

KEEPING
LOVE ALIVE
AS
MEMORIES
FADE

*The 5 Love Languages® and
the Alzheimer's Journey*

Deborah Barr, MA, MCHES, RHEd

Edward G. Shaw, MD, MA

GARY CHAPMAN, PhD

NORTHFIELD PUBLISHING | CHICAGO

LOVE: IT'S ALL IN YOUR HEAD



Below you will see 30 paired statements. Please circle the letter next to the statement that best defines what is most meaningful to you in your relationship. Both statements may (or may not) sound like they fit your situation, but please choose the statement that captures the essence of what is most meaningful to you, the majority of the time. Allow 10 to 15 minutes to complete the profile. Take it when you are relaxed, and try not to rush through it. If you prefer to use the free interactive version of this profile online, please visit 5lovelanguages.com.

It's more meaningful to me when . . .

- | | | |
|---|--|---|
| 1 | I receive a loving note/text/email for no special reason from my loved one. | A |
| | my partner and I hug. | E |
| 2 | I can spend alone time with my partner—just the two of us. | B |
| | my partner does something practical to help me out. | D |
| 3 | my partner gives me a little gift as a token of our love for each other. | C |
| | I get to spend uninterrupted leisure time with my partner. | B |
| 4 | my partner unexpectedly does something for me like filling my car with gas or doing the laundry. | D |
| | my partner and I touch. | E |
| 5 | my partner puts his/her arm around me when we're in public. | E |
| | my partner surprises me with a gift. | C |
| 6 | I'm around my partner, even if we're not really doing anything. | B |
| | I hold hands with my partner. | E |

KEEPING LOVE ALIVE AS MEMORIES FADE

7	my partner gives me a gift.	C
	I hear "I love you" from my partner.	A
8	I sit close to my partner.	E
	I am complimented by my loved one for no apparent reason.	A
9	I get the chance to just "hang out" with my partner.	B
	I unexpectedly get small gifts from my partner.	C
10	I hear my partner tell me, "I'm proud of you."	A
	my partner helps me with a task.	D
11	I get to do things with my partner.	B
	I hear supportive words from my partner.	A
12	my partner does things for me instead of just talking about doing nice things.	D
	I feel connected to my partner through a hug.	E
13	I hear praise from my partner.	A
	my partner gives me something that shows he/she was really thinking about me.	C
14	I'm able to just be around my partner.	B
	I get a back rub or massage from my partner.	E
15	my partner reacts positively to something I've accomplished.	A
	my partner does something for me that I know she doesn't particularly enjoy.	D
16	my partner and I kiss frequently.	E
	I sense my partner is showing interest in the things I care about.	B
17	my partner works on special projects with me that I have to complete.	D
	my partner gives me an exciting gift.	C

LOVE: IT'S ALL IN YOUR HEAD

- 18 I'm complimented by my partner on my appearance. A
my partner takes the time to listen to me and really understand my feelings. B
- 19 my partner and I share nonsexual touch in public. E
my partner offers to run errands for me. D
- 20 my partner does a bit more than his/her normal share of the responsibilities we share (around the house, work-related, etc.). D
I get a gift that I know my partner put thought into choosing. C
- 21 my partner doesn't check his/her phone while we're talking. B
my partner goes out of their way to do something that relieves pressure on me. D
- 22 I can look forward to a holiday because of a gift I anticipate receiving. C
I hear the words "I appreciate you" from my partner. A
- 23 my partner brings me a little gift after he/she has been traveling without me. C
my partner takes care of something I'm responsible to do but I feel too stressed to do at the time. D
- 24 my partner doesn't interrupt me while I'm talking. B
gift giving is an important part of our relationship. C
- 25 my partner helps me out when he/she knows I'm already tired. D
I get to go somewhere while spending time with my partner. B
- 26 my partner and I are physically intimate. E
my partner gives me a little gift that he/she picked up in the course of her normal day. C
- 27 my partner says something encouraging to me. A
I get to spend time in a shared activity or hobby with my partner. B

KEEPING LOVE ALIVE AS MEMORIES FADE

28	my partner surprises me with a small token of her appreciation.	C
	my partner and I touch a lot during the normal course of the day.	E
29	my partner helps me out—especially if I know they’re already busy.	D
	I hear my partner specifically tell me, “I appreciate you.”	A
30	my partner and I embrace after we’ve been apart for a while.	E
	I hear my partner say how much I mean to him/her.	A

Now go back and count the number of times you circled each individual letter and write that number in the appropriate blank below.

RESULTS

A: _____ WORDS OF AFFIRMATION

B: _____ QUALITY TIME

C: _____ RECEIVING GIFTS

D: _____ ACTS OF SERVICE

E: _____ PHYSICAL TOUCH

Which love language received the highest score?

This is your primary love language. If point totals for two love languages are equal, you are “bilingual” and have two primary love languages. And, if you have a secondary love language, or one that is close in score to your primary love language, this means that both expressions of love are important to you. The highest possible score for any single love language is 12.

LOVE: IT'S ALL IN YOUR HEAD



Below you will see 30 paired statements. Please circle the letter next to the statement that best defines what is most meaningful to you in your relationship. Both statements may (or may not) sound like they fit your situation, but please choose the statement that captures the essence of what is most meaningful to you, the majority of the time. Allow 10 to 15 minutes to complete the profile. Take it when you are relaxed, and try not to rush through it.

It's more meaningful to me when . . .

- | | | |
|---|---|---|
| 1 | someone I love sends me a loving note/text/email for no special reason. | A |
| | I hug someone I love. | E |
| 2 | I can spend alone time with someone I love—just us. | B |
| | someone I love does something practical to help me out. | D |
| 3 | someone I love gives me a little gift as a token of our love and concern for each other. | C |
| | I get to spend uninterrupted leisure time with those I love. | B |
| 4 | someone I love does something unexpected for me to help me with a project. | D |
| | I can share an innocent touch with someone I love. | E |
| 5 | someone I love puts their arm around me in public. | E |
| | someone I love surprises me with a gift. | C |
| 6 | I'm around someone I love, even if we're not really doing anything. | B |
| | I can be comfortable holding hands, high-fiving, or putting my arm around someone I love. | E |

KEEPING LOVE ALIVE AS MEMORIES FADE

7	I receive a gift from someone I love.	C
	I hear from someone I love that they love me.	A
8	I sit close to someone I love.	E
	I am complimented by someone I love for no apparent reason.	A
9	I get the chance to just "hang out" with someone I love.	B
	I unexpectedly get small gifts from someone I love.	C
10	I hear someone I love tell me, "I'm proud of you."	A
	someone I love helps me with a task.	D
11	I get to do things with someone I love.	B
	I hear supportive words from someone I love.	A
12	someone I love does things for me instead of just talking about doing nice things.	D
	I feel connected to someone I love through a hug.	E
13	I hear praise from someone I love.	A
	someone I love gives me something that shows they were really thinking about me.	C
14	I'm able to just be around someone I love.	B
	I get a back rub from someone I love.	E
15	someone I love reacts positively to something I've accomplished.	A
	someone I love does something for me that I know they don't particularly enjoy.	D
16	I'm able to be in close physical proximity to someone I love.	E
	I sense someone I love showing interest in the things I care about.	B

LOVE: IT'S ALL IN YOUR HEAD

17 someone I love works on special projects with me that I have to complete. D
someone I love gives me an exciting gift. C

18 I'm complimented by someone I love on my appearance. A
someone I love takes the time to listen to me and really understand my feelings. B

19 I can share a meaningful touch in public with someone I love. E
someone I love offers to run errands for me. D

20 someone I love does something special for me to help me out. D
I get a gift that someone I love put thought into choosing. C

21 someone I love doesn't check their phone while we're talking with each other. B
someone I love goes out of their way to do something that relieves pressure on me. D

22 I can look forward to a holiday because I'll probably get a gift from someone I love. C
I hear the words, "I appreciate you" from someone I love. A

23 someone I love and haven't seen in a while thinks enough of me to give me a little gift. C
someone I love takes care of something I'm responsible to do that I feel too stressed to do at the time. D

24 someone I love doesn't interrupt me while I'm talking. B
gift giving is an important part of the relationship with someone I love. C

25 someone I love helps me out when they know I'm already tired. D
I get to go somewhere while spending time with someone I love. B

KEEPING LOVE ALIVE AS MEMORIES FADE

26	someone I love touches my arm or shoulder to show their care or concern.	E
	someone I love gives me a little gift that they picked up in the course of their normal day.	C
27	someone I love says something encouraging to me.	A
	I get to spend time in a shared activity or hobby with someone I love.	B
28	someone I love surprises me with a small token of their appreciation.	C
	I'm touching someone I love frequently to express our friendship.	E
29	someone I love helps me out—especially if I know they're already busy.	D
	I hear someone I love tell me that they appreciate me.	A
30	I get a hug from someone whom I haven't seen in a while.	E
	I hear someone I love tell me how much I mean to him/her.	A

Now go back and count the number of times you circled each individual letter and write that number in the appropriate blank below.

RESULTS

A: _____ WORDS OF AFFIRMATION

B: _____ QUALITY TIME

C: _____ RECEIVING GIFTS

D: _____ ACTS OF SERVICE

E: _____ PHYSICAL TOUCH

Which love language received the highest score? This is your primary love language. If point totals for two love languages are equal, you are "bilingual" and have two primary love languages. And, if you have a secondary love language, or one that is close in score to your primary love language, this means that both expressions of love are important to you. The highest possible score for any single love language is 12.

DETERMINING THE LOVE LANGUAGE OF A PERSON WITH LATE MIDDLE-STAGE OR LATE-STAGE ALZHEIMER'S DISEASE

While there is value in knowing a person's primary pre-dementia love language, keep in mind that during late middle-stage and late-stage Alzheimer's disease, a person's love language may change. Therefore, after the midpoint of the disease, we recommend expressing love to persons with dementia using all five love languages. (We will share more about this in chapter 4, "Every Day Is the Best Day.")

If you do not know the natural pre-dementia love language of a person in late middle- or late-stage AD, but would like to make an "educated guess" about it, you may be able to deduce it through a two-step process:

Step One. Take the love languages quiz a second time on behalf of the person for whom you provide care, answering the questions the way you think he or she would have answered them before dementia.

Step Two. Answer the three questions below, which have been adapted from *The 5 Love Languages*[®] book:

1. Before dementia, how did your loved one most often express love to you and others?

People naturally tend to express love to others in the way that is most meaningful to them. If they regularly did acts of service for others, this may have been their own love language. If they consistently affirmed people verbally, then *Words of Affirmation* was likely their love language.

2. Before dementia, what did your loved one complain about most often?

If you or a family member went on a trip and came back empty-handed, did your loved one protest, “You didn’t bring me anything”? If so, *Gifts* may have been their main love language. If he or she complained, “We don’t ever spend time together,” their love language was probably *Quality Time*. Says Gary, “Your complaints reveal your inner desires.”

3. Before dementia, what requests did your loved one make most often?

If they asked, “Will you give me a back rub?” they were asking for physical touch. If they asked, “Would it be possible for you to clean out your closet this afternoon?” they were expressing their desire for an act of service.

Based on the results of the love languages quiz taken on behalf of the person with dementia, and the answers to the three questions above, I think the pre-dementia primary love language of the person for whom I provide care was _____. (Depending upon the progression of the disease, this love language may still be very important to the person.)

LOVE LANGUAGE
Words of Affirmation

Loving Considerations

EARLY AD: Focus on the feelings of the PWD rather than on facts.

Saying “we” instead of “he” or “she” enhances the relationship (“We had a setback” or “We had a wonderful day”).

Speak calmly, clearly, and gently.

MIDDLE TO LATE AD: Address fear and shadowing behavior with verbal reassurances: “I love you. You are safe, and everything is okay.”

Letters and cards are no longer meaningful when the PWD loses the ability to read.

Even when a PWD has difficulty understanding language, they still respond to the warmth in someone’s voice.

Loving Don’ts

Don’t drill the PWD for recall. (It won’t help!)

When others are present, don’t speak about the PWD in the third person (he, she). Acknowledge their presence and include them in the conversation, even if they cannot verbally contribute.

When the PWD is present, don’t recount to others what the person can no longer do; avoid the word *can’t* (“he can’t do that anymore”).

Don’t speak to the PWD in a patronizing way as if he or she were a child (“You ate your whole meal today!”).

Don’t argue about their perceptions of reality. Instead of contradicting or correcting, validate their feelings and steer the conversation in another direction.

Don’t raise your voice or speak sharply. This can create distress.

LOVE LANGUAGE

Physical Touch

Loving Considerations

EARLY AD: Physical closeness tells the PWD at an emotional level, “you are not alone.”

Be respectful of cultural preferences about physical touch, eye contact, and personal space.

MIDDLE TO LATE AD: Receiving many hugs at a family gathering may be too stimulating, causing the PWD to withdraw or become agitated (why one-on-one visits may work better than group visits). Combining touch with other stimulation, such as music, may also create sensory overload.

At the end of life, tender touch, such as stroking the loved one’s cheek, conveys love.

Loving Don’ts

To preserve the dignity and modesty of the PWD, if possible don’t involve family members in toileting or diapering and bathing. Instead, have same-sex paid or volunteer caregivers do this very personal caregiving.

Don’t forget to assess for pain. If a PWD is experiencing pain that they cannot describe, such as back pain or a headache, their response to another’s touch may change.

LOVE LANGUAGE

Quality Moments (Quality Time)

Loving Considerations

EARLY AD: Skills learned long ago, such as dancing and piano playing, are stored deep in the brain and retained for a long time. Such skills provide opportunities for sharing quality moments. Tap into the talents of the PWD for as long as possible!

MIDDLE TO LATE AD: Join the person in whatever they are doing, even if that means picking up sticks in the yard or coloring.

Music from the person's teen or young adult years may provide special comfort and enjoyment.

Agitation or restlessness in the evening (sundowning) may prevent you from enjoying one another's company, for example, watching TV together. Staying with the PWD during sundowning lets them know they are not alone in their suffering.

Loving Don'ts

Don't avoid answering hard questions from the PWD. Though the truth is sad, it can lead to a deeper emotional connection. Be patient if you must answer the same questions over and over. To the PWD, the question is new each time.

LOVE LANGUAGE

Receiving Gifts

Loving Considerations

EARLY AD: Appropriate gifts for people in early stage AD can be found online under the By Stage tab at <http://store.best-alzheimers-products.com>

Relationship-enhancing gifts provide shared experiences: music CDs, DVD movies, coloring books and markers, 50–500 piece puzzles.

MIDDLE TO LATE AD: Appropriate gifts for people in middle or late-stage AD can be found under the By Stage tab at <http://store.best-alzheimers-products.com>

Material gifts are no longer important. Favorite foods or treats may be more appreciated.

An iPod loaded with music is one of the most impactful of all gifts.

Loving *Don'ts*

Don't expect the same appreciation for gifts as the person may have previously shown. By late AD, many people have difficulty recognizing objects that might have delighted them as gifts in years past.

Don't give:

- * Lotions that might look like a beverage.
- * Full-length movies, difficult crossword puzzles, or novels.

EVERY DAY IS THE BEST DAY

ACTS OF KINDNESS (ACTS OF SERVICE)

Normally we think of an “act of service” as something utilitarian done to lighten the load of another, with the effort appreciated by the served person so much that they feel loved. Though care partners do countless acts of service for people with AD—administering medications, helping them dress, etc.—the PWD is not likely to appreciate the effort or perceive it as love. Dr. Williams said that for people with dementia, *Acts of Service* can be redefined “in a new way, to include preserving individuality and identity.” In chapter 2, Sally’s acts of service for her husband included arranging for him to accomplish tasks like “mowing” the yard and walking their dog, which make him feel useful. Dr. Williams described Sally’s effort on behalf of her husband as “an act of kindness.”

LOVE LANGUAGE <i>Acts of Kindness (Acts of Service)</i>	
Loving Considerations	Loving <i>Don'ts</i>
<p>EARLY AD: Be aware that <i>Acts of Service</i> may remind a PWD of their own inability to express love through an act of service, such as cooking a meal.</p> <p>MIDDLE TO LATE AD: Realize that doing acts of service for a PWD will not convey the same meaning it once did. Think in terms of doing <i>acts of kindness</i> rather than acts of service.</p>	<p>Don't discourage a PWD who wants to help. Find small tasks they can do, such as folding towels, or “washing” dishes so they feel they are making a contribution.</p> <p>Whenever possible, do <i>with</i> rather than <i>for</i>.</p>

Appendix A

40 Ways to Say “I Love You” in Middle- and Late-Stage Dementia

Research by Logsdon and Teri¹ suggests that there are 20 “pleasant activities” that people with dementia enjoy. We have combined these activities with a list from *Creating Moments of Joy*² by Jolene Brackey, and added some of our own ideas. Below, we have grouped all of these suggestions within the framework of the five love languages. As you have opportunity, let the list guide you in creatively expressing love. Remember that the further along a person is in their disease, the simpler your expressions of love must be.

ACTS OF KINDNESS (ACTS OF SERVICE)

- Look them in the eye when they speak to you no matter what they say or how they say it.
- Include them in conversations (rather than talk about them as if they are not present).
- Let them help in the kitchen, around the house, wherever and whenever they want to contribute.
- Help them groom (makeup, shave, comb hair, pick out clothing).
- Advocate for them.

KEEPING LOVE ALIVE AS MEMORIES FADE

- Smile at them as you come and go.
- People with AD have trouble making decisions, yet feel devalued if not allowed to participate in decisions that affect them. So, let them choose between two options you have pre-approved (red shirt/blue shirt).
- When they complain or are delusional, empathize (“I am so sorry that happened”), then gently distract them with something pleasant.
- Let them be right.

WORDS OF AFFIRMATION

- Tell them, “I love you.”
- Answer each repeated question as if it were being asked for the first time.
- Talk to them (even if they can’t talk back)—about their life growing up, marriage, children, grandchildren, work, and hobbies.
- Tell them they look handsome/beautiful (even if it’s the same outfit they wore yesterday and it’s dirty).
- Help them write a card or letter and sign it.
- Sing them to sleep.
- Tell them that you have taken care of everything.
- Tell them you are proud of all the things they accomplished in life.
- Brag about them to others while they are present.

RECEIVING GIFTS

- Give them a piece of chocolate, ice cream cone, chocolate chip cookie, or whatever they love.

40 WAYS TO SAY "I LOVE YOU" IN MIDDLE- AND LATE-STAGE DEMENTIA

- Give them a surprise package to open.
- Send a card to them in the mail.
- Give them an iPod loaded with music from their teen and young adult years.
- Bring them a coloring book with some markers or crayons.
- Be generous with the gift of your time.

QUALITY MOMENTS (QUALITY TIME)

- Read to them or, if they can, have them read to you or a grandchild.
- Reminisce about old times and important events of history as you look at a photo album or family movies.
- Watch a favorite movie over and over.
- Go for a ride in the car.
- Bake some cookies.
- Laugh and giggle—they may join in.
- Color in a coloring book or do a puzzle with them.
- Tell stories.

PHYSICAL TOUCH

- Hold hands and take a walk.
- Give a hug (and kiss, if appropriate).
- Sit close by or hold them if they're afraid, angry, or agitated.
- Rub their feet or their back or gently stroke their cheek.
- Let them hold a baby, puppy, or doll.
- File and/or put polish on their fingernails and toenails.
- Dance or move to music with them.
- Massage their hands and arms with lotion.

Appendix C

Suggested Resources

THE 5 LOVE LANGUAGES®

Books, eBooks, audiobooks, DVDs, and mobile apps
available at www.5lovelanguages.com

The 5 Love Languages:® The Secret to Love That Lasts, Gary Chapman, Northfield Publishing, Chicago, 2015.

The 5 Love Languages,® Singles Edition, Gary D. Chapman, Northfield Publishing, Chicago, 2014.

Online Love Languages Quiz: <http://www.5lovelanguages.com/profile/>

ALZHEIMER'S DISEASE

Reference Books

The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss. Nancy L. Mace, MA and Peter V. Rabins, MD, MPH, Grand Central Life & Style; 5th edition, September 25, 2012.

Mayo Clinic Guide to Alzheimer's Disease: The Essential Resource for Treatment, Coping and Caregiving. Petersen, R., ed., Rochester, MN: Mayo Clinic Health Solutions, 2009.

The Alzheimer's Action Plan. P. Murali Doraiswamy, MD, Lisa P. Gwyther, MSW, and Tina Adler, St. Martin's Press, New York, NY, 1st edition, April 2008.

Books for Care Partners and Persons with Dementia

Living with Alzheimer's & Other Dementias: 101 Stories of Caregiving, Coping, and Compassion. Amy Newmark and Angela Timashenka Geiger, 1st Edition, Chicken Soup for the Soul Publishing, Ltd., Cos Cob, CT, 2014.

Coping with Behavior Change in Dementia: A Family Caregiver's Guide. Beth Spencer and Laurie White, 1st Edition, April 3, 2015.

Creating Moments of Joy for the Person with Alzheimer's or Dementia: A Journal for Caregivers, Jolene Brackey, 4th Edition, Purdue University Press, West Lafayette, IN, 2007.

Healing Your Grieving Heart When Someone You Care About Has Alzheimer's: 100 Practical Ideas for Families, Friends, and Caregivers, Alan D. Wolfelt PhD and Kirby J. Duvall MD, Companion Press, Ft. Collins, CO, 2014.

Living Your Best with Early-Stage Alzheimer's: An Essential Guide, Lisa Snyder MSW LCSW, Sunrise River Press, North Branch, MN, 2010.

Practical Dementia Care, Peter V. Rabins, Constantine G. Lykestos, and Cynthia D. Steele (ed), 3rd edition, Oxford University Press, April 29, 2016.

Thoughtful Dementia Care: Understanding the Dementia Experience, Jennifer Ghent-Fuller, 1st Edition, Thoughtful Dementia Care, Inc., 2012.

When Caring Takes Courage: A Compassionate, Interactive Guide for Alzheimer's and Dementia Caregivers, Mara Botonis, Outskirts Press, Inc., 2014.

Books for Children

What's Happening to Grandpa? Maria Shriver, Little, Brown Books for Young Readers, 2004.

Always My Grandpa: A Story for Children about Alzheimer's Disease, Linda Scacco, Magination Press, 2005.

Wilfrid Gordon McDonald Partridge, Mem Fox, Kane/Miller Book Publishers, 1989.

SUGGESTED RESOURCES

Resources from the National Institute on Aging

Alzheimer's Disease: Unraveling the Mystery, National Institute on Aging, Publication No. 08-3782. Download PDF at <https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-unraveling-mystery/more-information>.

Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging, Publication Number 09-6173, March 2010. Order hard copy or download PDF from Contact Alzheimer's Disease Education and Referral (ADEAR) Center 1-800-438-4380. www.nia.nih.gov/alzheimers.

Available online or as PDF download from <https://www.nia.nih.gov/alzheimers>

Alzheimer's Disease Fact Sheet

Alzheimer's Disease Genetics Fact Sheet

Alzheimer's Disease Medications Fact Sheet

Forgetfulness: Knowing When to Ask for Help

Legal and Financial Planning for People with Alzheimer's Disease Fact Sheet

Understanding Memory Loss: What to Do When You Have Trouble Remembering

Websites

Alzheimer's Association. <http://www.alz.org>

Alzheimer's Disease Education and Referral Center (ADEAR). <https://www.nia.nih.gov/alzheimers/>

Alzheimer's Foundation of America. <http://www.alzfdn.org>

AARP Home & Family Caregiving. <http://www.aarp.org/home-family/caregiving/>

The Family Caregiver Alliance. <https://www.caregiver.org>

The Hartford Publications Home and Car Safety Guides

<https://www.thehartford.com/resources/mature-market-excellence/publications-on-aging>

Alzheimer's Caregiver Page

<https://www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html>

Guidelines for initiating meaningful, quality home visits with people who have Alzheimer's disease and related dementia. <http://www.wistatedocuments.org/cdm/ref/collection/p267601coll4/id/157>

Alzheimer's Association Resource Listing: <http://www.alz.org/library/lists.asp#useful>

Alzheimer's Disease International: <http://www.alz.co.uk/>

Videos, Movies, and Documentaries

Accepting the Challenge: Providing the Best Care for People with Dementia (produced by Alzheimer's North Carolina, Inc.). <http://www.healthpropress.com/product/accepting-the-challenge/>

Inside the Brain: Unraveling the Mystery of Alzheimer's Disease. <https://www.nia.nih.gov/alzheimers/alzheimers-disease-video>

About Dementia Videos (*Dementia 101*, *Teepa's GEMS*, *Brain Changes*, *Challenging Behaviors*, *Meaningful Activities*, *Music*). Teepa Snow—Positive Approach to Brain Change. <http://teepasnow.com/resources/teepa-tips-videos/>

The Forgetting—A Portrait of Alzheimer's. <http://www.pbs.org/theforgetting/watch/>

Alive Inside (Henry's Story). YouTube.com

The Alzheimer's Project, HBO Documentary. HBO.com/alzheimers/

I'll Be Me (the Glen Campbell Sunset Tour). <http://glencampbellmovie.com>

Still Alice Trailer. <http://sonyclassics.com/stillalice/>

SUGGESTED RESOURCES

Newsletters

Caregiver, newsletter of the Duke Alzheimer's Family Support Program. Written by Lisa Gwyther, LCSW and Bobbi Matchar, MSW, available at: <http://www.dukefamilysupport.org/>

Perspectives, quarterly newsletter for people with dementia and their care partners. Written by Lisa Snyder, LCSW, UCSD Shiley-Marcos Alzheimer's Disease Research Center, available by request from: lsnyder@ucsd.edu

OTHER DEMENTIAS

Frontotemporal Dementia

Books and Booklets

What If It's Not Alzheimer's? A Caregiver's Guide to Dementia, Gary Radin and Lisa Radin, Prometheus Books, 3rd edition, 2014.

Frontotemporal Disorders: Information for Patients, Families, and Caregivers, National Institute of Neurological Disorders and Stroke, Publication No. 14-6361. Download PDF or order hard copy at <https://www.nia.nih.gov/alzheimers/publication/frontotemporal-disorders/basics-frontotemporal-disorders>

Websites

The Association for Frontotemporal Degeneration (AFTD). <http://www.theaftd.org>

FTD Care Partnering. <http://ftdsupport.com>

UCSF Medical Center. <http://memory.ucsf.edu/ftd/>

FTD Resource Page. <https://www.nia.nih.gov/alzheimers/publication/frontotemporal-disorders-resource-list>

Lewy Body Dementia

Books & Booklets

A Caregiver's Guide to Lewy Body Dementia, Helen Buell Whitworth and James Whitworth, Demos Health, 2010.

Lewy Body Dementia: Information for Patients, Families, and Professionals, National Institute of Neurological Disorders and Stroke, Publication No. 15-7907. Download PDF or order hard copy at <https://www.nia.nih.gov/alzheimers/publication/lewy-body-dementia/introduction>

Websites and Other

Lewy Body Dementia Association. www.lewybodydementia.org/

NINDS Dementia With Lewy Bodies Page

<http://www.ninds.nih.gov/disorders/dementiawithlewybodies/dementiawithlewybodies.htm>

Lewy Body Dementia, Mayo Clinic website, <http://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/basics/definition/CON-20025038?p=1>

Lewy Body Digest e-newsletter. Subscribe at <https://www.lbda.org/content/sign-lewy-body-digest-0>

Vascular Dementia

National Stroke Association: <http://www.stroke.org/we-can-help/survivors/stroke-recovery/post-stroke-conditions/cognition/vascular-dementia>

National Institute of Neurological Disorders and Stroke: http://www.ninds.nih.gov/disorders/multi_infarct_dementia/multi_infarct_dementia.htm

Notes

Chapter 1: Ed and Rebecca: A Love Story

1. Alzheimer's Association, "Younger/Early Onset Alzheimer's," <http://www.alz.org>.
2. George Kraus, *Helping the Alzheimer's Patient: Plain Talk and Practical Tools* (DVD), presented through PESI, copyright 2011, MEDS PDN, Eau Claire, WI.
3. Alzheimer's Association, "2016 Alzheimer's Disease Facts and Figures," http://www.alz.org/documents_custom/2016-facts-and-figures.pdf, 10, 17, 18, 19, 30, 32.

Chapter 2: Love: It's All in Your Head

1. Gary Chapman, *The 5 Love Languages®: The Secret to Love that Lasts* (Chicago: Northfield Publishing, 2015), 31–32.
2. *Strong's Exhaustive Concordance of the Bible*, "Hesed." Strong's number 2617.
3. Lois Tverberg, "Hesed: Enduring, Eternal, Undeserved Love," Our Rabbi Jesus (blog), May 2, 2012, <http://ourrabbijesus.com/hesed-enduring-eternal-undeserved-love/>.
4. Chapman, *The 5 Love Languages®*, 35–115.
5. "Dementia and the Brain," Alzheimer's Society, Factsheet 456LP, last reviewed September 2014, https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=114.
6. S.J. Cutler. "Worries about getting Alzheimer's: who's concerned?," *Am J Alzheimers Dis Other Demen* 30, no. 6 (2015): 591–8. doi: 10.1177/1533317514568889. Epub 2015 Feb 4.
7. Maia Szalavitz, "Friends With Benefits: Being Highly Social Cuts Dementia Risk by 70%," *Time*, May 2, 2011, <http://healthland.time.com/2011/05/02/friends-with-benefits-being-highly-social-cuts-dementia-risk-by-70/>.
8. Honor Whiteman, "Alzheimer's Association International Conference 2015: the highlights," *Medical News Today*, July 23, 2015, <http://www.medicalnews-today.com/articles/297228.php>.
9. Tjalling Jan Holwerda et al., "Feelings of loneliness, but not social isolation, predict dementia onset: results from the Amsterdam Study of the Elderly (AMSTEL)," *J Neurol Neurosurg Psychiatry* 85, no. 2 (2014): 135–42.

10. Thai Nguyen, "Hacking Into Your Happy Chemicals: Dopamine, Serotonin, Endorphins and Oxytocin," *Huffington Post*, http://www.huffingtonpost.com/thai-nguyen/hacking-into-your-happy-c_b_6007660.html/. Updated: December 20, 2014.
11. Chapman, *The 5 Love Languages*[®], 156.
12. James Beauregard, "Dementia: Behavioral Health Assessments and Interventions for Practitioners," Cross Country Education Seminar, October 9, 2015, Greensboro, NC. Workbook, 94.
13. Gary W. Small et al., "Diagnosis and treatment of Alzheimer disease and related disorders: consensus statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society," *JAMA* 278, no. 16 (1997): 4–6.

Chapter 3: Alzheimer's Disease Puts Love to the Test

1. George Kraus, *Helping the Alzheimer's Patient: Plain Talk and Practical Tools* (DVD), presented through PESI, copyright 2011, MEDS PDN, Eau Claire, WI.
2. Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day: A Family Guide for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss* (Baltimore: The Johns Hopkins University Press, 2011), 37.
3. Kraus, *Helping the Alzheimer's Patient: Plain Talk and Practical Tools*.
4. Carole B. Larken, "Me and My Alzheimer's Shadow," <http://www.alzheimersreadingroom.com>.
5. Peter V. Rabins, foreword to *The Longest Loss: Alzheimer's Disease and Dementia*, eds. Kenneth J. Doka and Amy S. Tucci (Washington, D.C.: Hospice Foundation of America, 2015), iii–iv.
6. Alzheimer's Association, "2016 Alzheimer's Disease Facts and Figures," http://www.alz.org/documents_custom/2016-facts-and-figures.pdf, 32.
7. Alzheimer's Association, "2016 Alzheimer's Disease Facts and Figures," 36.
8. U.S. Department on Health and Human Services, Office of Women's Health, "Caregiver Stress: Frequently Asked Questions," www.womenshealth.gov.
9. Alzheimer's Association, "2016 Alzheimer's Disease Facts and Figures," 36.
10. C. Cooper, A. Selwood, M. Blanchard, Z. Walker, R. Blizard, and G. Livingston. (2009). "Abuse of people with dementia by family carers: representative cross sectional survey," *British Medical Journal*, 338, b155.
11. A. Wigglesworth, L. Mosqueda, R. Mulnard, S. Liao, L. Gibbs, and W. Fitzgerald, "Screening for abuse and neglect of people with dementia," *Journal of the American Geriatrics Society* 58, no. 3 (2010): 493–500.
12. Johns Hopkins Medicine, "Spouses Who Care For Partners With Dementia at Sixfold Higher Risk of Same Fate: Stress of caregiving may be to blame," press release May 5, 2010, <http://www.hopkinsmedicine.org>.
13. Richard Schulz and Scott R. Beach, "Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study," *JAMA* 282, no. 23 (1999): 2215–2219.
14. Alzheimer's Association, "2015 Alzheimer's Disease Facts and Figures," 39.

NOTES

15. National Institute on Aging, National Institutes of Health, *Alzheimer's Disease: Unraveling the Mystery*. Publication No. 08-3782. <https://www.nia.nih.gov/alzheimers/publication>.
16. Alan D Wolfelt, "Dispelling Five Common Myths About Grief" (seminar handout), Exploring Complicated Mourning: Sudden Death and Trauma Loss, seminar presented at Hospice of Davidson County, Lexington, NC, October 21, 2015.
17. Pauline Boss, *Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief* (San Francisco: Jossey-Bass, 2011), 165.
18. Chapman, *The 5 Love Languages®: The Secret to Love that Lasts* (Chicago: Northfield Publishing, 2010), 44.
19. Ibid., 53.
20. Ibid., 78.
21. Ibid., 170.
22. Alzheimer's Association, "2016 Alzheimer's Disease Facts and Figures," 19.
23. Alzheimer's Association, "Cultural Competence," http://www.alz.org/Resources/Diversity/downloads/GEN_EDU-10steps.pdf.
24. Mace and Rabins, *The 36-Hour Day*, 407.
25. Debbie Barr, *A Season at Home: The Joy of Fully Sharing Your Child's Critical Years* (Grand Rapids: Zondervan, 1993), 168.
26. Lauren G. Collins and Kristine Swartz, "Caregiver Care," *American Family Physician* 83, no. 11 (2011): 1310. www.aafp.org/afp.
27. Johns Hopkins Medicine, "Spouses Who Care For Partners With Dementia at Sixfold Higher Risk of Same Fate: Stress of caregiving may be to blame," press release May 5, 2010, <http://www.hopkinsmedicine.org>.
28. Akemi Hirano et al., "Influence of regular exercise on subjective sense of burden and physical symptoms in community-dwelling caregivers of dementia patients: A randomized controlled trial," *Arch Gerontol Geriatr* 53, no. 2 (Sep–Oct 2011): e158–63. doi: 10.1016/j.archger.2010.08.004. Epub 2010 Sep 17.
29. Massachusetts General Hospital, "How to Lower Risk for Beta-Amyloid Accumulation," *Mind, Mood & Memory* 11, no. 9 (2015): 4.

Chapter 4: Every Day Is the Best Day

1. Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day: A Family Guide for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss* (Baltimore: The Johns Hopkins University Press, 2011), 384.
2. Alan D Wolfelt, "Exploring Complicated Mourning: Sudden Death and Trauma Loss," seminar presented at Hospice of Davidson County, Lexington, NC, October 21, 2015.
3. Alzheimer's Society, "Dementia and the Brain," Factsheet 456LP, last reviewed September 2014, https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=114.
4. Juebin Huang, "Brain Dysfunction by Location," Neurologic Disorders, Merck Manuals Professional Edition, <http://www.merckmanuals.com/home/brain,-spinal-cord,-and-nerve-disorders/brain-dysfunction/brain-dysfunction-by-location>.

5. J. Riley McCarten, "Clinical evaluation of early cognitive symptoms," *Clin Geriatr Med* 29, no. 4 (2013): 791–807. doi: 10.1016/j.cger.2013.07.005.
6. Eric H. Chudler, "Lobes of the Brain," Neuroscience for Kids, <https://faculty.washington.edu/chudler/lobe.html>.
7. Cedars-Sinai Medical Center, "Neurons in Brain's 'Face Recognition Center' Respond Differently in Patients with Autism," press release Nov. 20, 2013, <http://cedars-sinai.edu/About-Us/News/News-Releases-2013/Neurons-in-Brains-Face-Recognition-Center-Respond-Differently-in-Patients-With-Autism.aspx>.
8. Mace and Rabins, *The 36-Hour Day*, 385.
9. Karen Leigh, "Communicating with Unconscious Patients," *Nursing Times* 97, no. 48 (2001): 35.
10. Geoffrey Lean, "Locked in a coma, I could hear people talking around me," *The Telegraph*, November 24, 2009, <http://www.telegraph.co.uk/news/health/6638155/Locked-in-a-coma-I-could-hear-people-talking-around-me.html>.
11. Joanne Koenig Coste, *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease* (New York: Mariner Books, 2004), 7.
12. John Riehl, "Alzheimer's patients can still feel the emotion long after the memories have vanished," IowaNow, September 24, 2014, <http://now.uiowa.edu/2014/09/alzheimers-patients-can-still-feel-emotion-long-after-memories-have-vanished>.
13. Edmurie Guzma et al., "Feelings Without Memory in Alzheimer Disease," *Cogn Behav Neurol* 27 (2014): 117–129.
14. Paul R. McHugh, foreword to *The 36-Hour Day*, xviii.
15. Gary Chapman, *The 5 Love Languages®: The Secret to Love that Lasts* (Chicago: Northfield Publishing, 2015), 31, 44.
16. Sophie Behrman et al., "Considering the senses in the diagnosis and management of dementia," *Maturitas* 77, no. 4 (2014): 305–310.
17. Jolene Brackey, *Creating Moments of Joy for Persons with Alzheimer's or Dementia*, 4th Edition (West Lafayette, IN: Purdue University Press, 2007), 13.
18. Chapman, *The 5 Love Languages®*, 79.
19. Gary Chapman and Ross Campbell, *The 5 Love Languages® of Children* (Chicago: Northfield Publishing, 2012), 8.

Chapter 5: Facilitating Love

1. Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day: A Family Guide for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss* (Baltimore: The Johns Hopkins University Press, 2011), 17–18.
2. Merriam-Webster Dictionary, "language," <http://www.merriam-webster.com/dictionary/language>.
3. Alzheimer's Foundation of America, "Music," <http://www.alzfdn.org/educationandcare/musictherapy.html>.

NOTES

- Jonathan Graff-Radford, "How can music help people who have Alzheimer's disease?", www.mayoclinic.org/diseases-conditions/alzheimers-disease/expert-answers/music-and-alzheimers/faq-20058173.
- L.E. Maguire et al., "Participation in Active Singing Leads to Cognitive Improvements in Individuals with Dementia," *J Am Geriatr Soc.* 63 (2015): 815–816. doi: 10.1111/jgs.13366.
- Alissa Sauer, "5 Reasons Why Music Boosts Brain Activity," *Alzheimers.net* (blog), July 21, 2014, <http://www.alzheimers.net/2014-07-21/why-music-boosts-brain-activity-in-dementia-patients/>.
- Nicholas R. Simmons-Stern et al., "Music as a memory enhancer in patients with Alzheimer's disease," *Neuropsychologia* 48, no. 10 (2010): 3164–3167. Published online May 7, 2010. doi: 10.1016/j.neuropsychologia.2010.04.033.
- Conan Milner, "Opera Singer Turned Neuroscientist Uses Music as Medicine for Dementia, Autism, and More," *Epoch Times*, November 26, 2015 (last updated May 25, 2016), <http://www.theepochtimes.com/n3/1905111-opera-singer-turned-neuroscientist-uses-music-as-medicine-for-dementia-autism-and-more/>.
- John Schmid, "Music Therapy for Alzheimer's," *Best Alzheimer's Products*, November 4, 2014, <http://www.best-alzheimers-products.com/music-therapy-alzheimers.html>.
- Loretta Quinn, "A Music Therapist Looks at Dementia," *Best Alzheimer's Products*, November 6, 2014, www.best-alzheimers-products.com/music-therapist-looks-dementia.html.
- Earl Henslin, *This is Your Brain on Joy: How the New Science of Happiness Can Help You Feel Good and Be Happy* (Nashville: Thomas Nelson, 2008), 47–48.
- Mary Ellen Geist, "The Healing Power of Music," *AARP Bulletin*, July/August 2015.
- Mary Mittelman, "NYU Caregiver/Family Counseling Intervention," address at Wake Forest School of Medicine Dementia Counseling and Care Conference, Winston-Salem, NC, May 8–10, 2014.
- Sylvia Sörensen et al., "How effective are interventions with caregivers? An updated meta-analysis," *Gerontologist* 42, no. 3 (2002): 356–372.

Chapter 6: Stories of *Hesed*

- Gary Chapman, *The 5 Love Languages®: The Secret to Love that Lasts* (Chicago: Northfield Publishing, 2010), 40.
- Gary Chapman, *The 5 Love Languages®*, 44.
- Mayo Clinic, "Lewy body dementia," <http://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/basics/definition/con-20025038>.
- Lewy Body Dementia Association, "Capgras Syndrome in DLB Associated with Anxiety and Hallucinations," <https://www.lbda.org/content/capgras-syndrome-dlb-associated-anxiety-and-hallucinations-0>.
- Alzheimer's Association, "Frontotemporal Dementia," <http://www.alz.org/dementia/fronto-temporal-dementia-ftd-symptoms.asp>.

6. The Association for Frontotemporal Degeneration, “FAQ,” <http://www.theaftd.org/life-with-ftd/newly-diagnosed/faq>.
7. University of California, San Francisco, “Frontotemporal Dementia Overview,” <http://memory.ucsf.edu/ftd/overview>.
8. Gary Chapman, *The 5 Love Languages*®, 151–158.

Chapter 7: Voices of Experience

1. Jennifer Ghent-Fuller, *Thoughtful Dementia Care: Understanding the Dementia Experience*, 1st Edition (Thoughtful Dementia Care, Inc., 2012), Kindle location page 166.

Chapter 8: The Journey No One Wants to Take

1. Alzheimer’s Association, “2016 Alzheimer’s Disease Facts and Figures,” http://www.alz.org/documents_custom/2016-facts-and-figures.pdf, 17, 23, 56.

Appendix A: 40 Ways to Say “I Love You” in Middle- and Late-Stage Dementia

1. Rebecca G. Logsdon and Linda Teri, “The Pleasant Events Schedule-AD: Psychometric Properties and Relationship to Depression and Cognition in Alzheimer’s Disease Patients,” *The Gerontologist* 37, no. 1 (1997): 40–45.
2. Adapted from *Creating Moments of Joy for Persons with Alzheimer’s or Dementia*, 4th edition by Jolene Brackey. Used by permission of Purdue University Press.

Appendix B: For Those Who Want to Know More

1. Steven A. Goldman, “Brain,” Merck Manual, Consumer Version, <https://www.merckmanuals.com/home/brain,-spinal-cord,-and-nerve-disorders/biology-of-the-nervous-system/brain>.
2. Brain Injury Alliance of Utah, “Cognitive Skills of the Brain,” <http://biau.org/about-brain-injuries/cognitive-skills-of-the-brain/>.
3. J. Riley McCarten, “Clinical evaluation of early cognitive symptoms,” *Clin Geriatr Med.* 29, no. 4 (2013):791-807. doi: 10.1016/j.cger.2013.07.005.
4. Alzheimer’s Association, “Posterior Cortical Atrophy,” <http://www.alz.org/dementia/posterior-cortical-atrophy.asp>.
5. Bonnie Badenoch, *Being a Brain-Wise Therapist: A Practical Guide to Interpersonal Neurobiology*, 1st edition (New York: W. W. Norton & Company, 2008).
6. Attachment & Emotion Regulation: Brain-Based Therapy and Practical Neuroscience, Audio CD, PESI, Inc. CMI Education. Copyright 2012.
7. Alzheimer’s Association, “2016 Alzheimer’s Disease Facts and Figures,” http://www.alz.org/documents_custom/2016-facts-and-figures.pdf, 7.