving family.
27. My dog understands every word I say; there would be a hole in our lives if she wasn't here.
28. Don't ever give up!

**Blessed are
the Flexible
for They
Shall Not Be
Bent out of
Shape**