

Resources for Spiritual Care and Dementia

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Take a daily walk. Exercise is a great stress reducer. Taking the time to stroll through the neighborhood or local park is like a deep calming breath for the body and emotions. If you are a jogger, go jogging. The point is to get away for a moment, get the body moving, and enjoy a change of scenery as you go.

Keep a journal. Daily journaling is a way to outwardly express your thoughts and emotions and can act as a relief valve for emotions that are building up inside. It can also give you a better perspective. Sometimes we need to see what we are thinking and feeling to sort it out.

Pursue personal interests. If you have a hobby or activity -- like writing poetry, photography, crafts, painting, knitting, reading, gardening, or listening to music, that has always been fun and brought you a sense of joy and contentment -- make time each day for your personal pleasurable pursuits.

Maintain friendships. We need our connection to others for the enjoyment of company and for comfort and support. Make regular weekly dates with friends and meet for coffee. Join a book club or start a book club.

Learn ways to relax. Try breathing exercises and muscle relaxation exercises. Schedule a massage. Take a weekly yoga or tai chi class. Cannot get away? Pop in a yoga or tai chi video and follow along.

Make your health a priority. Eat well-balanced meals, get plenty of rest, drink plenty of fluids. Find inspirational quotes that lift your spirits and display them where you can read them each day. Remember to laugh each day. Hug and be hugged.

To offer the very best care to others, you must take care of yourself too. It's not selfish, it's wise.

~ From The Cancer Blog

When you are exhausted, take a moment to bring **full awareness to your body's experience**. Notice your breathing, notice what is, honor what you are experiencing with no need to change it. Just be present to yourself in the moment.

When resistance gets in the way of what you are doing – try **naming** what you are doing – even naming it aloud. Be in the moment doing what you are doing.

When you find yourself wanting something from someone or wanting them to be different than they are – **drop the wanting** and want nothing.

When your mind is busy as you are listening ~ considering whether you agree or disagree, wondering what will happen next or thinking about what has just happened ~ **focus on listening**, let thoughts drift pass like clouds, and return to listening. You will feel more present, alert and caring.

When you have to wait for whatever reason, do not look for something to fill the time rather **allow space for empty time**, just take note of what is happening around and within you. Notice breathing, thoughts and receive a moment of peace as you do nothing but remain aware of what is.

Use a red traffic light as a time to rest the mind. Give gentle attention to your breathing. Let thoughts come and go. Be aware of the motor running, the feel of the steering wheel. Be present in the moment. **Focus on what is, not what is next.**

~ Nina Livingston, Hospice Chaplain, Rochester, New York

Organizations:

Alzheimer's Disease Education and Referral (ADEAR) Center
P.O. Box 8250
Silver Spring, MD 20907-8250
Phone: 1-800-438-4380
Website: www.nia.nih.gov/alzheimers

Alzheimer's Association
Phone: 1-800-272-3900
Website: www.alz.org

Alzheimer's Foundation of America
Phone: 1-866-232-8484
Website: www.alzfdn.org

Eldercare Locator
Phone: 1-800-677-1116
Website: www.eldercare.gov

University of California-San Francisco's Memory and Aging Center
memory.ucsf.edu/education/diseases

Inspired Caregiving

“Love begins by taking care of the closest ones – the ones at home.” – Mother Teresa

“If you find it in your heart to care for someone else, you will have succeeded.” – Maya Angelou

“The love we give away is the only love we keep.” – Elbert Hubbard

“The capacity to care is the thing which gives life its deepest meaning and significance.”
- Pablo Casals

“Laughter is the shortest distance between two people.” - Victor Borge

“Always remember that you are braver than you believe, stronger than you seem and smarter than you think.” Winnie the Pooh

“To care for those who once cared for us is one of the highest honors.” – Tia Walker

“There is no perfect way to take care of an elderly parent except with the most love and patience you are able to muster on that particular day.” AgingCare.com

“I am only one but I am one, I cannot do everything but I can do something. And I will not let what I cannot do interfere with what I can do.” – Edward Everett Hale

“True love is not a feeling by which we are overwhelmed. It is a committed, thoughtful decision.” – M. Scott Peck

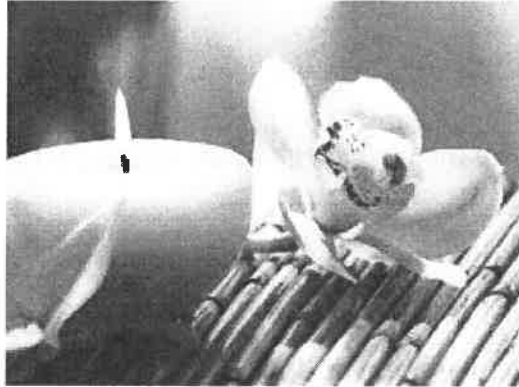
“Never get tired of doing little things for others. For sometimes those little things occupy the biggest part of their hearts.” – Ida Azhuri

“God gave burdens, he also gave shoulders.” – *Yiddish Proverbs*

“Physical strength is measured by what we can carry; spiritual by what we can bear.” –
Unknown

“Things turn out best for those who make the best of the way things turn out.” – *Jack Buck*

“Caregiving often calls us to lean into love we didn't know possible.” –Tia Walker



Take care of yourself so that you can care for others with inspiration

As often as possible:

- Get a good night's rest
- Eat a healthy diet
- Get regular exercise
- Schedule on-going support

Create images in your mind that make you feel delighted

Experience natural beauty that inspires

Listen to music that you enjoy

Plant a plant

Look at the stars

Remember this is not about me and I am not a victim

Make the best memories you can with the one for whom you are caring

Keep a journal

Write a blog

Amidst all the task of caring giving, do something personal and enjoyable for the one you are caring for – rub feet, brush hair, put on make-up, paint finger nails.

Remember that a good laugh and a long sleep are two of the best cures for anything.

Communicating with Persons who have limited capacity to verbally communicate

The medical community advises that even when a person is unable to communicate verbally, they may retain the capacity to hear and understand. Based on that presumption and our desire to offer as much comfort and care as possible to those we serve, we do not hesitate to speak to people who cannot communicate verbally and tell them about the day, about things that are going on in the world, about what is going on in the place they live, about who you are and why you have come to see them. We seek to learn about their lives and interest by calling family members and caregivers so that we can talk about interests that they may have and offer them support. Or if we do not have access to significant others to contact we take our cues from the surroundings and make mention of photographs or cards, books or trinkets. We take the opportunity to use gentle touch and to advise them that we have come to be with them for a little while. We offer the reading of scripture or inspirational literature that to them is meaningful, the singing of songs that we think might be encouraging or meaningful and the praying of prayers on their behalf. We can also use the time to hold the family of the person and those who care for the person in prayer. We avoid saying things in front of the person that we do not intend for them to hear. We are mindful that our interaction with the person may model for the family ways that they might interact with their loved one.

When the person is minimally communicative we practice patience. Often it takes longer for a person to process information. It might not be that they do not intend to answer us – it might be that we do not allow them enough time to articulate a response.

Tips for your interaction include:

- Speak in clear, simple language. Face the person to allow them to see your mouth and facial expression - it will help them understand what you are saying.
- Speak slowly and clearly rather than loudly.
- Encourage the aphasic individual to speak by engaging in conversation on a level they can handle. Look at pictures and photographs and discuss them. Help with word finding if they get stuck, but first allow them to try for themselves.
- Listen carefully and patiently, even if the person's speech is hard to understand. Compliment them on their progress, no matter how small.
- Avoid condescension. Treat the aphasic person like the mature adult they are.
- One on one conversation is easiest for an aphasic person - two or more people speaking at the same time can be confusing and make comprehension impossible.
- Be sensitive to the struggle and if the attempts at conversation seem more troubling than helpful simply be present to the person.

Do not underestimate the power of your presence and loving concern for others. You represent sacredness and holiness to others and help them feel it within themselves.

Communication Do's and Don'ts?

Do

Avoid becoming frustrated by empathizing and remembering the person can't help their condition. Making the person feel safe rather than stressed will make communication easier. Take a short break if you feel your fuse getting short.

Keep communication short, simple, and clear. Give one direction or ask one question at a time.

Tell the person who you are if there appears to be any doubt.

Call the person by name.

Speak slowly. The person may take longer to process what's being said.

Use closed-ended questions which can be answered "yes" or "no." For example, ask, "Did you enjoy the beef at dinner?" instead of "What did you have for dinner?"

Find a different way to say the same thing if it wasn't understood. Try a simpler statement with fewer words.

Use distraction or fibs if telling the whole truth will upset the person with dementia. For example, to answer the question, "Where is my mother?" it may be better to say, "She's not here right now" instead of "She died 20 years ago."

Use repetition as much as necessary. Be prepared to say the same things over and over as the person can't recall them for more than a few minutes at a time.

Use techniques to attract and maintain the person's attention. Smile, make eye contact, use gestures, touch, and other body language.

Don't

Ever say things like: "Do you remember?" "Try to remember!" "Did you forget?" "How could you not know that?!"

Ask questions that challenge short-term memory such as "Do you remember what we did last night?" The answer will likely be "no," which may be humiliating for the person with dementia.

Talk in paragraphs. Instead, offer one idea at a time.

Point out the person's memory difficulty. Avoid remarks such as "I just told you that." Instead, just repeat it over and over.

Talk in front of the person as if he or she were not present. Always include the person in any conversation when they are physically present.

Use lots of pronouns such as "there, that, those, him, her, it." Use nouns instead. For example, instead of "sit there" say "sit in the blue chair."

Use slang or unfamiliar words. The person may not understand the latest terms or phrases.

Use patronizing language or "baby talk." A person with dementia will feel angry or hurt at being talked down to.

Use sarcasm or irony, even if meant humorously. Again, it can cause hurt or confusion.



PSALM 139 FOR CAREGIVERS

O God, you know my heart,
and only you understand how hard
I have tried to care for my loved one.
You know that I hardly have time to sit down
or care for myself;
you know the long hours I spend
working and serving my loved one.
Only you know the depth of anger I feel
toward my family for their lack of help,
and you know the harsh words I often speak
to the one I love—even before I say them.
I find it hard to hear your gentle voice
telling me to slow down,
not to fall prey to anxiety,
and to stop and rest in you.
You bless me even when I fail miserably,
when I get down on myself,
when I feel guilty for not doing enough.
Such understanding and grace are
beyond my comprehension.
I can never get away from you;
I cannot outlive your love.
If I have good days with my loved one,
when they have flashes of recognition,
you are there, celebrating with me.
If I sink down into the pits of despair
when everything is going wrong,
you are also there.

If I allow my mind to wander to more pleasant places,
you are there.
When the darkness of being on call around the clock
engulfs me and I want to scream,
you stand beside me and calm me.
And when I am tempted to believe that
all of this effort is wasted,
when I think I am wasting my life,
caring for something that will never come to fruition,
you hold me closest to your heart.
You know what it is like to experience
dark nights of the soul.
Even though my loved one has this dreadful
brain disease and no longer knows who I am,
I will still believe their soul is alive
and reaches out to me.
Even when they sit and stare into nothingness,
I know that you have knitted them in the womb
and made them a person,
and nothing can ever take away their personhood.
Search me, O God, and know my heart.
This experience tests my faith,
but you will sustain me in my weariness;
You will help me get through this terrible time.
Help me to love my loved one with your love
and to hold their hands and stay with them
until they rest safely in your embrace.

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Marie Thibault

Communication Tips for Visiting

Middle to Late Stages of Dementia

- Approach from the front and then sit down/get down on their level. Don't hover.
- Smile and look into their eyes when talking.
- Always greet them by their preferred name. Identify yourself and say why you're there. Speak slowly and clearly.
- Be prepared with a few things to talk about when you visit so that your conversation can be more narrative than dialogical.
- Use simple sentences, allowing the person time to process the idea being presented. Be patient for their response. BUT, if it becomes obvious they cannot find/form words to respond, move on to another topic.
- Avoid asking a lot of questions. Try to take the word *remember* out of your vocabulary.
- Do not argue. You will not win, and frustration will only increase – on both sides.
- Enter their reality.
- Be watching their body language and facial expressions for change in affect.
- Remember that only 7% of communication occurs through words ... 93% of communications happens through facial expressions, body language, voice tone and inflection.
- When their words may not make sense, listen closely for the emotional feelings being expressed and enter into the person's world. Mirror words and emotions. Try repeating whatever sounds they are making. Reply really? Or, Really!!