

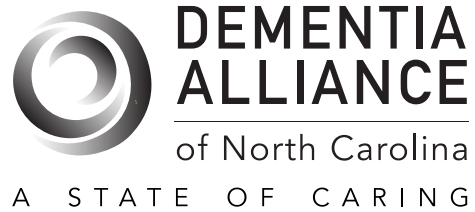
APPENDIX

Support Group Facilitator MANUAL



DEMENTIA
ALLIANCE
of North Carolina

A STATE OF CARING



APPENDIX A:

Support Group Forms & Examples



**DEMENTIA
ALLIANCE**

of North Carolina

A STATE OF CARING

9131 Anson Way, Ste. 206,
Raleigh, NC 27615
(919) 832-3732

www.DementiaNC.org

Support Group Information Form

Leader Name: _____ County: _____

Address: _____

City: _____ State: _____ Zip: _____

Home Phone #: () _____ - _____ Cell Phone #: () _____ - _____

Email: _____

Will you be facilitating an existing support group? ☐ Yes ☐ No ☐ Co-facilitator

Will you be facilitating a new support group? ☐ Yes ☐ No ☐ Co-facilitator

Starting Date? _____

Who is the primary contact for the group?

Name: _____ Phone No. _____

Email: _____

Is the support group general in nature or specific to a group of people (Male caregivers? Daughters?
or type of dementia? Please specify: _____

How often does/will group meet? (Monthly, bi-weekly, etc.) _____

What day of the week will your group meet? _____

What time of the day will your group meet? _____

**Again, for our listings, tell us about your meeting schedule (First Tuesday of each month 11AM-12:30PM)*

****Please inform us if this information changes***

Where will your group meet? _____

Is the group 'open' or 'closed'? ☐ open ☐ closed

Any other information you would like to share with us? _____

Please return this form to:

Dee Dee Harris, Director of Family Services and Support, dharris@DementiaNC.org
Dementia Alliance of North Carolina, 9131 Anson Way, Ste. 206, Raleigh, NC 27615

Once received, this information will be used to list your support group contact information
on the DA-NC website, support group list and with other organizations. Thank you.

"New Member Packets" for Support Group Members

(This is an example used for DA-NC Caregiver Support Groups.)

Contents placed in pocket-folder

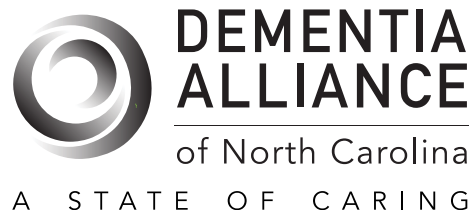
RIGHT-SIDE POCKET:

- DA-NC Program & Services brochure RACK card
- Coping Strategies for Caregivers handout
- Support Group Member Mailing List & Interest Form(*)
- Group Member Contact & Information Form(*)
- "Common Dementias" handout (*)
- "AD: What Everybody Needs to Know" handout/or other dementia handouts (*)
- Event flyers: DA-NC Walk info, fundraisers, workshops, conferences, etc.

LEFT-SIDE POCKET:

- Your Support Group Meeting Calendar
- Your Support Group "Guidelines" handout (*)
- "Are You in Need of a Support Group/How to Find..." handout (*)
- "I Joined a SG and ..." handout (*)
- "Ten Tips for Family Caregivers" handout (*)
- "Caregiver Coping Strategies" handout (*)
- "10 Warning Signs of Caregiver Stress" handout (*)
- "The Ten Absolutes of Caregiving" handout (*) on rack card

() These items are found in the Handbook for Support Group Facilitators*



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SUPPORT GROUP GUIDELINES

It is okay to remain silent.

Group time is confidential – what is said in group, stays in group.

Avoid side-conversations.

Be respectful while others are sharing.

Be aware of your time, don't monopolize, and allow time for others.

Everyone is in a different place – we don't judge but accept and support.

Those new to the group can go first but they don't HAVE to share.

There is no right or wrong answer or way to do things.

Don't interrupt.

Watch your language.

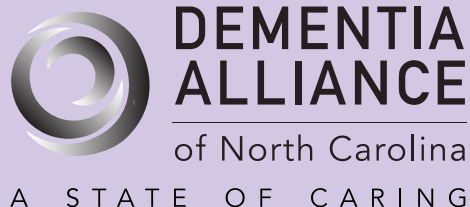
Share your resources – we don't endorse but we do share what has worked for us.

It is OK to cry, laugh, share, be emotional – this is a safe space.

All subjects are OK to discuss.

Do not bring a person living with dementia unless it is that type of group.

YOU ARE NOT ALONE!



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Support Group Member Mailing List & Interest Form

Name: _____

Address: _____

City: _____ County: _____

State: _____ Zip: _____

Home Phone #: () _____ - _____ Cell Phone #: () _____ - _____

Email: _____

I attend a support group lead by: _____ City: _____

I am interested in receiving the following information:

- | | |
|--|---|
| <input type="checkbox"/> Monthly DA-NC E-Newsletters | <input type="checkbox"/> Community Events/Fundraisers |
| <input type="checkbox"/> Education Workshops & Conferences | <input type="checkbox"/> Music & Memory at Home Kit |
| <input type="checkbox"/> Educational Materials | <input type="checkbox"/> Volunteer Opportunities |

Please notify us if you have a change in address so that we can keep our database up to date and you informed. Thank you for your assistance.

*Facilitators: Please ask all new support group members to complete this form.
After completion, please send to DA-NC Attn: Dee Dee Harris*



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www.DementiaNC.org

Welcome to Our Dementia Alliance of North Carolina Caregivers Support Group

Group Member Contact & Information

Date: _____ Group Member Name: _____

Address: _____

City: _____ State _____ Zip _____

Home Phone: _____ Cell Phone: _____

Email: _____

Emergency Contact Name: _____

Address: _____

City: _____ State _____ Zip _____

Home Phone: _____ Cell Phone: _____

Email: _____

Relationship to group member: _____

Other (if needed): _____



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Support Group Name: _____

Location: _____

Date: _____

MEETING SIGN-IN SHEET

1.	_____
2.	_____
3.	_____
4.	_____
5.	_____
6.	_____
7.	_____
8.	_____
9.	_____
10.	_____
11.	_____
12.	_____
13.	_____
14.	_____
15.	_____
16.	_____
17.	_____
18.	_____
18.	_____
19.	_____
20.	_____
21.	_____
22.	_____
23.	_____
24.	_____
25.	_____

Think About & Evaluate Your Support Group

The following are suggestions from current and past support group leaders.

This form is used to evaluate your group(s) and implement topics you feel would be helpful.

How do you get the info out about your meeting?

- ☐ Agency/other website ☐ DA-NC website
- ☐ Facebook ☐ Email
- ☐ Doctor's offices ☐ Phone Calls
- ☐ Community newspaper
- ☐ Agency/other newsletter
- ☐ Reminders to current members
- ☐ Other _____

Do you have a co-facilitator?

Who can you depend on to run the meeting if you are unavailable?

Are you a facilitator and a caregiver?

☐ YES ☐ NO

Is there a support system for you?

☐ YES ☐ NO

It is helpful to have a co-facilitator in case a member gets upset, a caregiver unexpectedly brings their loved-one with dementia, or there is an emergency during the group.

Your meeting begins when a member drives into the parking lot:

Is there ample parking? ☐ YES ☐ NO

Sufficient signage? ☐ YES ☐ NO

Easy access/ample parking? ☐ YES ☐ NO

Handicap access ☐ YES ☐ NO

Any safety hazards-lighting, construction, etc.

☐ YES ☐ NO

Doors unlocked for building security

☐ YES ☐ NO

Signs "Caregiver Support Meeting"

☐ YES ☐ NO

Welcoming the group members

- ☐ Nametags
- ☐ Sign-in sheet

☐ Use a computer spreadsheet w/names, ask to verify information when signing-in (APPENDIX A: 6)

☐ Ask new members to list name, address, email, phone (APPENDIX A: 5, Group Member Contact Information)

Are you serving refreshments?

☐ Member provided ☐ Leader provided

How do you introduce and welcome NEW members?

Do you know in advance new members are coming? ☐ YES ☐ NO

If a new member calls in advance, review meeting time, place, and mention that the group is for caregivers only (if this is the intent of the group) and not for the individual with dementia to come with them.

Get permission from new members before you share their information with others?

☐ YES ☐ NO

Provided new members with an information packet? ☐ YES ☐ NO

DA-NC provides the following in their new member packets: DA-NC info sheet with "The Ten Absolutes of Caregiving," support group meeting calendar, emergency contact form to fill out, "What you need to know about AD", "Common Dementias", upcoming event flyers/Walk info, support group guidelines for members, "Are you in need of a support group?", "I joined a support group...", and a "Caring for the Caregiver" Booklet.

Opening the Support Group Meeting

Do you begin with support group guidelines?

☐ YES ☐ NO

What are you using as guidelines?

Add to the guidelines as needed, ex. cussing

Be aware of how many guidelines you have.

(continued on page A:8)

Do you remind members of the meeting start and finish times? ☐ YES ☐ NO

Give "permission" to members to leave at designated time if meeting runs over.

Take care of announcements ("business") at the beginning of the meeting.

Do you share any roles with your co-facilitator? ☐ YES ☐ NO

Speakers

If you have a speaker, please leave ample time for caregiver discussion ☐ YES ☐ NO

Who do you use for speakers?

Does the speaker stay for sharing portion of the group? ☐ YES ☐ NO

If so, have you made the speaker aware of the group's confidentiality? ☐ YES ☐ NO

Have you asked for the group's permission? ☐ YES ☐ NO

We need to be aware of speakers making our members feel pressured into a service or way of thinking. It cannot be their marketing tool. You have a responsibility to protect the group.

Group discussion

How do you determine who shares first?

☐ Go around the room?

☐ Let someone take the initiative to start?

☐ Asking new members to introduce themselves

☐ Open the floor for someone to volunteer to start

☐ Ask existing member to start so new members can follow their lead

Do participants feel emotionally safe with the group? ☐ YES ☐ NO

Are the members' needs being met? ☐ YES ☐ NO

Do participants have opportunity to share during meetings and individually before or after meetings? ☐ YES ☐ NO

Is confidentiality an issue? ☐ YES ☐ NO

Are the group and the group facilitator(s) dependable? ☐ YES ☐ NO

Are new participants overwhelmed or frightened by what they heard at the meeting? ☐ YES ☐ NO

Do you open with a question, poem, short story, prayer, joke or other?

Reminder to facilitators: -Group time is not about us, the group is designed and encouraged for caregivers to share amongst each other.

Our role is to encourage their dialogue while respecting their right to be silent.

We should share only when necessary and refrain from 'our story' unless it is pertinent and beneficial to other members. When members look to us for answers we should redirect that back to the members for dialogue.

For example; if as a leader I know someone has already experienced this I will ask them if they would like to share that with the group.

How do you work with 'challenging' group members?

☐ The "fixer"

☐ The "monopolizer"

☐ The "criticizer" (comes for 'criticism & tea')
The one who brings their loved-one with dementia to meeting unannounced?

Are some members dominating the group to the exclusion of less assertive members? ☐ YES ☐ NO

Are participants respectful of others decisions? ☐ YES ☐ NO

Are members "stuck" in their situation? ☐ YES ☐ NO

Are participants "bored?" ☐ YES ☐ NO

(continued on page A:9)

Example: The member that repeats their same story each month - Ask them "what has been going on with you since you last attended support group?"

For more specific suggestions, please refer to your support group manual or call our office.

How do you end the group?

Is there a reminder that the meeting time is almost over? ☐ YES ☐ NO

Example: "We have ten minutes left and I want to make sure we allow everyone an opportunity to share"

What if someone hasn't shared yet?

Do you ask if those who haven't spoken want to speak? ☐ YES ☐ NO

What are your closing remarks?

Example: "Thanks for sharing, we look forward to seeing you next month, we are here if you need us"

- ☐ Other: Prayer, story, poem
- ☐ Give permission to leave since support group time is 'officially' over.
- ☐ Offer to remain for individual questions and to allow time for the group to mingle following group time

Follow-up after meeting and ongoing reminders

How do you do this?

☐ Email ☐ Phone call

Do you update absent members of announcements? ☐ YES ☐ NO

Do you out to new members after their first group meeting? ☐ YES ☐ NO



**DEMENTIA
ALLIANCE**

of North Carolina

A S T A T E O F C A R I N G

Community Education Meeting
SUPPORT GROUP & EDUCATION SURVEY

1. Are you interested in participating in an ongoing support group meeting for caregivers of individuals with dementia?

2. Are you interested in attending community education workshops and/or conferences?

3. What day/s of the week would be best for you? (Please circle your choices)

M T W Th F Sa Su

4. What time of day is best for you? (Please circle your choices)

Mornings Afternoons Evenings

5. Does this location meet your needs? (Please check one) ☐ YES ☐ NO

If not, why?

6. What topics would you be interested in learning more about?

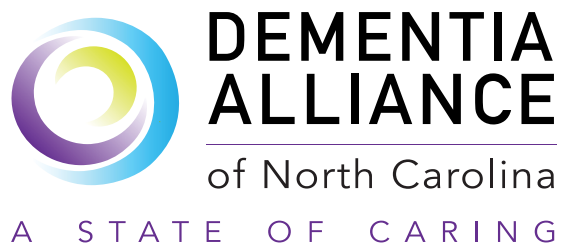
7. Other comments

Thank you for coming and for your feedback

ATTENDEE NAME _____

ATTENDEE PHONE NO. _____

ATTENDEE EMAIL _____



Plan for the Year: _____

[illegible][illegible]



Virtual Support Group Guidelines:

1. Be conscientious about who is around us during our call:
 - We always want to make sure that we keep what we share confidential.
 - Out of respect for them, want to make sure that the person living with dementia is not around.
2. If your loved one or others are around and you cannot get to a private place you may want to try using a headset or ear phones.
3. When you are not speaking, be sure to mute yourself.
4. If at any time you get disconnected just click or call and do the same process again and it will reconnect you.

Tools for Reaching a Remote Audience

Given the current COVID-19 crisis, outreach and education is taking place at a distance. This tip sheet provides an overview of some popular tools to reach out to and connect with your audience.

The National Council on Aging does not endorse any of these platforms or applications and recognizes that all tools have advantages and disadvantages. We hope this will help you find the tools that are right for you and your community.

TOOLS TO DELIVER CLASSES ONLINE

Facebook Live	
Overview	A feature of the Facebook social network that broadcasts footage in real-time by utilizing one's camera on a computer or a mobile device.
Pros	<ul style="list-style-type: none"> • It can be used to reach a very large already built in audience, for example, with over a 1 billion users on Facebook. • It is totally free. • You don't need to have a Facebook account to view a Facebook Live broadcast. • You can decide who you want to view the live stream. • Facebook users can engage with the live video as viewers can comment on the stream and give instant feedback.
Cons	<ul style="list-style-type: none"> • Resolution is HD, but only 720p HD, which is good but not the best video quality • If the stream is not set up to be shared with a general public audience, you will then need to sign up for Facebook. • It can be a little slow at times, especially if one's internet connection is not strong.
Learn more	<ul style="list-style-type: none"> • Facebook Live overview • Tips for using Facebook Live • How to Use Facebook Live: The Ultimate Guide • The Complete Guide To Facebook Live Streaming in 2020

FreeConferenceCall.com	
Overview	HD audio conferencing and online meetings with screen sharing and video conferencing for up to 1,000 participants.
Pros	<ul style="list-style-type: none"> • Free teleconferences for up to 1,000 participants after you sign up for a free account. The service also accepts funds through their "pay what you can" model for those who would like to contribute. • Users receive an email report after each meeting with details about participants and meeting duration. • Calls can be recorded for a small fee.
Cons	<ul style="list-style-type: none"> • A short ad for the service plays when users join the call. • Audio quality lags at times due to congestion.

	<ul style="list-style-type: none"> Free webinars and screen sharing are also available, but some user reviewers for the video service are negative.
Learn more	<ul style="list-style-type: none"> About us: FreeConferenceCall.com FreeConferenceCall.com Teleconferencing Service 5 best practices for handling conference calls

Google Hangouts	
Overview	Free messaging, voice, and video calls.
Pros	<ul style="list-style-type: none"> Allows you to call any phone number in the world and allows for status messages, videos, and emojis to be sent in video or voice calls – group or individual. The basic platform is free for anyone with a Google account. Conversations (not video calls) can include up to 150 people. Hangouts is built into Gmail, YouTube, and Google Voice, plus there are Hangouts apps for iOS, Android, and the web.
Cons	<ul style="list-style-type: none"> To use the free version participants must have and use Google accounts (with G Suite you can include a phone number and PIN on each of your meetings with no other configuration required). To have the full Google Hangouts Meet (video) capability you need to purchase G Suite (starting at \$6 per user per month). Video calls are capped at 100 (Gmail, G Suite Basic), 125 (Business) or 250 (Enterprise) people.
Learn more	<ul style="list-style-type: none"> Learn how to use Hangouts Meet Hangouts Help Community Start a Video Call in Hangouts

GoToMeeting	
Overview	An online meeting, desktop sharing, and video conferencing software package.
Pros	<ul style="list-style-type: none"> Offers connection to Office 365 for users to schedule, manage, and join online meetings directly from their Outlook calendar. The pay version provides unlimited cloud recording and storage. A free version with limited meeting time and users is available. A long track record with an established reputation in the field (over 15 years of business) versus newer solutions with less history like Zoom.
Cons	<ul style="list-style-type: none"> Basic annotation tools for screen sharing; no whiteboarding (unlike Zoom). For anything beyond 40-minute meetings you will need to purchase a license (starting at \$12 per user per month).
Learn more	<ul style="list-style-type: none"> GoToMeeting User Guide COVID-19: A Guide to Working Remotely GoToMeeting Attendee Guide

GroupMe	
Overview	A free mobile group messaging app owned by Microsoft.
Pros	<ul style="list-style-type: none"> • Free to users. • You don't need to have the app to use GroupMe (can be used over SMS). • Even those without smart phones can join.
Cons	<ul style="list-style-type: none"> • Does not have the end-to-end encryption offered by WhatsApp for security. • The search function within the app is clunky and hard to use.
Learn more	<ul style="list-style-type: none"> • GroupMe review • Group SMS on GroupMe • 15 Group Messaging Mobile Apps

Microsoft Teams	
Overview	An Office 365 communication and collaboration platform that keeps workplace calls, chat, video meetings, and file storage all in one place.
Pros	<ul style="list-style-type: none"> • Free with Office 365 subscriptions (discounted subscriptions apply for nonprofits starting at \$3 per month per user). • Includes features like scheduling assistance, meeting note taking, screen sharing, meeting recording, and instant messaging. • Offers the ability to hold large meetings, webinars, company-wide events, and presentations live with up to 10,000 attendees inside or outside your organization.
Cons	<ul style="list-style-type: none"> • Users will need an Office 365 subscription for some features. • Additional features will require add on subscriptions with added costs.
Learn more	<ul style="list-style-type: none"> • Microsoft Teams help and learning • Enable distance learning with Microsoft Teams for free • Office 365 Nonprofit plans

OneClick.chat	
Overview	A web-based video chat platform. OneClick.chat also offers a video communications platform aimed at events, where presenters can speak to a distributed audience that can later be split into discussion groups.
Pros	<ul style="list-style-type: none"> • Ease of use—just one click. • No downloads or add-ons are required to log on. • User receive a custom and permanent link that gives them control of their meeting room. • Research funded by the National Institute on Aging has shaped the design of the products. • Currently undertaking specific research on the platform and social isolation with adults 70+ through NIH funding. • Also received grant funding to host virtual Tai Chi classes from Georgia Tech.
Cons	<ul style="list-style-type: none"> • A one-month trial is free, but beyond that the service starts at \$15 per month for meeting rooms and \$100 a month for a basic live event hosting subscription (a 20% discount is offered to non-profit organizations).

	<ul style="list-style-type: none"> • The meeting room functionality is capped at twelve participants. • The platform cannot support devices that are more than five years old.
Learn more	<ul style="list-style-type: none"> • NIH awarded OneClick.chat a grant to help fight social isolation. • OneClick.chat partners with Georgia Tech to Tackle Aging and Disability-Related Needs • OneClick.chat Frequently Asked Questions • Overview video of OneClick.chat

Skype	
Overview	A telecommunications application that specializes in providing video chat and voice calls between computers, tablets, mobile devices, the Xbox One console, and smartwatches over the Internet. Skype also provides instant messaging services.
Pros	<ul style="list-style-type: none"> • Offers live subtitles for the hard-of-hearing. • Users can make free international calls (if the person they are calling also uses Skype). • Provides end-to-end encryption for security. • Skype Translate lets people talk in different languages while still understanding each other. • Integrates with Alexa, the digital assistant that comes with Amazon Echo devices.
Cons	<ul style="list-style-type: none"> • Since the platform's sale to Microsoft in 2011 there have been rumors it will be replaced with Microsoft Teams. • You will need to purchase a premium version to take advantage of some of the app's most helpful features.
Learn more	<ul style="list-style-type: none"> • What Is Skype and How Does It Work? • Getting to know Skype 8 • Skype Support Desk

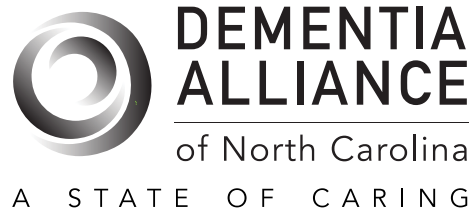
WhatsApp	
Overview	A free messaging and voiceover IP platform owned by Facebook that has more than 1.5 billion monthly active users.
Pros	<ul style="list-style-type: none"> • Free to users. • Can be used for individual chats, group chats, or broadcast lists. • With group chats, you can share messages, photos, and videos with up to 256 people at once. • Messages are end-to-end encrypted for security and privacy.
Cons	<ul style="list-style-type: none"> • Participants will have to download the app to participate. • Users will need to have a smart phone to join the conversation. • Instructions are different for users of iPhones or Androids.
Learn more	<ul style="list-style-type: none"> • WhatsApp overview • Learn how to use WhatsApp Messenger • How to use group chats and broadcast lists in WhatsApp

YouTube Live	
Overview	Free messaging, voice, and video calls.
Pros	<ul style="list-style-type: none"> • Live streaming via webcam is an easy way to go live without the need for an encoder. • You can start streaming from your laptop/desktop computer using your webcam anytime. • Live streams can be public, unlisted, or private. • Analytics from your live stream are available to you after your event.
Cons	<ul style="list-style-type: none"> • You cannot stream on a mobile device unless you have at least 1,000 subscribers. • You cannot see participants.
Learn more	<ul style="list-style-type: none"> • Introduction to live streaming • YouTube Live FAQs • Streaming tips

Zoom	
Overview	A cloud platform for video and audio conferencing, collaboration, chat, and webinars across mobile devices, desktops, telephones, and room systems.
Pros	<ul style="list-style-type: none"> • High video and audio quality. • You can see videos of other participants in a small floating panel while you're sharing your screen so that you can gauge their reaction while you're presenting. • Breakout rooms are helpful when teaching a larger group. • It is easy to record and share meetings. • Intuitive and easy to use platform. • Integration with Calendly (free online scheduling software)
Cons	<ul style="list-style-type: none"> • Forty-minute limit on free account calls. • Zoom requires participants to download an app and/or a browser extension to join. • As of March 31, 2020 new data was released that highlighted security concerns and weaknesses in the Zoom platform (learn more here).
Learn more	<ul style="list-style-type: none"> • Guide to Educating Through Zoom • Tips and Tricks for Teaching Over Video • Zoom Support during the COVID-19 pandemic (includes tutorials and training videos) • How to Keep the Party Crashers from Crashing Your Zoom Event • Secure Your Meetings with Zoom Waiting Rooms • 13 Zoom video chat tips, tricks and hidden features • Video chat with Zoom (SeniorPlanet.org resource—check their website for regular livestreaming classes) • Zoom at Your Own Risk

TOOL TO HELP PARTICIPANTS SIGN WAIVERS

DocuSign	
Overview	Provides eSignature, a way to sign electronically on different devices.
Pros	<ul style="list-style-type: none">• Allows you to have documents signed without physical contact or using the postal system.• Integrates with Dropbox, Google Drive, and more.• Allows you to automate workflows and processes (including generation, review, and approvals).• Signatures processed by DocuSign are compliant with the US E-SIGN Act and the European Union's eIDAS regulation, including EU Advanced and EU Qualified Signatures.
Cons	<ul style="list-style-type: none">• After a free trial the service starts at \$10 per user per month.• Time is required to learn the new technology.
Learn more	<ul style="list-style-type: none">• DocuSigning FAQs• How do I sign a DocuSign document?• DocuSign Tour



APPENDIX B:

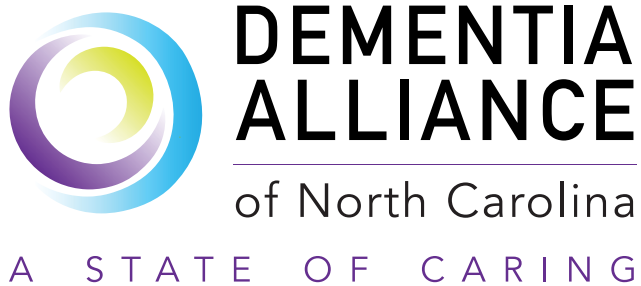
Media & Public Relations Information

Dementia Alliance of North Carolina Brand Standards

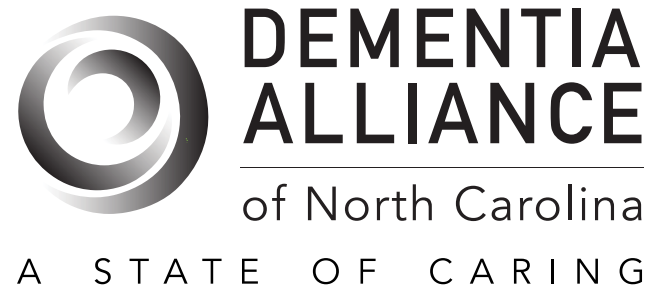
As a **Certified Support Group Facilitator** you are encouraged to include official logos and to maintain color standards in all of your outreach and marketing materials. The logo, along with the updated mission-oriented tagline, A State of Caring, is available in two formats:

Logo Standards:

Horizontal Full Color



Horizontal Black & White



Vertical Full Color



Vertical Black & White



Uses:

Dementia Alliance Color Standards:

Website Design >>

#00AEEF

#662D91

#D7DF23

#000000

Traditional
Printing,
Newspapers &
magazines >>>>

cmyk: 100, 0, 0, 0

cmyk: 75, 100, 0, 0

cmyk: 20, 0, 100, 0

cmyk: 75, 68, 67, 90

Desktop print >>
and digital files,
email, social
media, etc.

rgb: 0, 174, 239

rgb: 102, 45, 145

rgb: 215, 223, 35

rgb: 0, 0, 0

Sample Press & News Releases:

Below are a few tips to get your story noticed more quickly:

1. Today's busy reporters usually prefer a news release be sent by e-mail. Simply type the text of the news release in the body of the e-mail message and attach a Dementia Alliance of North Carolina logo, along with any photos you want featured in the story if it is run.
2. Research the proper departments for your story and send along to specific reporters that cover each department. CC the news editor as well.
3. There is high turn over rate in many news outlets, so maintain a list of contacts and update the list as needed.
4. Thank writers and news outlets when your stories are published. Be sure to share links on your social media channels and tag Dementia Alliance of North Carolina.

SAMPLE 1: BROADCAST RELEASE (TV, Radio)

Date: ...day, month, year

Prepared by:

Your name

Certified Support Group Facilitator

Your telephone number

Your e-mail address

For Immediate Release:

Title examples:

Dementia Support Group Meeting in (name of city/location); or (name of person) to Speak at Local Dementia Support Group Meeting

Text of news release could contain the following information:

Dementia Alliance of North Carolina announces the ____name of month, first, etc.____ meeting of its ____city/location____ Alzheimer's Disease and Dementia family support group. The meeting will be held on the _____ of every month, from _____ to _____ (a.m./p.m.) at _____ address/name of site_____.

The meeting will feature a presentation by name of presenter (include biographical information if available).

Participants in support groups receive emotional support and practical assistance in coping with the numerous issues they face as caregivers along with information about research, local government programs and other activities.

SAMPLE 2: General Press Release or Media Advisory

Date: ...day, month, year

Prepared by:

Your name

Certified Support Group Facilitator

Your telephone number

Your e-mail address

For Immediate Release:

Title:

Dementia Support Group Meets Monthly

Attention: Planning/Assignment Desk


WHO: State who you are—for instance, the Dementia Alliance of North Carolina's Support Group of (name of city or location).

WHAT: State what the event or activity or program is about, such as "Monthly support group meeting" or "(name of person) to speak at Community Caregiver Workshop."

WHEN: Provide date and time.

WHERE: Provide location, address, contact information for directions (i.e. phone number or website), if available.

GENERAL INFORMATION: Provide pertinent information. This is where you would include the reasons why the event or activity is important.



Are You in Need of a Support Group?

- Do you need caregiving resources for your area?
- Are you feeling stressed and overwhelmed?
- Are you depressed? Tired? Rundown?
- Would you like to have additional caregiving coping strategies?
- Would you like to have the support of other caregivers who “understand” caregiving?
- Do you want a support system?
- Ever wanted to have someone be there for you?
- Would you like to acquire more education from other caregivers?

If you answered “yes” to one of these questions, we encourage you to attend one of the support groups in your community!

How to Find the Right Support Group for YOU!

Things to consider when looking for a support group in your community:

- How often does the group meet? Monthly, Bi-monthly
- What time of day is convenient for you? Evening, Daytime
- Is the location of the group easily accessible for you? Consider travel time
- What kind of group is it? Caregivers, Individuals w/ Dementia, Male only, other?
 - Is the group for support or education, or a combination of both?
 - What is the size of the group?

Joining a group is EASY:

1. Visit our website at www.DementiaNC.org/SupportGroups
2. Locate a group in your county that fits with your schedule
3. Call or email the facilitator listed, they would love to hear from you!



**DEMENTIA
ALLIANCE**
of North Carolina

A STATE OF CARING



Community Dementia Workshop

*Are You Caring for Someone
with Memory Problems?*

*We Can Help You Focus
on What's Important!*

Enter DATE:

Enter TIME:

Enter Location:

Enter Address::

Enter City, NC Zip

**Please pre-register by
(enter date)**

Enter phone #:

Sponsored by:

Enter Your Group name

*Note: This will be supplied as a
Word Template you can edit with
your groups' information*

FREE COMMUNITY WORKSHOP

- Does Someone You Love Have MEMORY PROBLEMS?
- Are you concerned and not sure how to help?
- Are you feeling frustrated? Alone? Overwhelmed? Frightened?

Come to this workshop...

It will provide you with:

- Information
- Knowledge
- Resources
- Connections
- Skills
- Hope
- Understanding
- Power



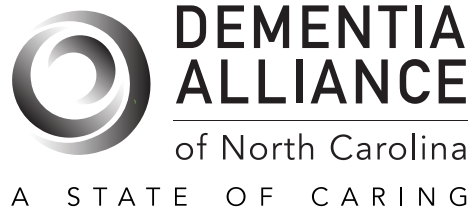
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APPENDIX C:
Alzheimer's Disease & Related Dementias
Educational Information

What is Mild Cognitive Impairment (MCI)?

In contrast to Alzheimer's disease (AD) where other cognitive skills are affected, mild cognitive impairment (MCI) is defined by deficits in memory that do not significantly impact daily functioning. Memory problems may be minimal to mild and hardly noticeable to the individual. Writing reminders and taking notes allow a person to compensate for memory difficulties. Unlike AD where cognitive abilities gradually decline, the memory deficits in MCI may remain stable for years. However, some individuals with MCI develop cognitive deficits and functional impairment consistent with AD. Whether MCI is a disorder distinct from AD or a very early phase of AD is a topic of continuing investigation. The diagnosis of MCI relies on the fact that the individual is able to perform all their usual activities successfully, without more assistance from others than they previously needed.

Signs & Symptoms of MCI

Typically, memory complaints include trouble remembering the names of people they met recently, trouble remembering the flow of a conversation and an increased tendency to misplace things or similar problems. In many cases, the individual will be quite aware of these difficulties and will compensate with increased reliance on notes and calendars. These problems are similar, but less severe, than the neuropsychological findings associated with Alzheimer's disease. In some cases, the patient may have mild difficulties with daily activities, such as performing hobbies.

The medical evaluation should include a thorough exploration of the memory complaints, including what type of information is being forgotten and when, the duration of the problem, and whether other cognitive complaints are occurring (problems with organization, planning, visuospatial abilities, etc.). The physician should be aware of the patient's medical history, the medications taken, etc. As subjective memory complaints can be associated with depression, screening for depressive symptoms is always warranted. Depending on the results of this evaluation, further testing may be necessary, including blood-work and brain imaging. This evaluation is similar to that given to individuals with more severe memory problems, and is directed towards better defining the problem and looking for medical conditions that might have an effect on the brain (infections, nutritional deficiencies, autoimmune disorders, medication side effects, etc.). The medical history usually requires the participation of a knowledgeable informant.

Additional assessment could include neuropsychological testing to document objectively any memory deficit and to assess its severity. Although normal performance on neuropsychological testing does not guarantee that the individual will not develop dementia, the current data indicate that normal results are relatively reassuring, at least for the next few years.

Progression of MCI

Certain features are associated with a higher likelihood of progression from MCI to Alzheimer's. These include confirmation of memory difficulties by a knowledgeable informant (such as a spouse, child or close friend), poor performance on objective memory testing, and any changes in the ability to perform daily tasks, such as hobbies or finances, handling emergencies or attending to one's personal hygiene.

(continued)

Treatment of MCI

There is currently no specific treatment for MCI. As new medical interventions for Alzheimer's disease are developed, these are likely to be tried on patients with MCI as well. If data from such trials indicates a beneficial effect in slowing cognitive decline, the importance of recognizing MCI and identifying it early will increase. However, it is important to remember some drugs may impair memory, especially in older adults. Examples are Valium®, Ativan®, Benadryl®, Tylenol PM®, Advil PM® (both contain Benadryl®), Cogentin® and many others. A very careful assessment of medications is essential when considering a diagnosis of MCI.

A general recommendation for individuals concerned about their memory would be to discuss these concerns with their significant other (friend, spouse, child, etc.), as well as their physician. Bringing the outside informant to the physician appointment is often very helpful in the evaluation process.

Source: <http://memory.ucsf.edu/print/education/diseases/mci>



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THE IMPORTANCE OF EARLY DIAGNOSIS OF DEMENTIA AND INFORMATION ABOUT THE DIAGNOSIS PROCESS.

This information may be helpful to people who have concerns about dementia or to those who are concerned about their family members or friends.

Promoting early diagnosis of dementia

The early symptoms of dementia can include memory problems, difficulties in word finding and thinking processes, changes in personality or behavior, a lack of initiative or changes in day to day function at home, at work or in taking care of oneself. This information does not include details about all of these warning signs, so it is recommended that you seek other sources of information. If you notice signs in yourself or in a family member or friend, it is important to seek medical help to determine the cause and significance of these symptoms.

Obtaining a diagnosis of dementia can be a difficult, lengthy and intensive process. While circumstances differ from person to person, we believe that everyone has the right to:

- A thorough and prompt assessment by medical professionals
- Sensitive communication of a diagnosis with appropriate explanation of symptoms and prognosis
- Sufficient information to make choices about the future
- Maximal involvement in the decision making process
- Ongoing maintenance and management
- Access to support and services

For some people, there may be barriers to diagnosis, especially to an early diagnosis. These include the belief that memory problems are a normal part of ageing, the perceived stigma attached to dementia, the lack of a cure and fear about the future. However, there are many reasons why early diagnosis is important, some of which are detailed within this page. Early diagnosis and awareness about dementia are the first steps in designing management strategies. As more effective treatments become available in the future, early diagnosis will become even more important.

What are the benefits of early diagnosis?

Early planning and assistance

Early diagnosis enables a person with dementia and their family to receive help in understanding and adjusting to the diagnosis and to prepare for the future in an appropriate way. This might include making legal and financial arrangements, changes to living arrangements, and finding out about aids and services that will enhance quality of life for people with dementia and their family and friends. Early diagnosis can allow the individual to have an active role in decision making and planning for the future while families can educate themselves about the disease and learn effective ways of interacting with the person with dementia.

Checking concerns

Changes in memory and thinking ability can be very worrying. Symptoms of dementia can be caused by several different diseases and conditions, some of which are treatable and reversible, including infections, depression, medication side-effects or nutritional deficiencies. The sooner the cause of dementia symptoms is identified; the sooner treatment can begin. Asking a doctor to check any symptoms and to identify the cause of symptoms can bring relief to people and their families.

Treatment

There is evidence that the currently available medications for Alzheimer's disease may be more beneficial if given early in the disease process. These medications can help to maintain daily function and quality of life as well as stabilize cognitive decline in some people; however, they do not help everyone and they are not a cure. Early diagnosis allows for prompt access to medications and medical attention.

Health management

Receiving a diagnosis can also help in the management of other symptoms which may accompany the early stage of dementia, such as depression or irritability. Also reviewing management of other medical conditions is critical, as memory problems may interfere with a person remembering to take important medications such as for diabetes, heart disease or high blood pressure.

Who diagnoses dementia?

The General Practitioner (GP) or Primary Care Physician (PCP) is usually the first contact when concerns about thinking or memory arise. The GP/PCP will take a medical history and may carry out a brief test of memory and concentration. If the GP/PCP is concerned about the possibility of dementia, the person may be referred to a specialist. It is important to remember that the choice of doctor is up to you – so if after your visit you are still concerned and wish a referral to a specialist, you may wish to ask for a second opinion.

Specialists such as neurologists, geriatricians, psycho-geriatricians, psychiatrists, and neuropsychologists have a more detailed knowledge of the memory and behavior changes associated with dementia and may perform or arrange in-depth assessments, brain scans and blood tests.

Memory clinics incorporate a range of specialists involved in the diagnosis of dementia. While they provide diagnostic services for all types of dementia, they often offer specialist services for younger-onset or rare forms of dementia.



The diagnosis process

The first step in the diagnosis process is to assess symptoms through a thorough medical history, physical examination and evaluation of memory and thinking abilities. Other causes of dementia-like symptoms must be ruled out through laboratory tests and in some cases, brain scans. The next step is to determine the cause of the dementia, most commonly Alzheimer's disease, vascular dementia, Lewy body dementia or frontotemporal dementia.

Medical history

The doctor will obtain a complete medical and family history. Questions will be asked about forgetfulness, orientation, problem solving, coping with everyday life, alcohol consumption and medication usage. The doctor needs to establish when the change in function was first noticed, whether the change was sudden or gradual and whether the person's difficulties are getting worse. Determining the onset and progression of symptoms can help to differentiate types of dementia. Descriptions

of the person's difficulties from family members, obtained if the person consents, are vital in the diagnosis process.

Medical testing

- Medical tests, including blood, urine and genetic tests, as well as brain scans, are sometimes used in the diagnosis of dementia.
- Blood or urine tests are carried out to exclude other causes of dementia symptoms, by testing for infections, vitamin and nutrient levels, as well as kidney, liver and thyroid function.
- Genetic testing is only performed in rare cases where there is a family history of younger-onset dementia and is currently not a common practice in the diagnosis of dementia. Although researchers have identified some more common genes, such as ApoE 4, which increases the risk of developing Alzheimer's disease, these genes do not cause the disease. Currently available genetic tests for ApoE 4 do not reliably aid in predicting who will develop Alzheimer's disease.
- Brain scans can be used to detect brain tumors, strokes or brain hemorrhages, brain shrinkage and increased pressure of fluid in the brain. Routine brain scans include computerized tomography (CT) scans and magnetic resonance imaging (MRI). These procedures produce an image of the brain, allowing the identification of abnormal changes. These scans are relatively non-invasive and are only used for diagnosis in certain cases.
- CT scanning involves use of specialized x-rays to generate a 3-D image of brain structure and is useful to rule out other causes of symptoms. MRI uses a strong magnetic field and radio waves instead of x-rays to produce a 3-D image. MRI can be used to rule out other causes, find characteristic patterns of brain damage, and differentiate between types of dementia.
- Brain scans do not always show abnormalities in people diagnosed with dementia, as sometimes there are no visible changes in

the brain. Sometimes, brain scans can be used to determine the type of dementia. A person with vascular dementia might show evidence of strokes or other vascular changes in the brain, whereas a person with Alzheimer's disease might show either brain shrinkage or no changes at all.

- Other types of brain scans are used primarily in research studies. SPECT (Single Photon Emission Computed Tomography) is a brain scanning technique used primarily in research studies that can show functional changes in brain activity. fMRI (Functional Magnetic Resonance Imaging) also provides information about brain function as well as structure and is typically used in research studies. PET (Positron Emission Tomography) is another type of functional brain imaging, typically used in a research setting.

Psychological evaluation

Tests of mental functioning are very important in the diagnosis process. These tests are used to determine the extent of any memory or thinking problems and can be used to track progression over time.

Initial dementia screening tests can be quite brief and simple, such as giving the date, copying a diagram, learning a short list of words, or naming common objects. Common brief assessments include the Mini-Mental State Examination (MMSE), the Brief Cognitive Rating Scale and the Alzheimer's Disease Assessment Scale - Cognitive (ADAS-Cog). Some people perform well on brief screening tests but memory and thinking impairments may be found with more comprehensive testing. Additionally, some tests have been shown to have educational, social and cultural biases.

Brief screening tests can be followed up by more detailed tests of mental function. These tests are known as neuropsychological tests and examine different areas of function such as memory, language, reasoning, calculation and ability to concentrate.

These tests are able to distinguish between different patterns of decline and are therefore

important in helping to identify the type of dementia affecting the individual.

Types of Dementia

There are many different causes of dementia. The most common is Alzheimer's disease, which is associated with distinctive changes in the brain. While Alzheimer's disease can develop in younger people, it is most common after the age of 65 years. Vascular dementia is thought to be the second most common form of dementia and is associated with problems of blood circulation in the brain. However, mixed dementia containing elements of vascular dementia and Alzheimer's disease is also common.

Other causes of dementia include Dementia with Lewy Bodies and Fronto-temporal dementia. Dementia with Lewy Bodies is marked by a fluctuating mental state, hallucinations and motor problems, while Fronto-temporal dementia typically occurs between 45 and 65 years of age and involves profound personality and behavioral changes.

There are many other possible causes of dementia including Huntington's disease, Creutzfeld-Jacob Disease, Alcohol-related dementia and Parkinson's disease. It is important to obtain an accurate diagnosis to maximize benefits from treatment and understand more about prognosis and symptoms.

After the diagnosis

Early diagnosis of dementia is the first step in understanding and managing the condition. Communicating a diagnosis of dementia can allow for planning to begin. Early diagnosis of dementia means that in the vast majority of cases, it is appropriate for people to be told about their diagnosis, as they have a right to information about their health.

In the past, some people argued against telling a person of their diagnosis because of the belief that there is no benefit in knowing, the fear of provoking distress, and that the diagnosis would be difficult for the person to understand. However, although many people with early stage dementia will initially feel



'shattered' by the diagnosis, many also say that they feel a sense of relief that the cause of their difficulties is identified, and knowing the diagnosis can increase their sense of independence and enable an active role in planning for their future.

It can be difficult to take in information at the time of diagnosis, so scheduling another time to talk to the doctor is important. Take time and ask as many questions as you like. It may also be helpful to have someone supportive with you at the time of diagnosis. You may want to ask your doctor about the possible benefits of medication and side effects.

Life doesn't stop with a diagnosis. There are many available sources of support, which can help you, as well as families and friends.

Source: <https://www.dementia.org.au/information/diagnosing-dementia/early-diagnosis-of-dementia>
Dementia Australia, "Early diagnosis of Dementia"

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Common Dementias Explained

Overview

Dementia can be caused by a number of different conditions; it is a symptom of neurodegenerative diseases like Alzheimer's, frontotemporal dementia or corticobasal degeneration. The term "dementia" describes a progressive, degenerative decline in cognitive function that gradually impairs memory and the ability to learn, reason, make judgments, communicate and carry out daily activities. While it often includes memory loss, memory loss by itself does not mean that a person has dementia. Dementia affects more than 50 million people worldwide.

Alzheimer's Disease (AD)

Alzheimer's disease is a progressive, degenerative brain disease that slowly erodes memory and thinking skills, and eventually even the ability to carry out simple tasks. It is the most common cause of dementia. Alzheimer's may occur in combination with vascular dementia, or other dementias.

Frontotemporal Dementia (FTD)

Frontotemporal dementia is a group of related conditions resulting from the progressive degeneration of the temporal and frontal lobes of the brain. These areas of the brain play a significant role in decision-making, behavioral control, emotion and language. Common forms of FTD:

Primary Progressive Aphasia (PPA)

Is caused by degeneration in the areas of the brain that control speech and language. This type of aphasia begins gradually, with speech or language symptoms that will vary depending on the brain areas affected by the disease.

Progressive Supranuclear Palsy (PSP)

A degenerative disease of the brain leading to difficulties with walking and balance, problems with eye movements, changes in behavior, difficulty with speech and swallowing, and dementia.

Corticobasal Degeneration

A progressive neurological disorder that affects nerve cells that control walking, balance, mobility, vision, speech and swallowing.

Behavioral Variant FTD (bvFTD)

Involves changes in personality, behavior, judgment. Behavior and poor judgment go unnoticed by the individual. Inappropriate and impulsive behaviors are common along with apathy and loss of initiative. Memory generally not affected.

Lewy Body Dementias

Lewy body dementias include dementia with Lewy bodies (DLB) and Parkinson's disease with dementia (PDD) and are the second most frequent cause of dementia in elderly adults. Common symptoms include problems with movement, visual hallucinations, and fluctuations in thinking skills or attention.

Mild Cognitive Impairment

In contrast to Alzheimer's where other cognitive skills are affected, mild cognitive impairment (MCI) is defined by deficits in memory that do not significantly impact daily functioning. Memory problems may be minimal to mild and hardly noticeable to the individual.

Vascular Dementia

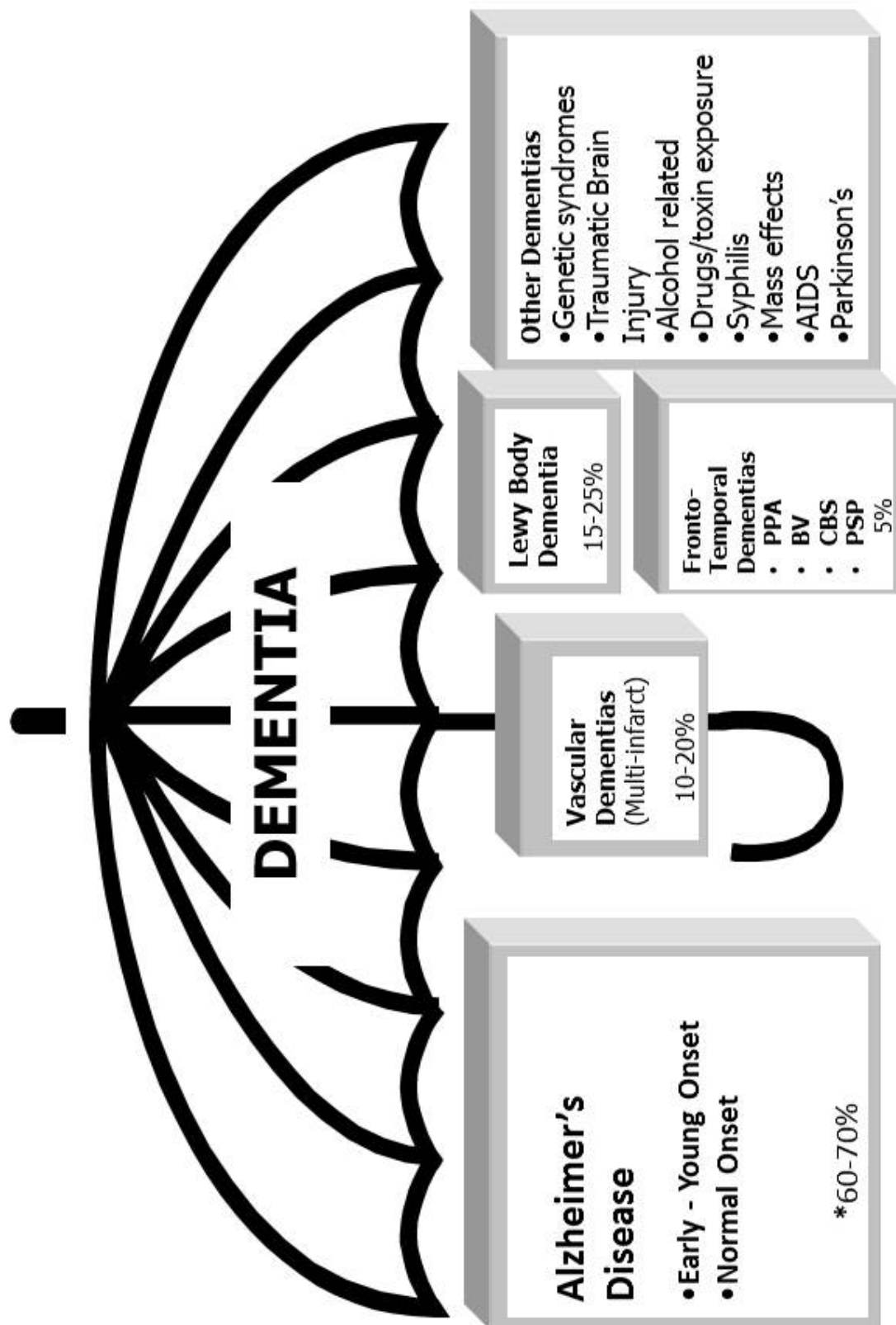
Vascular dementia is a subtly progressive worsening of memory and other cognitive functions due to chronic, reduced blood flow in the brain, eventually resulting in dementia. Clinically, patients with vascular dementia may look very similar to patients with Alzheimer's, and the two diseases are very difficult to distinguish from each other. Vascular dementia may occur in with Alzheimer's disease.

(<http://memory.ucsf.edu/education/diseases>)



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*Percentages from D. Kaufer, MD, UNC-CH, Carolina Alzheimers Network, Aug. 2010

Alzheimer's Disease (AD): What Everybody NEEDS to Know

What is Dementia?

Dementia is a non-specific term used to describe a person having changes in brain function that interfere with ability to function and do everyday activities.

The person with dementia has problems in multiple areas of brain function. These problems can include; memory, language, impulse control, ability to do things for self, personality, understanding of time, etc.

Common types of dementia include: Alzheimer's disease, vascular dementia, Lewy body dementia, frontal-temporal dementia (FTD) and mixed dementia (more than one type of dementia occurring in the same brain). Different types of dementia impact the brain in different ways, have different symptoms, cause changes in different abilities...in different orders...and at different rates.

What is Alzheimer's Disease?

Alzheimer's disease is one type of dementia. It is a progressive and terminal disease. The changes typically occur slowly, over months and years, not hours and days.

If the person has a sudden change in health status, living situation or caregiver system (for example, death of a spouse) he or she may APPEAR to change quickly. The brain has actually been changing slowly but since the person was in a routine, the person's abilities weren't being challenged and he or she was relying on OLD patterns and memories to function.

The pattern and progression of the disease is predictable BUT the experience is individual and ultimately, the person's entire life is affected by Alzheimer's disease.

What are the early signs?

Early signs might include:

- Memory loss of recent events and information
- Confusion about place and time
- Familiar tasks become challenging
- Trouble finding words, finishing thoughts and sentences, following directions
- Decreased reasoning ability and altered judgment
- Changes in mood and personality, frequent mood swings, disinterest or withdrawal, suspicion
- Difficulty with complex mental tasks, planning, problem solving



How is Dementia Different from Aging and Forgetfulness?

- Aging happens to everyone. Dementia is ALWAYS a disease; it DOESN'T happen to everyone.
- With forgetfulness, new information can be stored; it may take more effort or practice, but new information can “stick”. With dementia, new information cannot be predictably retained.
- Forgetful people can use reminders, calendars, lists and to be able to DO. With most dementias, these prompts CANNOT help after the earliest stages.
- Being forgetful makes an independent life *difficult*; having dementia makes independent life *impossible*.

What is “Normal Aging”?

Normal aging includes:

Being more forgetful

Taking longer to learn new information

Requiring more practice to learn new skills or technologies (you can do it, just have to try harder than you used to)

Having more trouble recalling people's names (more than you used to have)

Knowing the word you want but hesitating, eventually finding the word (more often than you used to)

Diagnosis makes a difference!

Early diagnosis is important and accurate diagnosis is critical!

Why? Because!

1. Early treatment is more effective than waiting.
2. Early and accurate diagnosis allows for **better** planning and opportunity to **include** the person with dementia in the process. Planning makes a difference in options the person may have as the disease leads to changes in abilities and needs.

How is Alzheimer's disease diagnosed?

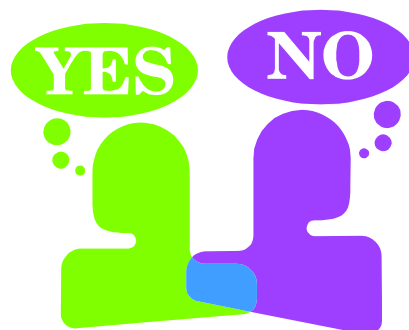
Diagnosis is complicated and includes gathering lots of information, including:

1. History of the changes
2. Health history
3. Medication review
4. Physical exam (especially focusing on neurological and cardiovascular systems)
5. Laboratory studies
6. Imaging study of the brain (MRI, CT, PET)
7. Cognitive assessment (what's working well and what's not working well)
8. Emotional assessment
9. Other tests (ECG, EEG etc. as indicated)



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What's Happening to Them?



Understanding Symptoms

What Happens Next and What Remains?

Melanie Bunn, RN, MSN, GNP
Teepa Snow, MS, OTR/L, FAOTA

- ◆ Dementia Care & Training Specialists
- ◆ Consulting Associates, Duke University School of Nursing

Dementia Alliance of North Carolina

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What is Normal and What is Not?

Normal Aging Changes:

- Slower to think
- Slower to do
- Hesitates more
- More likely to 'look before you leap'
- Know the person but not the name
- Pause to find words
- Reminded of the past
- For you, it's harder than before...
- Prompts help! (reminders)
- You can learn NEW Things – It takes longer!

Not Normal Aging Changes:

- Can't think the same
- Can't do like before
- Can't get started
- Can't seem to move on
- Doesn't think it out at all
- Can't place the person
- Words won't come – even later
- Confused about past versus now
- For you it's TOTALLY DIFFERENT
- Reminders DON'T Help!
- You can't hold onto NEW stuff

Ten Warning Signs:

- 1 – memory loss for recent or new information – repeats self frequently
- 2 – difficulty doing familiar, but difficult tasks – managing money, medications, driving
- 3 – problems with word finding, mis-naming, or mis-understanding
- 4 – getting confused about time or place - getting lost while driving, missing several appointments
- 5 – worsening judgment – not thinking thing through like before
- 6 – difficulty problem solving or reasoning
- 7 – misplacing things – putting them in 'odd places'
- 8 – changes in mood or behavior
- 9 – changes in typical personality
- 10 – loss of initiation – withdraws from normal patterns of activities and interests

What Could It Be... It Might NOT be Dementia

- Worsening of another medical condition
- Medication side-effect
- Undetected hearing loss or vision loss
- Depression
- Acute illness
- Untreated emotional or physical pain
- Other things...

SO... Get it CHECKED OUT ... Carefully & Thoroughly

What is Dementia?

- ◆ It is NOT part of normal aging! It is a disease!
- ◆ It is more than just forgetfulness - which is part of normal aging
- ◆ It makes independent life impossible



Dementia

- ◆ is an umbrella term that includes many cognitive loss conditions
- ◆ includes some reversible conditions - so should be checked out carefully

Alzheimer's Disease -

- ◆ is the most common type of dementia
- ◆ is caused by damage to nerves in the brain and their eventual death
- ◆ has an expected progression with individual variations - about 8-12 years
- ◆ will get worse over time - we can't stop it!
- ◆ is a terminal disease - there is NO known cure at this time!

Vascular Dementia (Multi-Infarct) -

- ◆ is caused by damage to the *blood supply* to the nerves in the brain
- ◆ is spotty and *not* predictable
- ◆ may *not* change in severity for long periods, then there are sudden changes

Lewy Body Dementia -

- ◆ problems with movement – falls & stiffness
- ◆ visual hallucinations & nightmares
- ◆ fluctuations in performance – day/day

Frontal-Temporal Dementias -

- ◆ Problem behaviors – poor impulse control
- ◆ Difficulty with word finding
- ◆ Rapid changes in feelings and behaviors

Symptoms Common to Most Dementias... Over time...

- ◆ It affects a person's entire life...It causes the brain to shrink & stop working
- ◆ It steals memories - the most recent first, but eventually almost all...
- ◆ It steals your ability to use language ... leaves you with some 'skills'
- ◆ It steals your ability to understand what others mean & say
- ◆ It steals reasoning and logic
- ◆ It robs you of relationships
- ◆ It makes even the 'familiar' seem odd and scary
- ◆ It steals your ability to care for yourself and move around safely
- ◆ It robs you of impulse control - takes away emotional and mood control

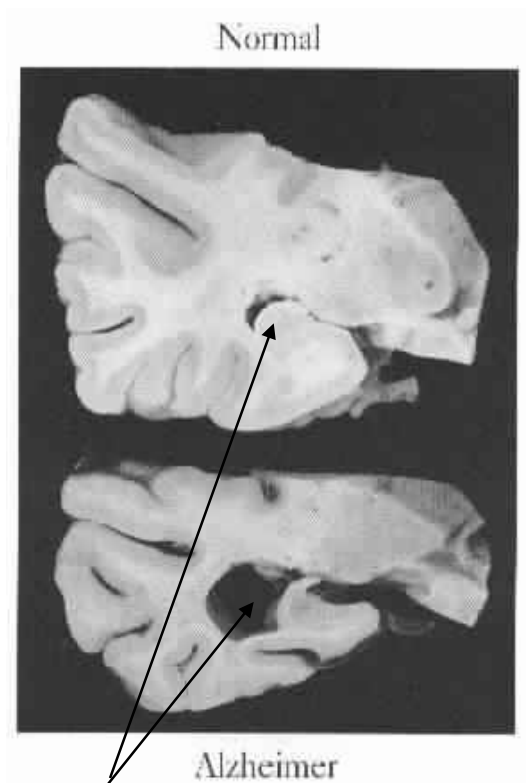
Drug Treatment for Alzheimer's

- ◆ Drugs to improve chemicals in the brain so nerve activity might happen
- ◆ Drugs to treat depression
- ◆ Drugs to control distressing hallucinations, severe paranoia, or unprovoked violence
- ◆ No vaccines or cures...yet
- ◆ No way to stop the disease...yet

Have a good family history for staying alert and 'with it' – genetics do play a part

- ◆ Eat healthy & moderately (Heart-Smart)
- ◆ Exercise your body --- 100 minutes/wk ***
- ◆ Exercise your brain --- challenge yourself
- ◆ Eat fish --- 1 time a week
- ◆ Control your BP & sugar & weight
- ◆ ** consult your MD first

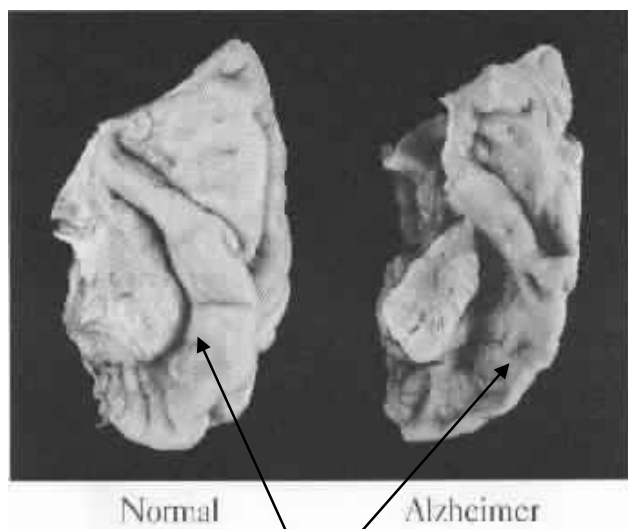
Prevention –



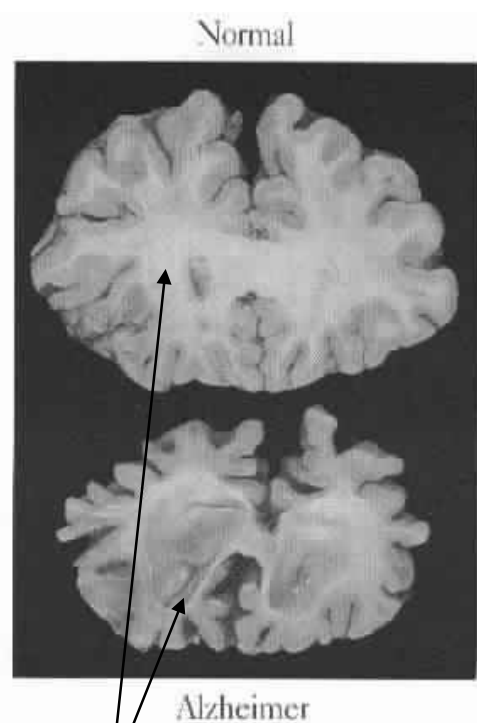
The ability to remember information...



The ability to use words and language...



The ability to understand what is being said...



The ability to control your impulses, temper, & moods...

Reprinted with permission from: *A Broken Brain*. Dementia Education & Training Program, University of Alabama, 1995.

Melanie Bunn RN, MS, GNP, Dementia Alliance of North Carolina and Teepa Snow MS, OTR/L, FAOTA, Positive Approach, LLC

REALIZE ...

It Takes TWO to Tango ... or tangle...

- By managing your own behavior, actions, words & reactions you can change the outcome of an interaction.
- Being 'right' doesn't necessarily translate into a good outcome for both of you
- Deciding to change your approach and behavior WILL REQUIRE you to stay alert and make choices... it is WORK
- It's the relationship that is MOST critical NOT the outcome of one encounter

As part of the disease people with dementia 'tend to' develop typical patterns of speech, behavior, and routines. These people will also have skills and abilities that are lost while others are retained or preserved.

Typically Lost – can't use

Memory skills

- immediate recall
- short term memory
- clarity of time and place
- depth of categorical information
- relationships & specifics

Understanding skills

- interpretation of abstract meaning
- early - misses ¼ words
- later – misses ½ words
- subtle emotions, 'unspoken' agreements
- at the end – most words

Language use skills

- specific word finding
- descriptive abilities
- reading for content
- content of speech
- spoken communication
- words
- meaningful 'yes' and 'no'
- socially acceptable expressions of emotion
- verbal communication of needs and desires

Emotional & Impulse control skills

- ability to 'demand' respect
- ability to limit or control emotions
- ability to control impulsive speech
- ability to control impulsive actions
- don't act out when 'pushed'
- ability to keep private thoughts and actions in private places

Preserved – can or may use

Memory skills

- long ago memories
- emotional memories
- confabulation
- procedural memories
- awareness of familiar versus unfamiliar

Understanding skills

- 'gets' the concrete meaning
- picks out familiar or meaningful words
- covers well
- facial expressions that are consistent with the message being sent

Language use skills

- desire to communicate
- ability to use hands or actions to describe
- reading aloud
- rhythm of speech
- para-verbal communication (how you say it)
- music and song
- automatic speech
- swearing, sex words, 'socially unacceptable' words
- non-verbal communication of needs and desires

Emotional & Impulse control skills

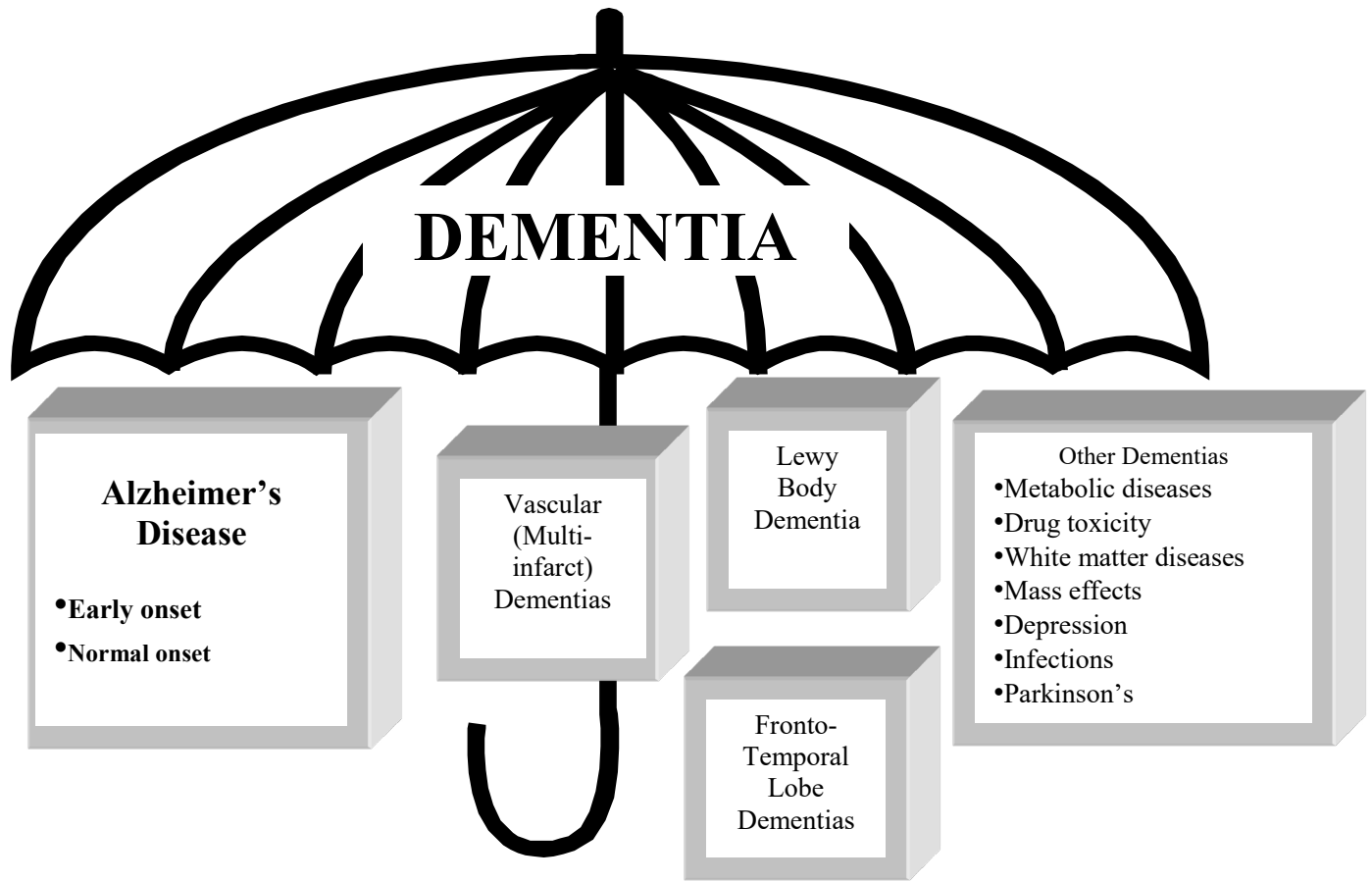
- desire to be respected
- ability to feel emotions and have needs
- say what is on your mind – with errors
- do what you want to do
- sometimes, feel badly after its done
- sometimes, behaving differently in 'public' if cues are strong

Motor Skills & Sensory Processing

- at first very little as far as skills go
- later – initiation or getting started
- later – parts of tasks get left out/skipped
- mis-interprets sensory information
- organized scanning is lost
- visual field is restricted
- may become hypersensitive OR hyposensitive to touch, sound, light...

Motor Skills & Sensory Processing

- the movement patterns for pieces of tasks
- gross motor movements last longer than fine motor
- can often do the mechanics – BUT not safely or well
- looks for stuff – seeks out things
- mouth (lips, tongue), fingers and palms, soles of feet, & genitalia or 'private body parts'
- recognize faces, voices – familiar from not familiar



- Alzheimer's**
- New info lost
 - Recent memory worse
 - Problems finding words
 - Mis-speaks
 - More impulsive or indecisive
 - Gets lost
 - Notice changes over 6 months – 1 year

- Vascular**
- Sudden changes
 - Picture varies by person
 - Can have bounce back & bad days
 - Judgment and behavior 'not the same'
 - Spotty losses
 - Emotional & energy shifts

- Lewy Body**
- Movement problems - Falls
 - Visual Hallucinations
 - Fine motor problems – hands & swallowing
 - Episodes of rigidity & syncope
 - Nightmares
 - Fluctuations in abilities
 - Drug responses can be extreme & strange

- Frontal-Temporal**
- Many types
 - Frontal – impulse and behavior control loss
 - Says unexpected, rude, mean, odd things to others
 - Dis-inhibited – food, drink, sex, emotions, actions
 - Temporal – language loss
 - Can't speak or get words out
 - Can't understand what is said, sound fluent – nonsense words

Progression of the Disease – Levels of Cognitive Loss

Level 5 (Diamond) – *Early Loss – Running on Routine – Repeating Stories*

- Some word problems and loss of reasoning skill
- Easily frustrated by changes in plans or routines
- Seeks reassurance but resents take over
- Still does well with personal care and activities
- Tends to under or over-estimate skills

Level 4 (Emerald) – *Moderate Loss - Just Get It Done! – Wanting a Purpose and a Mission*

- Gets tasks done, but quality is poor
- Leaves out steps or makes errors and WON'T go back and fix it
- Can help with lots of things – needs some guidance as they go
- Likes models and samples – uses others' actions to figure out what to do
- Asks "what /where/when" LOTS
- Can do personal care tasks with supervision & prompts
- Still very social BUT content is limited and confusing at times

Level 3 (Amber) – *Middle Loss - See It/Touch It/Take It/Taste It – Hunting & Gathering*

- Handles almost anything that is visible
- Does not recognize other's ownership
- Can still walk around and go places
- Language is poor and comprehension very limited - does take turns
- Responds to tone of voice, body language and facial expression
- Loses the ability to use tools and utensils during this level
- Does things because they feel good, look good, taste good – refuses if they don't
- Stops doing when it isn't interesting anymore
- Can often imitate you some – But not always aware of you as a person

Level 2 (Ruby) – *Severe Loss – Gross Automatic Action – Constant GO or Down & Out*

- Paces, walks, rocks, swings, hums, claps, pats, rubs....
- Frequently ignores people and small objects
- Doesn't stay down long in any one place
- Often not interested in/aware of food – significant weight loss expected at this level
- Can grossly imitate big movements and actions
- Generally enjoys rhythm and motion – music and dance

Level 1 (Pearl) – *Profound Loss - Stuck in Glue – Immobile & Reflexive*

- Generally bed or chair bound – can't move much on own
- Often contracted with 'high tone' muscles - primitive reflexes reappear
- Poor swallowing and eating
- Still aware of movement and touch
- Often sensitive to voice and noise - startles easily to sounds, touch, movement...
- Difficulty with temperature regulation
- Limited responsiveness at times
- Moves face and lips a lot, may babble or repeatedly moan or yell
- Give care in slow, rhythmic movements and use the flats of fingers and open palms
- Keep your voice deep, slow, rhythmic and easy as you talk and give care

DIAMOND - Level 5 - Minimal Loss – 'Needs Routines'

Resident Behaviors:

Approach - Social Behaviors

- Can initiate social greetings and interactions
- Responds to social greetings
- Will look to see who is at door and respond to a 'knock'
- Carries on conversations - takes turns, asks questions, answers questions (*may be wrong*)
- Seeks out familiar when stressed, unfamiliar when bored
- Uses verbal cues and visual information (*may misinterpret*)
- Can choose and select from among options
- Speed may be slowed

Task Behaviors

- Often lacks initiation for task start-up
- Uses routines and habits to get through the day
- Can physically perform routine self-care and 'work-related' tasks
- Speed may be slowed
- Prefers to have options and to be in-charge of activities
- Follows daily routines and schedules with minimal prompts or reminders
- Blames self or others for errors
- Stops doing tasks that are too challenging or asks someone else to do them

Caregiver Behaviors:

Approach Behaviors

- Use preferred name
- Ask permission to enter space - acknowledge response
- Engage in conversation
- Offer information about the day, activities, self
- Provide options for time use

Task Behaviors

- Prompt and support start of tasks
- Offer options for tasks
- Follow routines
- Hi-light changes in routines
- Use social interaction to engage the person in tasks
- Engage in social exchange during tasks

Environmental Considerations:

Approach Environments

- Treat the 'room' as personal space
- Make sure personal space is respected
- Ask permission - Turn on the lights
- Ask permission - Turn off the TV/Radio if interacting
- Get to resident's eye level - sit down to interact or walk along side

Task Environments

- label locations and storage spaces clearly
- keep things in familiar spaces
- honor location preferences
- use hi-lighted colors or contrasts to emphasize areas
- provide task lighting to focus attention to next task
- limit distractions BUT honor visual and auditory preferences (TVs, radios....)
- make sure all necessary items are present for tasks

EMERALD - Level 4 - Task Oriented - 'Getting Things Done'

Resident Behaviors:

Approach - Social Behaviors

- Can initiate social greetings and interactions - often with a request for information or help
- Responds to social greetings - handshakes & eye contact
- Has very short conversational interchanges - can't come up with much content
- Picks up on selected words or ideas and goes off-target in conversations
- Can make simple choices with two options - may need items presented physically or gestured to
- May carry on conversation with another resident with some assist from staff or the environment

Task Behaviors

- Often starts or repeats tasks if given a visual cue (objects, pictures, people, furniture) to do so
- Uses visual information - objects & pictures, gestures, environmental aids
- Uses verbal cues that are short, concrete, or step-by-step
- Has difficulty interpreting written information - looks at it, but loses its meaning
- Forgets and leaves out steps in familiar tasks
- Repeats familiar activities several times a day - not remembering they have been done already - especially if the visual cues or environmental cues are still there
- Will not do tasks, even if they are very familiar **if** the cues are missing (eating, shaving, washing)
- Has a poor quality of performance, since it is more important to do it
- Asks repeatedly what they are supposed to do, where to be

Caregiver Behaviors:

Approach Behaviors

- Use preferred name
- Offer your hand - may maintain hand contact to help stay connected
- Keep information short and concrete
- Answer questions with a concrete suggestion and gesture or object presentation
- Offer concrete choices with objects or gestures for 'what to do'
- Use aids during conversation - pictures, objects, environmental information

Task Behaviors

- Pre-set up objects and space for tasks
- Set out items in sequence for task completion, put them away as the step is finished
- Monitor and guide verbally and visually through each step
- Assist with touch or guidance only for the step causing difficulty, then verbal or visual cues
- Stay down and to the side for activities
- Expect slowing and difficulty with step to step transitions
- Provide stability and support, don't push or pull to get action... GUIDE only
- Eliminate extraneous chatter or social conversation during task completion

Environmental Considerations:

Approach Environments

- Treat the 'seating surface' as personal space
- Make sure personal space is respected
- Tell & then turn on the lights
- Tell & then turn off the TV/Radio if interacting
- Get to resident's eye level - sit down to interact or walk along side

Task Environments

- Keep surfaces clear and present only what is to be used - pre-set areas with task cues and objects
- Use 'locked' areas to store items that should be used with staff help
- Have objects and areas visible throughout the day to encourage activities
- provide task lighting to focus attention to the task
- eliminate or limit non-task distractions, visual and verbal

AMBER - Level 3 – Using Hands to Handle - 'Touch, Feel, and Taste'

Resident Behaviors:

Approach - Social Behaviors

- Misses some approach information
- May look at your hand or what you are holding, rather than you as a person
- Initiates contact with touching, single word, or eye contact
- Often responds with facial expression imitation
- Leaves interactions without closure
- Has minimal ability to take turns or converse
- Seeks out pleasurable stimulation from objects, people, and the environment
- Avoids, escapes, or resists unpleasant stimulation

Task Behaviors

- Focuses on objects, visible cues, textures, & colors
- Touches and holds onto items and props
- Skill at tool use will vary greatly, but there is an interest in them
- Attention may be very intense on one item/action OR may be very scattered moving from one item to another randomly
- May put non-food objects in the mouth to eat or explore them
- May engage in familiar actions/activities repeatedly regardless of need or results
- May continue an activity once assisted to initiate and stimulation old habits
- May actively resist movement to the next step of a task, helped with clear and strong cues
- May exhibit negative affect and attempts to leave tasks if they are 'unpleasant'
- Can attend only to one thing at a time, is distracted by activity, movement, talking, visual info

Caregiver Behaviors:

Approach Behaviors

- Use preferred name
- Offer your hand – use preferred client hand and use thumb control position from outset
- Use hand-under-hand palm to palm contact to provide clear connection & encourage attention
- Use familiar greeting and smile to start interactions
- Maintain hand contact for next interaction

Task Behaviors

- Place visual cues in work space as they are to be used in the activity
- Guide using hand-under-hand technique or demonstration to help initiate the tasks
- Break all tasks down into short, simple action steps
- Use hand under hand technique for table top and personal care tasks to get started & change steps
- Give simple 2-3 word directions, using inflection and gestures while helping with the movement
- Limit talking during a task, as it may halt action
- Expect to help to start and transition between steps
- Don't try to go back and 'fix' missed steps – wait to the next rendition

Environmental Considerations:

Approach Environments

- Treat the immediate area and surfaces around the person as personal space
- Put chairs at right angles to each other for communicating and working
- Provide light for area that highlights the work space
- Limit visual information not related to tasks, offer visual cues to help initiate actions

Task Environments

- Keep work surfaces clear and have tools or props available only as they are to be used
- Use firm, supportive sitting surfaces (upright chairs with foot resting support and armrests)
- Use task lighting to help focus attention on the task area
- Eliminate extra noise, movement, and activities during a task

RUBY - Level 2 – Gross Movement – ‘Stop and Go Slow’

Resident Behaviors:

Approach - Social Behaviors

- May disregard you as a person
- Will look and investigate parts of you (hand, arm, hair, shirt)
- May not extend hand or respond to approach
- Typically will respond with look, glance, word, or attention to preferred name and touch
- Grasp is reflexive and release is inconsistent
- Tends to ignore others
- Speed will be slowed

Task Behaviors

- If moving, tends to keep moving
- If still, tends to stay still
- Minimal ability to use hands and tools
- Able to mimic only grossly for movement and action
- Speed will be slowed
- May halt and not be able to move to the next step of a task without physical assist
- May refuse or become distressed about tasks that don't feel good
- May have rocking, humming, or clapping during a task

Caregiver Behaviors:

Approach Behaviors

- Use preferred name
- Offer your hand on the person's lap - slide it into the person's palm if there is no response
- Use hand-under-hand palm to palm contact to reduce risk of grasping that can be painful
- Determine hand choice to offer or use prior to acting
- Use single word greeting and smile
- Maintain hand contact for next interaction

Task Behaviors

- Eliminate all but basic, required materials, props for the activity
- Allow gross movement while doing tasks or offering hand-under-hand technique
- Use hand under hand technique for table top and personal care tasks
- Demonstrate the motor task you want the person to do
- Give single word directions, using inflection and gestures while helping with the movement
- Limit talking during a task, as it may halt action
- Use imitation of gross action to help get action started
- Expect to do a majority of all tasks

Environmental Considerations:

Approach Environments

- Treat the 'person' as personal space
- Put chairs at right angles to each other for communicating
- Provide light for area
- Provide auditory and tactile information simultaneously

Task Environments

- Keep work surfaces clear and have tools or props available only for your use
- Use firm, supportive sitting surfaces (upright chairs with foot resting support and armrests)
- Use task lighting
- Eliminate extra noise, movement, and activities during a task
- Keep space warm
- Have all items at hand for your use

PEARL - Level 1 – Reflexive – ‘Minimal Contact with the Outside World’

Resident Behaviors:

Approach - Social Behaviors

- May attend to, respond to, OR *startle* to voice, touch, temperature, sounds
- Eye contact is poor and may be absent
- Ability to reach out is minimal
- Grasp and flexion patterns are strong and reflexive to movement and touch
- Release is not voluntary
- Moaning or sound production is common with contact

Task Behaviors

- Moves into flexion patterns with activities and stretching
- Has a strong grasp reflex if palm is touched or stimulated
- Can't actively 'let go' of objects without help most of the time
- Has poor protective reactions to oral intake, oral care, movement, positioning
- No awareness of 'risky' responses to care
- Reflexive speech and swearing may be elicited with *startle*, movement, or action
- Quick movements or actions will produce fearful, angry, or anxious motor behaviors

Caregiver Behaviors:

Approach Behaviors

- Move slowly and keep voice calm and soothing and slow
- Make sure hands are all 'warm' prior to contact
- Use flats of fingers and palms of hands when giving care
- Use hand-under-hand palm to palm contact to manage grasping that will occur
- Maintain a point of contact for the entire interaction
- Say 'Hi, (name), this is (your name), I am going to help you...'

Task Behaviors

- Move slowly and talk slowly focusing on comfort and soothing content and tone
- Keep one hand on the person at all times
- Tell the person in simple terms what you are doing, step-by-step as you are doing it
- Give person time to relax between tasks
- Make sure materials and supplies are warm and pleasant to touch
- Hold the person's hand in thumb control position at all times when trying to move arms or place a hand roll or object in the hands to control grasp reflex
- Use 'safest' positioning and techniques for task performance when reflexes are impaired
- Expect to do a majority of all tasks
- Consider humming or singing, *if* this is soothing to the person

Environmental Considerations:

Approach Environments

- Treat the 'person' as personal space
- Turn off other stimulation when giving care
- Provide light for area – ensure light is NOT in the person's eyes
- Provide auditory and tactile information simultaneously
- Close off interaction prior to leaving

Task Environments

- Be aware of and control all sensory components in activities – smell, touch, taste, sound, and sight
- Use comfortable but supportive sitting (special upright seating for oral care and intake)
- Use task lighting that is focused on the task not the person
- Eliminate loud noise, fast movements, or bright lights during a task
- Keep space warm and control air flow into the space (close doors)
- Arrange props and supplies within arm reach prior to starting task



Learning the Basics on How to Connect

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A Positive Physical Approach for Someone with Dementia

1. **Knock** on door or table - to get attention - signal your approach
2. **Stop moving** at the boundary between public & personal space – **6 ft out** - get permission to enter or approach
3. **Open hand motion near face and smile** – look friendly and give the person a visual cue – make eye contact – open hand near face – cues eyes to look there
4. Call the person by preferred **name** OR at least say **“Hi!”** – avoid endearments
5. Move your hand out from near your face to a greeting **handshake** position – make sure they notice you hand out to shake – then stand tall and move forward **SLOWLY**
6. Approach the person from the **front** – come in within 45 degrees of center - visual
7. **Move slowly** – one step/second, stand tall, don't crouch down or lean in as you move toward the person
8. Move toward the right **side of the person** and offer your hand - give the person time to look at your hand and reach for it, if s/he is doing something else – offer, don't force
9. Stand to the side of the person at arm's length – respect intimate space & be supportive not confrontational – but don't go too far back' – stay to the front - visual
10. **Shake hands** with the person – make eye contact while shaking
11. Slide your hand from a 'shake' position to **hand-under-hand** position – for safety, connection, and function
12. Give your name & greet – “I'm (name). It's good to see you!”
13. **Get to the person's level** to talk – sit, squat, or kneel if the person is seated and stand beside the person if s/he is standing
14. NOW, deliver your message...

Approaching When the Person is DISTRESSED! -Some CHANGES –

1. *Look concerned* not too happy, if the person is upset
2. *Let the person move toward you*, keeping *your body turned to the side* (supportive – not confrontational) –
3. *If the person is seated* & you **DON'T** get permission to enter personal space – turn sideways & kneel at 6' out – offer greeting & handshake again – look for an OK to come into their personal space – it will usually come at this time (submissive posture)
4. After greeting... try one of *two options*...
 - a. “Sounds like you are (give an emotion or feeling that seems to be true)???”
 - b. Repeat the person's words to you... If s/he said, “Where's my mom?” you would say “You're looking for your mom (pause)... tell me about your mom...” If the person said “I want to go home!”, you would say “You want to go home (pause)... Tell me about your home...”.

BASIC CARD CUES – WITH Dementia

- Knock – Announce self
- Greet & Smile
- Move Slowly – Hand offered in 'handshake' position
- Move from the front to the side
- Greet with a handshake & your name
- Slide into hand-under-hand hold
- Get to the person's level
- Be friendly -make a 'nice' comment or smile
 - Give your message... simple, short, friendly



Communicating - Talking

First -

ALWAYS use the **positive physical approach!**

Then -

- Pay attention to the **THREE** ways you communicate

1 - How you speak

- **Tone** of voice (**friendly** not bossy or critical)
- **Pitch** of voice (**deep** is better)
- **Speed** of speech (**slow and easy** not pressured or fast)

2 - What you say

THREE basic reasons to talk to someone

1 - To get the person to **DO something (5 approaches to try)**

- 1 - give a short, direct message about what is happening
 - 2 - give simple choices about what the person can do
 - 3 - ask the person to help you do something
 - 4 - ask if the person will give it a try
 - 5 - break down the task - give it one step at a time
- ** only ask "Are you ready to..." If you are willing to come back later **

2 - Just to have a **friendly interaction** - to talk to the person

- ♦ go slow - Go with Flow
 - ♦ acknowledge emotions - "sounds like..., seems like..., I can see you are..."
 - ♦ use familiar words or phrases (what the person uses)
 - ♦ know who the person has been as a person what s/he values
 - ♦ use familiar objects, pictures, actions to help & direct
 - ♦ be prepared to have the same conversation over & over
 - ♦ look interested & friendly
 - ♦ be prepared for some emotional outbursts
 - ♦ DON'T argue... - BUT don't let the person get into dangerous situations
- REMEMBER - the person is doing the BEST that s/he can
AND GO with the FLOW!

3 - Deal with the person's **distress or frustration/anger**

- ♦ Try to figure out what the person really **NEEDS or WANTS**
("It sounds like..." "It looks like..." "It seems like..." "You're feeling...")

- ♦ Use **empathy** not forced reality or lying
- ♦ Once the person is listening and responding to you **THEN** -
 - **Redirect** his attention and actions to something that is OK **OR**
 - **Distract** him with other things or activities you know he likes & values

Always BE CAREFUL about personal space and touch with the person especially when s/he is distressed or being forceful

3 - How you respond to the person

- ♦ use positive, friendly approval or praise (short, specific and sincere)
- ♦ offer your thanks and appreciation for his/her efforts
- ♦ laugh with him/her & appreciate attempts at humor & friendliness
- ♦ shake hands to start and end an interaction
- ♦ use touch - hugging, hand holding, comforting **only IF** the person wants it

If what you are doing is NOT working -

- **STOP!**
 - BACK OFF - give the person some space and time
 - Decide on what to do differently...
 - *Try Again!*

Key Points About 'Who' the person is....

- preferred name
- introvert or extrovert
- a planner or a doer
- a follower or a leader
- a 'detail' or a 'big picture' person
- work history - favorite and most hated jobs or parts of jobs
- family relationships and history - feelings about various family members
- social history - memberships and relationships to friends and groups
- leisure background - favorite activities & beliefs about fun, games, & free time
- previous daily routines and schedules
- personal care habits and preferences
- religious and spiritual needs and beliefs
- values and interests
- favorite topics, foods, places
- favorite music and songs - dislike of music or songs
- hot buttons & stressors
- behavior under stress
- what things help with stress?
- handedness
- level of cognitive impairment
- types of help that are useful

Types of Help - Using Your Senses

Visual -



Written Information - Schedules and Notes

Key Word Signs - locators & identifiers

Objects in View - familiar items to stimulate task performance

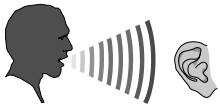
Gestures - pointing and movements

Demonstration - provide someone to imitate

Auditory -

Talking and Telling - give information, ask questions, provide choices

Breaking it Down - Step-by-Step Task Instructions



Using Simple Words and Phrases - Verbal Cues

Name Calling - Auditory Attention

Positive Feedback - praise, "yes", encouragement

Tactile - Touch -

Greeting & Comforting - handshakes, hugs, 'hand-holding'



Touch for Attention during tasks

Tactile Guidance - lead through 'once' to get the feel

Hand-Under-Hand Guidance - palm to palm contact

Hand-Under-Hand Assistance - physical help

Dependent Care - doing for & to the person

Personal History

Areas to Explore	What Did You Find Out?
Preferred Name	
Preferred Hand	
Living Situations & history (where are you from today & originally, who do & did you live with, what type places did you live in (house, apt, farm...))	
Marriage history & status (who's involved, has been involved, and how do you feel about them?)	
Family history & membership (who's who and how do you feel about them? Think about several generations....)	
Work history (what jobs have you had in your life? How did you feel about them? What are some jobs you would have loved to do, but never did?)	
Leisure history (what do and did you do for fun and in your spare time? How do you feel about 'having fun'? What would you like to do if you had the money? time? Skill?)	
Spiritual history (what religion do you and did you follow, how involved are you and were you, and how important is it to you? How do you feel about other religions?)	
Personal care practices & history (eating habits, sleeping habits, grooming habits, bathing habits...)	
Time Use History (schedules & routines.... When do you and would you like to do things?)	
Important Life Events (what are some things that were very important to or happened to you? Do others know about these events?)	
Hot Buttons (what are things/activities /topics/ actions that really tend to upset you?)	
Chill Pills (what are things/activities/topics/ actions/people that really help you calm down?)	

Having a Conversation

To Start Talking.....

First _

- **Recognize** the person and their situation or feelings (don't lie and don't be cruel...)
- **Use EMPATHY** – “it looks like...”, “it sounds like....”, “it seems like...”

Then _

- If in *early stages* of the disease, gently offer orienting information
- If in the *middle or later stages* of the disease, figure out the meaning of the behavior or words and use...
- ◆ ***Redirection*** – same type of activity in a more acceptable manner, or with ‘safer’ materials, or in a safer space (Example: cleaning out cabinets rather than the crash cart)
- ◆ ***Distraction*** – changing to a different but equally valued activity (Example: looking for her cat that no longer exists to helping to put away dishes from the dish drainer and clean up the dining room)

When having a conversation...

- use familiar phrases or words to help the person 'talk'
- use familiar objects or actions to give a focus for the interaction
- be prepared to have the SAME conversation over, and over, and over.....
- use your non-verbal interaction skills to show interest and engagement
- be prepared for unexpected emotional shifts and outbursts
(*remember* - it's part of the disease)
- don't try to correct the person... GO WITH THE FLOW! - use empathy not reality!

Communication - When Words Don't Work Anymore...

Keys to Success:

- Watch movements & actions
- Watch facial expressions and eye movements
- Listen for changes in volume, frequency, and intensity of sounds or words
- Investigate & Check it out
- Meet the need

It's all about Meeting Needs...

- Physical needs
- Emotional needs

Probable Needs:

Physical

- Tired
- In pain or uncomfortable
- Thirsty or Hungry
- Need to pee or have a BM or already did & need help
- Too hot or too cold

Emotional

- Afraid
- Lonely
- Bored
- Angry
- Excited

What Can You Do?

- *Figure it out...Go thru the list*
- *Meet the need... Offer help that matches need*
- *Use visual cues more than verbal cues*
- *Use touch only after 'permission' is given*

Connect – Visually, Verbally, Tactilely

Protect Yourself & the Person – use Hand Under Hand & Supportive Stance techniques

Reflect – copy expression/tone, repeat some key words, move with the person

Engage – LISTEN with your head, your heart, and your body

Respond – try to meet the unmet needs, offer comfort and connection

***** IF IT DOESN'T seem to be working – STOP, BACK OFF – and then TRY AGAIN –
changing something in your efforts (visually, verbally, or through touch/physical
contact)*****

When Helping Physically to Do THINGS...

Remember to do things WITH the person, NOT TO the person!

Always CONNECT first

Visually
Verbally
Physically
Emotional
Spiritually

Take it slow – look for and wait for responses before moving on... Double check CUES!

Take a look around - Check out the environment or setting and set-up –

Is it clear what is supposed to happen?

Is it possible something is triggering the behavior or refusal?

Is it possible to create a stronger sense of privacy and competence?

Does the person feel OK, having you there?

Are you respecting intimate space & personal space?

If what you are trying is NOT working, STOP and BACK OFF!

Think about what might be getting in the way, change something, then try to re-approach

Make Sure – you are:

Limiting verbal information

Sending POSITIVE and FRIENDLY non-verbal cues

Taking your time to CONNECT

Letting the person know what you want – THINK about ONE step at a time

Show them what you want – model it, gesture through it, point to it...

Respecting personal & intimate space

ALWAYS, be willing to give up your agenda if you are having trouble getting the connection – you can always come back and try again, if they like you!

If it seems like they are getting upset with you...

Consider saying, “I’m sorry, I am bothering you, I didn’t mean to...”

Consider asking for a very ‘short’ commitment –

“Help me for 2 minutes & then I will leave”

Consider saying “Do you want to be alone?”

Stop talking or TRYING for a while and see what happens

Vascular Dementia

Vascular dementia results from conditions that damage your brain's blood vessels, reducing their ability to supply your brain with the large amounts of nutrition and oxygen it needs to perform thought processes effectively. Vascular dementia is a general term describing problems with reasoning, planning, judgment, memory and other thought processes caused by brain damage from impaired blood flow to your brain.

You can develop vascular dementia after a stroke blocks an artery in your brain, but strokes don't always cause vascular dementia. Whether a stroke affects your thinking and reasoning depends on your stroke's severity and location. Vascular dementia also can result from other conditions that damage blood vessels and reduce circulation, depriving your brain of vital oxygen and nutrients.

Common conditions that may lead to vascular dementia include: stroke (infarction) blocking a brain artery, narrowed or chronically blocking damaged brain blood vessels, increasing age, history of heart attack, strokes or mini strokes, atherosclerosis, high cholesterol, high blood pressure, diabetes, smoking, atrial fibrillation.

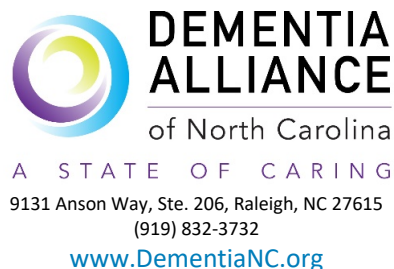
Vascular dementia varies depending on the part of your brain where blood flow is impaired. Symptoms often overlap with those of other types of dementia, especially Alzheimer's disease. Vascular dementia symptoms may be most clear-cut when they occur suddenly following a stroke. When changes in your thinking and reasoning seem clearly linked to a stroke, this condition is sometimes called "post-stroke dementia."

Another characteristic pattern of vascular dementia symptoms sometimes follows a series of strokes or mini strokes. In this pattern, changes in your thought processes occur in noticeable "steps" downward from your previous level of function, unlike the gradual, steady decline that typically occurs in Alzheimer's disease.

Vascular dementia can also develop very gradually, just like Alzheimer's disease. What's more, vascular dementia and Alzheimer's often occur together. Studies show that people with dementia symptoms usually have brain changes typical of more than one type. Some doctors call this condition "mixed dementia."

Vascular dementia symptoms may include: confusion, trouble paying attention and concentrating, reduced ability to organize thoughts or actions, decline in ability to analyze a situation, develop an effective plan and communicate plan to others, difficulty deciding what to do next, problems with memory, restlessness and agitation, unsteady gait, depression.

Source: www.mayoclinic.com



Frontotemporal Degeneration (FTD)

Frontotemporal degeneration (FTD), also commonly referred to as frontotemporal dementia, fronto-temporal lobar degeneration (FTLD), or Picks disease, is a disease process that causes changes in behavior and personality, language and/or motor skills, and a deterioration in a person's ability to function. FTD represents an estimated 10%-20% of all dementia cases. Currently, there are no treatments to slow or stop the progression of FTD. The course of the disease ranges from 2 to over 20 years, with a mean course of 8 years from the onset of symptoms. Accurate diagnosis is crucial, as some medications used to treat other disorders may be harmful in a person with FTD.

FTD is distinct from other forms of dementia in two important ways:

- Onset of FTD often occurs in a person's 50s and 60s; the average age of diagnosis is about 60, which is a full 10 years before the average Alzheimer patient is diagnosed. Thus, FTD can affect work and family in a way dementia in older patients does not.
- The hallmark of FTD is a gradual, progressive decline in behavior and/or language (with memory usually relatively preserved). As the disease progresses, these deficits cause significant impairment in social and/or occupational functioning and result in an increasing dependency on caregivers.

Frontotemporal degeneration is characterized by progressive atrophy of several different areas of the brain, particularly the frontal and/or temporal lobes, the parts of the brain that control "executive functions" such as decision-making, personality, social behavior and language. Because of the nature of these symptoms (and the fact that a patient is often "too young" for dementia to be considered), FTD is often initially misdiagnosed as a psychiatric problem or movement disorder, such as Parkinson's disease. Alzheimer's disease is another possible misdiagnosis.

The FTD disorders consist of:

- Behavioral variant FTD (bvFTD),
- Primary progressive aphasia (PPA), non-fluent & agrammatic
- Semantic PPA; semantic dementia
- Logopenic variant PPA
- Progressive supranuclear palsy (PSP)
- Corticobasal degeneration (CBD)
- FTD with motor neuron disease
- Pick's disease

Source: www.theaftd.org



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Lewy Body Dementias

Lewy Body Dementias are the second most common form of dementia after Alzheimer's disease. They are often misdiagnosed, most commonly as Alzheimer's if the person presents with memory problems or Parkinson's if the present with movement problems.

Some people start out with movement problems (Parkinson's) and later develop dementia (Parkinson's dementia). Others start out with memory problems (Alzheimer's) and over time develop features leading to the Lewy Body diagnosis. A small amount of people start with neuropsychiatric issues (hallucinations, behavioral problems, difficulty with complex mental tasks) leading to an original diagnosis of Lewy Body dementia.

Common symptoms include:

- Dementia
- Hallucinations (usually but not always visual)
- Delusions
- Cognitive Fluctuations – unpredictable changes in concentration and attention – may cause daytime drowsiness, periods of staring into space, lethargy, or disorganized speech. Can have acute episodes of confusion lasting hours or days.
- Parkinson-like symptoms – rigidity or stiffness, shuffling gait, slowness of movement, tremor
- REM sleep behavior disorder: seem to act out dreams.
- Repeated falls and syncope
- Transient, unexplained loss of consciousness
- Visuospatial difficulties – depth perception, object orientation, directional sense
- Autonomic dysfunction – blood pressure fluctuations, heart rate variability, constipation, urinary problems, excessive sweating, decreased sweating/heat tolerance, dry eyes/mouth, swallowing problems

NOTE: Severe sensitivity to typical antipsychotic medications, sometimes prescribed for behaviors associated with dementia. They can cause increased problems with movement, confusion, and a syndrome causing fever, muscle rigidity and kidney failure.

Sources: www.mayoclinic.com/health/lewy-body-dementia & www.lbda.org



ADDITIONAL DEMENTIA RESOURCES:



www.lbda.org

LBD Caregiver Link: 800.539.9767

The Lewy Body Dementia Association (LBDA) is a 501(c)(3) nonprofit organization dedicated to raising awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and caregivers and promoting scientific advances. The Association's purposes are charitable, educational, and scientific.

Our Vision: A cure for Lewy body dementias and quality support for those still living with the disease.

Our Mission: Through outreach, education and research, we support those affected by Lewy body dementias.

History: LBDA was formed by a group of caregivers who met in an online LBD caregiver support group. Discussions about the need of support for LBD caregivers and the lack of public awareness about LBD led to the organization's incorporation. The directors of the LBDA Board are located throughout the United States, and LBDA volunteers are from the United States, Canada, and the United Kingdom. The association consists of a dedicated group of people from all walks of life who understand the struggles of other caregivers due to their personal LBD experiences.



www.theaftd.org

866-507-7222 (toll free/ Helpline)

We envision a world where FTD (frontotemporal degeneration) is understood, effectively diagnosed, treated, cured and ultimately prevented.

Our mission is to:

- Promote and fund research into finding the cause, therapies and cures for FTD (frontotemporal degeneration)
- Provide information, education and support to persons diagnosed with an FTD disorder, and for their families and caregivers
- Educate physicians and allied health professionals about frontotemporal degeneration and how to improve patient care
- Bring about greater public awareness of the nature and prevalence of frontotemporal degeneration and the needs of those who are coping with it
- Advocate with public officials and promote public and private programs that provide appropriate, affordable and high-quality, long-term health care and social services
- Facilitate the international exchange of ideas.

provided by



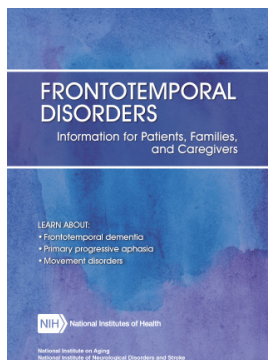
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ADDITIONAL DEMENTIA RESOURCES:

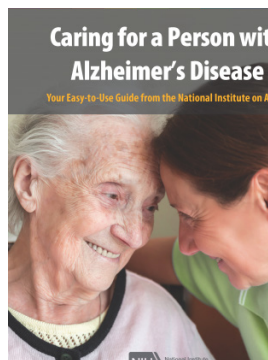
A wide variety of booklets, fact sheets and videos are available from National Institute of Health at:
<https://www.nia.nih.gov/health/alzheimers>

Below are a few booklets that are great to have on hand:



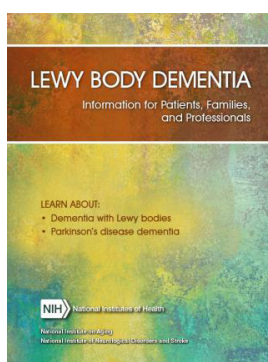
Frontotemporal Disorders: Information for Patients, Families & Caregivers

<https://order.nia.nih.gov/publication/frontotemporal-disorders-information-for-patients>



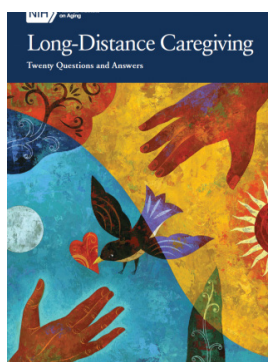
Caring for a Person with Alzheimer's Disease

<https://order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide>



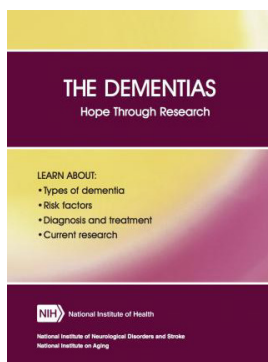
Lewy Body Dementia: Information for Patients, Families, and Professionals

<https://order.nia.nih.gov/publication/lewy-body-dementia-information-for-patients-families-and-professionals>



"So Far Away, Twenty Questions & Answers About Long-Distance Caregiving"

<https://order.nia.nih.gov/publication/long-distance-caregiving-twenty-questions-and-answers>



The Dementias: Hope Through Research

<https://order.nia.nih.gov/publication/the-dementias-hope-through-research>

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APPENDIX D:
*Information Pertaining to the Individual
With Alzheimer's or Related Dementia*



***I have I have a memory
impairment. Please be
aware of this during
our interaction.
Thank you!***

Phone: (919) 832-3732
www.dementianc.org



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www.dementianc.org

The Bill of Rights
By Individuals of Memory Loss
“Forget-Me-Nots” Support Group 2011

All individuals experiencing memory loss deserve the following rights:

- To be informed of one’s diagnosis and to be involved in one’s medical plan
- To be productive in work and play as long as possible
- To be treated like an adult and not like a child
- To be able to share and express feelings that are then taken seriously
- To make decisions for him/herself as long as he/she can
- To be a vital part of society just as we always have been
- To have our voice heard
- To be treated with respect and dignity as anyone else
- To have my strengths continue to be recognized



AN ALZHEIMER'S BILL OF RIGHTS

*Every person diagnosed with Alzheimer's disease or
a related disorder deserves the following rights:*

- ❖ To be informed of one's diagnosis
- ❖ To have appropriate, ongoing medical care
- ❖ To be productive in work and play for as long as possible
- ❖ To be treated like an adult, not like a child
- ❖ To have feeling expressed taken seriously
- ❖ To be free from psychotropic medications, if possible
- ❖ To live in a safe, structured and predictable environment
- ❖ To enjoy meaningful activities that fill each day
- ❖ To be outdoors on a regular basis
- ❖ To have physical contact, including caressing and hand-holding
- ❖ To be with individuals who know one's life story, including cultural and religious traditions
- ❖ To be cared for by individuals who are well-trained in dementia care

The Best Friends Approach to Alzheimer's Care by Virginia Bell and David Troxel, p. 38.



**DEMENTIA
ALLIANCE**
of North Carolina

A STATE OF CARING

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ACTIVITY BOXES

General Information: Activity Boxes can be used by visitors, volunteers and staff. They should contain all materials needed, be readily available, and include instructions. They should be stored away when not in use.

Examples of Instructions:

1. Gather your box and make sure everything is ready... THEN
2. Use a positive approach to engage the person

For people who are interacting with you:

- ask for their help or to try
- ask them to do the first step
- show them what to do
- gesture to the objects/task
- work alongside them

For people who are looking at your hand or other object: (non responsive)

- call their name again and wait for a response
- offer them an item, if they take it, offer another
- gesture to an object
- touch or tap an object

- show the person what to do, then hand them an object
- offer one object at a time, unless they take over

3. Give positive feedback - positive regard - thanks!

4. If the person is actively engaged with the box activity - AND is interacting with you:

- stay with them and engage them until they are done
- OR excuse yourself and find out if they need you there to continue - if so come back

AND is not interacting with you:

- move away from the person and monitor for completion
- check on progress quietly

5. When finished -

- put the box away for next time

Examples of Boxes



FLOWER ARRANGING

Materials -

- artificial flowers cut into single stems (leaves and flowers) - different colors
- plastic glasses or vases

Possible Activities

1. sort by color into groups
2. make up arrangements
3. put arrangements on tables for decorations
4. put flowers back into the box



PIPE CONSTRUCTION

Materials -

- Lots of 1 1/2" or 2" PVC pipe lengths (available at Home Depot or Lowes)
- Lots of connectors - 2-way, 3-way, 4-way
- pictures of completed patterns (for higher level folks)

Possible Activities

1. put pieces together
2. put pieces together following a pattern
3. take pieces apart
4. use as rhythm sticks while singing
5. sort into different types and sizes



SANDING BLOCKS

Materials -

- Several square 2x4" blocks with one side covered with a sheet of sandpaper that is secured with duct tape
- Pieces of wood that can be sanded
- Shapes that can be sanded

Possible Activities

1. sand pieces of wood
2. roll sanding paper against one another
3. handle the sand paper



APPLYING LOTION

Materials - (check for skin allergies first)

- Different lotions
- Scented lotions
- Unscented lotions

Possible Activities

1. have person apply lotion to self
2. apply lotion for the person on arms and hands
3. give a 'massage' or 'rub'



LAUNDRY KIT

Materials -

- clothes line
- clothes pins (clip and push on)
- washcloths
- pillow cases
- plastic bottle to put water in - used to wet items so that they need to be hung out
- small laundry basket
- clothespin bag

Possible Activities

1. have someone help you set up clothesline outside
2. put clothespins out on the line
3. take clothespins off the line
4. you wet the items - hang out the wash
5. sort clothespins - by color, by type
6. take in dry laundry
7. fold laundry
8. put laundry away in a drawer
9. put pillow cases on pillows
10. take down clothesline
11. hand you the clothespins
12. hand you the items to hang up
13. take items and put them in a basket as you take them off
14. handle the cloths

(continued)



OFFICE WORK

(this can be divided into several smaller kits)

Materials

- papers that have fold lines on them
(you fold them unfold and stack)
- envelopes
- colored paper - mixed or sorted
- box of paper clips
- stapler with staples
- calculator (hand operated and a electric one, if you can find one)
- pencils
- pencil sharpener
- worksheets
- blunt paper scissors
- tape with dispenser
- small pieces of colored paper, pictures, articles
- file folders
- hanging file holder
- index cards with an index card holder
- rubber bands
- junk mail
- business cards

Possible Activities

1. fold papers
2. stuff envelopes
3. take papers out of envelopes and open them up
4. sort papers by color
5. collate papers
6. paper clip papers together
7. staple papers together
8. file papers into file folders (maybe matching colors, letters, numbers or words)
9. put file folders into file folder holder (alphabetically or by words for some)

10. use calculator (use sheet of numbers to enter, give simple problems...)
11. sharpen pencils
12. tape pieces of paper of pictures onto page
13. cut up paper, cut out pictures, cut out ads
14. sort index cards by color
15. put index cards into a box - one at a time
16. take index cards out of the box
17. rubber band index cards
18. tape recipes/ads on index cards
19. open junk mail
20. rubber band business cards



YARN

Materials

- skeins of yarn
- small styrofoam balls to start wrapping yarn around
- knitting already started on large needles
- crocheted work already started - large crochet hook

Possible Activities

1. Wind yarn on ball
2. Pull yarn off ball, while you wind it
3. Pull yarn off skein while you wind it
4. Crochet - single or double
5. Pull out crocheted work
6. Knit
7. Pull out knitted work

(continued)



Utensils

Materials

- Sorting tray
- Plastic ware - different colors
- Metal ware
- Drying cloth - dish cloth
- silverware, silver paste, cleaning rags

Possible Activities

1. put utensils in tray - give sample
2. sort utensils by types (knives, forks, spoons)
3. sort utensils by color
4. place utensils out on tables for meals
5. pick up place settings not used and put them away
6. wash silverware and dry, then put away
7. polish the silver



DUSTING

Materials

- dust cloth
- lemon spray
- (dusty surfaces are needed for folks with higher skills)
- feather dusters (2 at least)

Possible Activities

1. Clear surface to be dusted
2. Put spray on rag
3. Dust surface
4. Wipe surfaces
5. Put items back in place
6. Dust off surfaces with feather duster
7. Run feather duster along walls and blinds



NUTS AND BOLTS

Materials

- Nuts (vary sizes)
- Washers (vary sizes)
- Bolts (vary sizes)
- Short metal plates with several holes through them
- Pieces of wood with holes drilled through them
- small containers with lids (margarine containers work well)
- crescent wrenches

Possible Activities

1. sort each item by size
2. sort by type (washers versus nuts, etc.)
3. put together/take apart nuts and bolts
4. put together/ take apart nuts, washers, bolts
5. put bolts through plates/wood and put on washers and put on nuts
6. use wrenches to tighten/loosen bolts and nuts

(continued)



COUPON CLIPPING

Materials

- blunt scissors
- magazines
- food stores flyers
- newspapers
- mailers
- folder
- small boxes
- small accordion file

Possible Activities

1. find coupons
2. cut out coupons
3. sort coupons
4. file coupons
5. talk about coupons
6. talk about food
7. talk about sales



FOLDING & HANGING CLOTHING

Materials

- variety of clothing items (Goodwill) - many of same things
- small laundry basket
- plastic hangers
- 'hanging' rack

Possible Activities

1. fold items - put in basket or drawer
2. put items on hangers
3. hang items
4. button buttons



WINDOW WASHING

Materials

- spray bottle of vinegar
- paper towels
- newspaper
- bag for trash

Possible Activities

1. spray windows
2. wipe windows with paper towels
3. wipe windows with newspaper
4. put used paper in trash bag



SWEEPING UP

Materials

- broom
- dust pan
- vacuum cleaner

Possible Activities

1. sweep floor
2. hold dust pan
3. run vacuum

(continued)



CAR CARE

Materials

- cleaning rags
- soap
- buckets
- squeegee
- polishing cloths
- wax
- window cleaner
- brushes
- hose
- nozzle

Possible Activities

1. wash cars
2. supervising washing cars
3. wash windows of cars
4. talk about cars
5. wax cars
6. dry cars
7. clean wheels



SNACK MAKING

Materials

- butter knife
- pitcher
- cup measure

- stirring spoon
- tray
- napkins
- paper cups
- paper plates
- supplies for preferred drinks and snacks

Possible Activities

1. make drink
2. make snack
3. serve drink
4. serve snack
5. clean-up after snack
6. deliver snacks



Stuffed Animals

Materials

- small stuffed animals of various types
- brushes
- ribbons
- collars

Possible Activities

1. holding and petting
2. brushing
3. stroking
4. setting them out
5. putting ribbons on them
6. putting collars on them
7. talking about animals
8. sharing them with someone else

(continued)



Hot Socks

Materials

- long sports socks
- large bag of uncooked rice
- large bag of dry beans
- large mouth funnel
- plastic measuring cup
- dried herbs (lavender, rosemary, lemon thyme...)
- (use of a microwave)
- basket to carry heated socks

Possible Activities

1. Make up socks
 - help pour rice/beans into socks
 - hold socks
 - hold funnel
 - measure rice/beans
 - select herbs to use
 - crush dried herbs
 - put herbs in sock
 - tie knot in sock OR tie with a ribbon
2. help microwave sock - 1-2 minutes on high
3. share socks with others
4. hold onto sock
5. put sock on shoulders, lap, arms, neck
6. get a massage with the sock
7. give you a massage with a sock
8. empty out socks for another day



BUTTON OR RIBBON SORT

Materials

- large assortment of buttons or ribbons
- lots of small containers
- small baggies

Possible Activities

1. sort buttons/ribbons into piles or containers
2. simplify sorting to match the person's abilities
3. have person put all buttons/ribbons back into one container
4. handle and count or move buttons from one container to another



COIN SORT

Materials

- large number of coins
- coin rolls
- containers
- plastic coin holders (they have preset levels for what goes in a roll)
- 'piggy bank' or other container with slit in the top of it

Possible Activities

1. Sort coins
2. Count out coins
3. Put coins in rolls
4. Handle the money
5. Put coins in a piggy bank
6. Give you coins to put in the rolls



SHOE CLEANING

Materials

- Dull/dirty shoes or boots
(Goodwill or Thrift Stores)
- polish
- cleaning rags
- polishing brush

Possible Activities

1. clean shoes
2. polish shoes
3. brush off shoes
4. shine shoes
5. pair up shoes



SOCKS SORT

Materials

- lots of socks of the same type
- lots of socks of different colors or types
- small basket

Possible Activities

1. sort socks by color
2. sort socks by type
3. pair up socks
4. fold/roll pairs
5. put socks in a drawer
6. put paired socks in the basket



MUSIC TIME

Materials

- CDs from the 20's, 30's, 40's
- Song sheets (mostly for you)

Possible Activities

1. singing
2. dancing
3. talking about memories
4. relaxing
5. encouraging folks to come to
a given location
6. encouraging folks to stay in
a given location



PILLOW STUFFING

Materials

- small sewn pillows with one end open
- long tube socks
- bags of polyester stuffing material
- safety pins, diaper pins or clothespins
- pieces of ribbon or cord

Possible Activities

1. stuff pillows
2. pin pillows shut
3. stuff socks
4. tie socks shut at various points along the
length making a 'caterpillar' type creature



NAIL CARE KITS

Materials

- Washcloths (some for wet and some for dry)
- basin to put warm wet washcloths in
- bag for used washcloths
- polish
- polish remover
- cotton balls and pads
- orange sticks
- emery boards
- nail clippers
- soaking dishes
- water pitcher
- lotion
- sealable bags to put used polish remover pads in (smell)

Possible Activities

1. do hand warm soaks with warm wet washcloth wraps
2. dry hands
3. clean around and under nails
4. apply lotion to nail areas and hands
5. remove old polish from nails
6. help with nail care, or have nail care done
7. select preferred color
8. help apply polish or have it applied
9. admire one another's nails
10. have the person do your nails
11. do toe nails (unless medical condition prohibits it)



FOOT CARE KITS

(make sure there are not conditions prohibiting foot care)

Materials

- basin
- towels
- baby oil
- lotion
- washcloths
- foot massage machine (available at drug stores and 'Walmart'- type stores) – must be cleaned between people and uses

Possible Activities

1. soak feet (might put some oil in the water)
2. rub feet
3. dry feet
4. put lotion on feet

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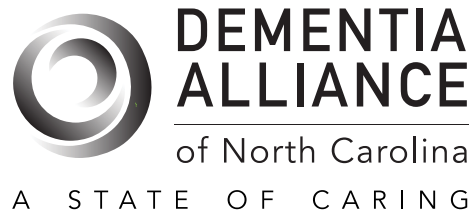
*Source: Teepa Snow, MS, OTR/L, FAOTA,
Dementia Care and Training Specialist
Positive Approach, LLC*

Activities To Do With a Person Who Has Dementia

- | | | |
|---|---|--|
| <ol style="list-style-type: none"> 1. Vacuum 2. Iron 3. Bake cookies 4. Read paper 5. Invite children to visit 6. Read out loud 7. Listen to music 8. Toss a ball 9. Color or Draw 10. Make lemonade 11. Wipe off table 12. Weed the garden 13. Make Pigs-in-a-Blanket 14. Spelling bee 15. Readers Digest 16. Fold clothes 17. Pet visit 18. Cut pictures out of old cards 19. Wash dishes 20. Bake bread 21. Sort objects by shape or color 22. Plant seeds 23. Look at family photos 24. Put silverware away 25. Make a Valentine's collage 26. Sing songs 27. Take a ride 28. Make a pie 29. Read a poem 30. Dye Easter eggs 31. Sort/match socks 32. Take a walk 33. String cheerios to hang for birds 34. String cranberries 35. Use your senses (smell & taste) 36. Name things that start with the letter "A" | <ol style="list-style-type: none"> 37. Reminisce about favorite memories 38. Clip coupons 39. Sort poker chips 40. Count things 41. Fold towels 42. Afternoon Tea 43. Reminisce - Inventions 44. Play a game 45. Paint 46. Make a collage from magazine pictures 47. Identify states and capitols 48. Make a family tree 49. Color American Flag 50. Cook hot dogs 51. Finish the cliché 52. Water house plants 53. Reminisce - first kiss 54. Play horseshoes 55. Dance 56. Sing a hymn 57. Make ice cream 58. Plant bulbs 59. Make greeting cards 60. Sort cards by suite 61. Write a letter 62. Dress in team colors 63. Pop popcorn 64. Name the U.S. Presidents 65. Give a manicure 66. Dance 67. Plant a tree 68. Make a May basket 70. Finish a famous saying 71. Feed the ducks 72. Mold dough or clay 73. Picture books 74. Put a simple puzzle together 75. Sand wood | <ol style="list-style-type: none"> 76. Rub on hand lotion 77. Decorate place mats 78. Arrange fresh flowers 79. Remember famous people 80. Rake leaves 81. Make a fruit salad 82. Sweep 83. Talk about famous events 84. Nursery Rhymes. You start 85. Make sandwiches 86. Dust furniture 87. Cut up paper/ Tear paper 88. Take care of bird cage or fish tank. 89. Trace/cut leaves 90. Simple trivia questions 91. Finish Bible quotes 92. Paint with string 93. Cut out pictures from magazines 94. Read/listen to a short story 95. Put coins in a jar 96. Sew simple stitches 97. Put seed in bird feeder 98. Play checkers 99. Wipe off patio furniture 100. Clean out pumpkin 101. Roll yarn 102. Reminisce about summer 103. Wash the car 104. Sort the recycling 105. Make a cake |
|---|---|--|



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APPENDIX E:

Medical & End-of-Life Information

Tube Feeding in People with Alzheimer's Disease

Melanie Bunn, RN, MS, GNP



Food is one of the most powerful ways we show love and affection for each other. We meet friends for lunch or coffee, remember fondly special family and holiday meals, and celebrate rites of passage with traditional recipes. From the moment of birth, our children are dependent on us for their food and survival.

When we care for relatives and friends with dementia, we continue to use food as a way of showing our love. Early in the disease well-loved dishes continue to have important physical and social benefits. Special dishes bring back memories and foster communication and interaction and familiar foods encourage appetite and intake.

In the middle stages of the disease, eating becomes more challenging. The person will lose the ability to manipulate utensils and may be overwhelmed with the choices to be made. The environment may distract the person and make it difficult to pay attention to eating. Weight loss is common and needs to be addressed by the caregiving team.

However, as the disease progresses the role of food changes. At the end of life, people with dementia develop difficulty with manipulating and swallowing food and lose their ability to digest food and absorb nutrition through their stomach and intestinal tract. They are at risk of aspirating (having food go into their lungs instead of their stomachs) and developing pneumonia. Malnutrition, dehydration and infection are some of the most common causes of death of people with dementia. Remember – this happens because of the progression of the disease and not lack of care.

Often, caregivers or the health care team raises the question of tube feeding. Families don't want their loved one to "starve to death" and professional caregivers are afraid of aspiration. Eating takes more time and energy and tube feeding might seem a more efficient method. Studies of end of life care of people with dementia consistently show that tube feeding neither improves the quality or quantity of life. It's not cheaper or quicker. Tube feeding does not prevent aspiration; the stomach contents can reflux and still pass into the lungs. At the end of life, food is not absorbed into the body for nutrition, but stays in the gut and causes gas and discomfort or passes out, unused, through the stool. In fact, as a person dies, the body releases chemicals (like endorphins) that prevent us from feeling hunger and thirst. Dying in this way seems to be a peaceful and natural process for the person with dementia.

As a loving caregiver, how do you deal with the important issue?

1. Advocate for your loved one. Ask, "Is this truly a terminal decline or are there reversible issues that need to be addressed?" Physical factors

(continued on back)

such as constipation, poor dentition, or medications can cause anorexia. Cognitive factors such as lack of attention span and inability to sequence could limit intake. Depression occurs in 50% of people with dementia and often results in loss of appetite. All these possibilities need to be addressed before moving into a palliative care approach.

2. Discuss end of life wishes. What kinds of care does the person with dementia want? Most people with dementia desire a natural and quiet end to their lives without a lot of medical interventions. Pass on to your own family and friends your own wishes.
3. Provided other types of comfort to the person at the end of life – touch and tone. Touch such as gentle massage or holding someone’s hand is a powerful method of communicating love and affection. Speaking softly, reciting prayers, singing familiar songs, and playing beloved music can provide tremendous comfort.
4. Use food and fluids more as treats rather than life sustaining items. Offer the person the taste of chocolate ice cream (or another favorite) on his or her tongue and observe the response.
5. Life and care is more than food. Spending time with the person just talking or sitting is more precious than battling to get another bite of food in.
6. Don’t feel guilty about not using artificial nutrition and tube feeding. Remember, the disease not the decision is causing the person’s death.
7. Find an educated and knowledgeable person with whom you can discuss these decisions. Many lay people and health care professionals are not informed about the science behind the difficulties with tube feeding.

For Additional Resources:

Medical Orders for Scope of Treatment (MOST) Form, must get original from physician.

- Example: <http://www.ncdhhs.gov/dhsr/ems/pdf/ncmostform.pdf>
- For Questions & Answers regarding the MOST form: http://www.ncmedsoc.org/non_members/public_resources/eol/FinalMOSTFAQs1.pdf

“Five Wishes” Form

- Example: <http://www.agingwithdignity.org/forms/5wishes.pdf>
- Originals may be located at local Hospice agencies or DA-NC

“Hospitalization Happens, A Guide to Hospital Visits for Your Loved Ones with Memory Disorders”

- http://www.nia.nih.gov/sites/default/files/hospitalization_happens_0.pdf

End of Life, Helping with Comfort and Care

- https://order.nia.nih.gov/sites/default/files/2017-07/End_of_Life_508.pdf

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APPENDIX F: *Caregiving Information*



ONE MOMENT PLEASE

***This restroom is being used
by a member of the opposite sex
to assist a family member.***

We'll be out in just a moment.

Thank you!

Tips for Traveling with a Loved One with Dementia



Planning ahead

- Have a bag of essentials with you at all times that includes medications, travel itinerary, a comfortable change of clothes, water, snacks and activities.
- Pack necessary medications, up-to-date medical information, a list of emergency contacts and photocopies of important legal documents.
- Create an itinerary that includes details about each destination. Give copies to emergency contacts at home. Keep a copy of your itinerary with you at all times.
- If you will be staying in a hotel, inform the staff ahead of time of your specific needs so they can be prepared to assist you.
- Travel during the time of day that is best for the person with dementia.

When does it make more sense to stay home?

Traveling is usually a lot easier when the person is in the earlier stages of dementia. Here are some useful tips to help you decide if staying at home makes more sense.

Does the person

- become anxious or agitated in new environments or around new people?
- constantly ask to go home even during short visits or trips?
- act verbally or physically abusive?
- have a problem with continence?
- wander?
- have great difficulty walking or have a risk of falling?
- need help with things like dressing, going to the bathroom, bathing, eating?
- have other serious medical issues and/or need a physician's ok to travel?

Travel tips

- If the trip is a go and it's going to be a long ride in the car, consider taking some short trips ahead of time to troubleshoot potential problems.
- Honor the person's usual schedule and stick to it as much as possible. Routine is critical, so if it is disrupted, expect there to be some agitation or increased confusion.
- Bring along familiar items, especially things that are soothing for the person: soft comfort items, special activities, books, pictures or favorite scented lotions. Be sure clothing is comfortable.
- Always allow for extra time.
- People with dementia often have better times of the day; try to schedule activities (driving, for instance) during those better times when the person is rested, fed and comfortable.
- Don't try to pack too much into one day. It may make more sense to break up a long drive with an overnight stay along the way. Rest can be critical (for both of you).
- Make sure the person is carrying or wearing some form of identification that includes your cell phone number. Kate Fallon, a licensed clinical professional counselor at Ageless Journeys, says a Safe Return bracelet is a great option.
- Take a photograph of your loved one so you'll know what clothes he/she is wearing ... just in case. In fact, take pictures along the way so you can document your trip and enjoy looking at them later.
- Carry all important documents yourself — tickets, passports, etc.
- In the airport, use family or handicapped restrooms if you're concerned about your person using it alone and be cautious about letting him/her wait outside when you're using the restroom.
- On the plane, try to get a seat close to the restroom.
- If you have special needs, let the airline know. Consider letting the flight attendants know you are traveling with someone who has dementia. (use companion cards to alert individuals discreetly)
- Carry as few bags as possible or have them checked straight through.
- Breathe
- Smile even if you don't feel like it. It's amazing how quickly a smile can turn things around

<https://advantagehomecaremaine.com/tips-for-traveling-with-a-loved-one-with-dementia/>

Bring an Ipod, mp3 player, or phone loaded with your loved one's favorite music and a pair of comfortable headphones





Holiday Stress and Caregiving

While everyone is enjoying the joy of the holiday season, there are many caregivers who just want the whole thing over with. Caregiving creates a level of stress unmatched by most endeavors. Add to that the extra stress of family gatherings, gift buying, cooking, and it is almost unbearable.

The following tips may help:

1. *Avoid being bound by past traditions.* Instead of hosting family members and guests, suggest that someone else host or enlist the help of friends and relatives for everything from cleaning to preparing food. A potluck is a great idea—you can even assign specific dishes!
2. *Shop non-traditionally as well.* The Internet or catalogs are fantastic ways to shop for food and gifts without leaving home. If you would rather go out, make lists of specific gifts for each person including where to go to get them.
3. *Make sure you leave enough time to enjoy the holidays.* It shouldn't be all about the hustle and bustle.
4. *Everything in moderation.* There are many temptations throughout the season---alcohol, sweets and rich food. Enjoy but don't over-indulge..
5. *Be prepared for unexpected circumstances.* Something may come up, and probably will, so remain flexible. If you can't change the situation, accept it and move on. Remember to laugh a lot!
6. *Continue your regular exercise routine (or start one) during the holidays.* Walking is a great way to stay in shape and there is something about pounding the pavement that helps release frustrations and clears your head. In wintery weather, you can walk on indoor tracks or in the nearest shopping mall. Some malls open early just for walkers.

Source: www.caregiver.com

Ideally caregivers should have a daily, weekly, monthly and yearly break.

- Daily-Half an hour of yoga, meditation, needlepoint, reading, etc.
- Weekly-A couple of hours spent away from the house at the mall, library, coffeehouse, etc.
- Monthly-An evening out with your friends, a play, a concert, etc.
- Yearly-A well-planned (and well-deserved) vacation.

Planning ahead for these breaks is imperative. You may need to arrange for respite care for your loved one.

Happy Holidays.



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Peace for the Holidays

By Melanie Bunn, RN, MS, GNP

Dementia Training Specialist, Dementia Alliance of North Carolina

The best of times, the worst of times might well describe the holiday experience of loved ones of people with dementia. With some reflection, planning and flexibility, the balance can be shifted from the worst to the best. Integrate the following suggestions as you plan your holiday events to create memories that bring laughter not tears and help you find joy in the moments.

- PRIORITIZE** Decide which family traditions are most important and which parts of those are truly meaningful. While the person with dementia may not be able to tolerate the entire ritual, often they can participate in well-chosen components.
- EMPATHIZE** View events through the eyes of the person with dementia. Changes in routines and environments can be difficult and frightening. Think about how decorations and events might confuse or be misinterpreted by the person with dementia.
- ADJUST** Consider modifying or simplifying plans. For example, small changes such as changing the time of an event to coincide with the person's best time of day or limiting numbers of people in the environment at any one time might make the experience better for everyone. Watch for signs of stress or distress and help the person find a place and time to relax and recover.
- CAPTURE** Record the memories of the person with dementia by encouraging reminiscence and storytelling to preserve family history. Use props like pictures, foods and decorations to trigger forgotten memories. Take candid multi-generational photos or video—they can be more touching and much easier than posed portraits.
- ENJOY** Make memories. Don't get so involved in the plans you forget the point of the activity or event. The experience might not be like it used to be, but you can still find the magical moments. Especially for the person who is grieving: Holidays are difficult when you're experiencing the loss or the losing of someone you care about. Be patient with yourself as you grieve and find support in comforting rituals and people. Do what's right for you as you look for new ways to find **Peace in the Holidays.**

P
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E



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How to Connect with the Person with Dementia:

Approach from the FRONT respecting personal space
Move SLOWLY in a non-threatening manner
Make EYE CONTACT
Initiate the greeting & introduce yourself
Move to the SIDE and OFFER YOUR HAND
Wait for their response
Make POSITIVE STATEMENTS: "Let's try..." or
"Could you please help with..."

Remember to...

- Stay calm and be understanding
- Speak slowly using a low pitched voice
- Be patient and flexible, go with the flow
- Step into their shoes to look for a reason for each behavior
- Ask questions using fill in the blanks
- Introduce yourself, "My name is xxx and you are?"
- Offer simple choices instead of asking yes/no questions
- Respect personal space
- Don't argue or correct

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When the person is in distress...

- Focus on their feelings
- Respond to the emotion, not to the action
- Ask the person to tell you more about it
- Move from talking first to then doing
(go for a walk, get a cup of coffee)

ALWAYS...

- Greet the person before moving into action
- Explain what is happening but keep it simple
- Don't take it personally
- Break the task down into single one at a time steps
- Give the person time, don't rush

It is common for the person with dementia to...

- Say or do things that are inappropriate
- Not respond the way you expect
- Say things that don't make sense
- Use words that are close but wrong
- Have poor grooming habits or look slightly off
- Repeat themselves or not remember instructions
- Deny what you know is true
- State as true what you know is false
- Appear irritated, scared, or too personal

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www.DementiaNC.org
(800) 228 - 8738

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The Ten Absolutes of

Caregiving

NEVER ARGUE	INSTEAD	Agree
NEVER REASON	INSTEAD	Divert
NEVER SHAME	INSTEAD	Distract
NEVER LECTURE	INSTEAD	Reassure
NEVER SAY "REMEMBER?"	INSTEAD	Reminisce
NEVER SAY "I TOLD YOU ..."	INSTEAD	Repeat & Regroup
NEVER SAY "YOU CAN'T ..."	INSTEAD	Find out what they CAN do
NEVER COMMAND, DEMAND	INSTEAD	Ask & Model
NEVER CONDESCEND	INSTEAD	Encourage & Praise
NEVER FORCE	INSTEAD	Reinforce



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Dementia Alliance of North Carolina

Comfort. Assistance. Resources. Education

Dementia Alliance of North Carolina has served local communities since 1981 as a 501 (c)(3) non-profit organization. One hundred percent of our funding stays here to improve lives of all North Carolinians impacted by dementia, engaging and empowering them through support, education and research.

CAREGIVER SUPPORT

- Individual and family counseling at no cost
- Support groups and support group facilitator training
- Caregiver resource referral and information
- Music & Memory at Home program
- Referrals and reimbursement for respite care

EDUCATION

- Community talks, workshops and conferences
- Seminars for family caregivers
- Training for professional groups and law enforcement

RESEARCH

- Funding research in NC to advance innovative therapies and reduce the number of individuals impacted by dementia

ADVOCACY

- For the rights of individuals living with dementia and their caregivers



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Caring for the **Caregiver**



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of North Carolina

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Trusted dementia navigation

At **Dementia Alliance of North Carolina (DA-NC)**, our primary focus is improving the lives of caregivers who, more often than not, have no prior experience and no other alternative when assuming their roles as caregivers.

*Our goal is to provide individualized **Comfort**, timely **Assistance**, relevant **Resources** and the latest in dementia **Education** to communities across North Carolina.
Count on our expert staff to walk with you and your family
as trusted guides on this journey.*

Compared with caregivers of people without dementia, **twice as many** dementia caregivers experience long-term stress from the financial, emotional, and physical difficulties of caregiving. Stress, if left unmanaged, can impact their physical health (reduced immune function, slow wound healing, increased incidence of hypertension and coronary heart disease).

Caregiver burnout is REAL.

Burnout is caused by long-term stress and occurs when you feel overwhelmed by the constant demands of caring for your loved one. If you're feeling stressed out in your caregiving role, **you're not alone**. Caregivers seldom take time to address their own needs.

Signs of caregiver burnout:

- Excessive use of alcohol, medications or sleeping pills
- Appetite changes — eating too much or too little
- Depression, hopelessness, feelings of alienation
- Losing control physically or emotionally
- Neglect or rough treatment of the person for whom you're caring
- Trouble falling or staying asleep
- Difficulty concentrating
- Missing appointments

How well you take care of yourself can have a huge impact not only on your own well-being, but on the person you most care about.

Caregiving for individuals with dementia, including Alzheimer's disease, is a rapidly growing sector of our older population:

- In North Carolina alone, an estimated **473,000** dementia caregivers are providing more than **538,000 hours** of unpaid care each year.
- Dementia caregivers have an estimated **\$375 million** in higher health care costs.
- The physical and emotional impact of dementia caregiving is estimated to have resulted in more than **\$10.2 billion** in health care costs in the U.S.

Resources:

NC County Health Data Book, 2020, Division of Public Health, NC Dept. Health and Human Services, State Center for Health Statistics

2019 Alzheimer's Disease Facts and Figures; Alzheimer's Association

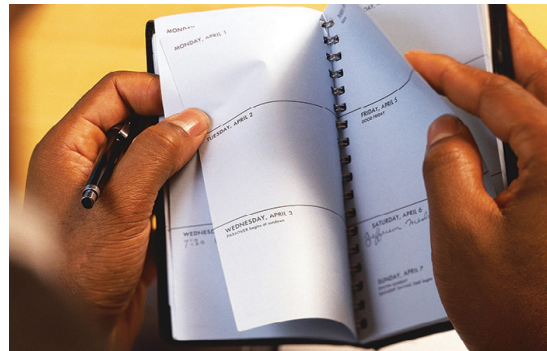
https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf



The good news is that burnout is preventable and reversible. If you recognized any of the warning signs, consider taking the steps below to get your life back into balance.

1. Shift your focus: By allowing time to focus on you, you're more apt to recognize early signs of chronic stress and caregiver burnout. Many people don't realize how gradually stress and burnout can add up. Becoming proactive and preventing burnout is better than needing to recover from it later.

2. Set aside "you" time: Even if you feel you don't 'need it,' take time doing something you love.



Add it to your calendar, like anything else as a reminder that you are committed to that "you" time. And stick to it.

3. Look for local support: Caregiver support programs are available through DA-NC. Simply hearing other caregiver experiences will help you feel less alone and "normalize" common feelings of helplessness, sadness, burnout and

frustration. When people offer to help, accept their offers and suggest specific things that they can do to help. If you feel depressed or anxious, consult your doctor for a referral to a mental health professional in your region

4. Exercise and relaxation:

Numerous studies have shown that moderate daily exercise, like walking and dancing can have a positive effect on stress. Likewise, relaxing activities can decrease stress; deep breathing used in yoga and meditation can reduce your heart rate and calm anxiety. Take a class and find your zen.



5. Rejuvenate and recharge:

Some people find that being in nature and engaging in outdoor activities very rejuvenating; consider stimulating your senses by visiting a museum, listening to music or attending a concert; participate in art or cooking classes; treat yourself to a massage or other pampering, feel-good experiences. **Think about what works best for you!**

(more on page 6)



Ask about Music & Memory at Home, a personalized music program offered by DA-NC:

- **Improved relationships:** provides increased engagement, joy and connection to past memories.
 - **Improved caregiver roles:** increases free time for caregiver when participants are listening to their personal play list.
 - **Improved quality of life:** increased energy levels and activity, lift in mood, and reduced anxiety.
-

6. Spend time with pets: Animals love unconditionally and have been shown to offer health benefits to humans; studies from the National Institute of Health have found that pet ownership can actually improve cardiovascular health. Spend more time with your pet; take longer walks with your dog or add more playtime for your cat.

7. Start socializing more: Caregivers spend so much time caring for loved ones that they often neglect to maintain friendships. Avoid narrowing your world to the point where all you do is work and provide care. Develop a personal support network that includes people who build you up and listen to your concerns without judgment.

Say Goodbye To Guilt

Acknowledge your feelings. It's important to understand that feelings of anger and resentment are common among caregivers. If these feelings begin to impact your relationships, seek assistance to **manage them in constructive, healthy ways.**

Think quality, not quantity. If you're feeling guilty that you aren't spending enough time with your loved ones, focus on how you can **improve the quality of your time together.** Listening to your mothers' Music & Memory playlist or challenging dad to a board game, may mean more to them than cleaning their kitchen or delivering a pot roast.

Establish priorities. While no one has the time or energy to do everything for everybody, you must find time (and energy) to do the things that are most important to you. By establishing priorities - and allowing some flexibility for the unexpected - you can help ensure that the most important needs and tasks are met.

Set limits. If your loved ones' constant demands are running you ragged, decide - and clearly acknowledge - what you're able and willing to do for them. By setting limits and standing behind them, you can help reduce the guilt trips that come when you can't meet their every demand.

(more on page 8)



Redefine your concept of caring.

If you find it difficult providing 'hands-on' care for your parent, don't feel guilty - simply think of other tangible ways you can help. Perhaps you're more comfortable paying for an outside caregiver or planting flowers your loved one enjoys. We all 'give care' differently - add value where you can make a difference.

Act from love, not from a sense of debt. If you think of caring for an aging loved one as repayment for all they did for you, you will always end up in the red. Instead, think of caregiving as one person helping another out of love.

Foster their independence.

Don't feel guilty for not doing things that your loved one could do for themselves. Instead, look for ways to help them do what they can. Providing a \$1.29 pill dispenser can help your parent become more independent - and free up precious time for you.

Don't succumb to peer pressure.

Acknowledge, but don't be overly influenced by advice you get from friends, family and coworkers. Do what your heart tells you is best and what your circumstances permit.

Face the facts. Despite how much you want to help, a time will come when your loved one will need round-the-clock care and constant supervision that you can't provide. When that happens, acknowledge that someone (or someplace) may be better equipped to provide the majority of that care than you are.

Find a new normal. Grieve for your losses then allow yourself to dream new dreams. Forgive yourself and others when things don't work out as originally planned. Concentrate on one day at a time.

Source: Alexis Abramson, Ph.D.

Let our dementia navigator guide your family's journey

For more than 40 years, **Dementia Alliance of North Carolina** has provided educational programs and support services for families across the state, and has funded dementia research at our state universities and institutions. Call or visit us today at:



(919) 832-3732

www.dementianc.org



Seek support from other caregivers. You are not alone!



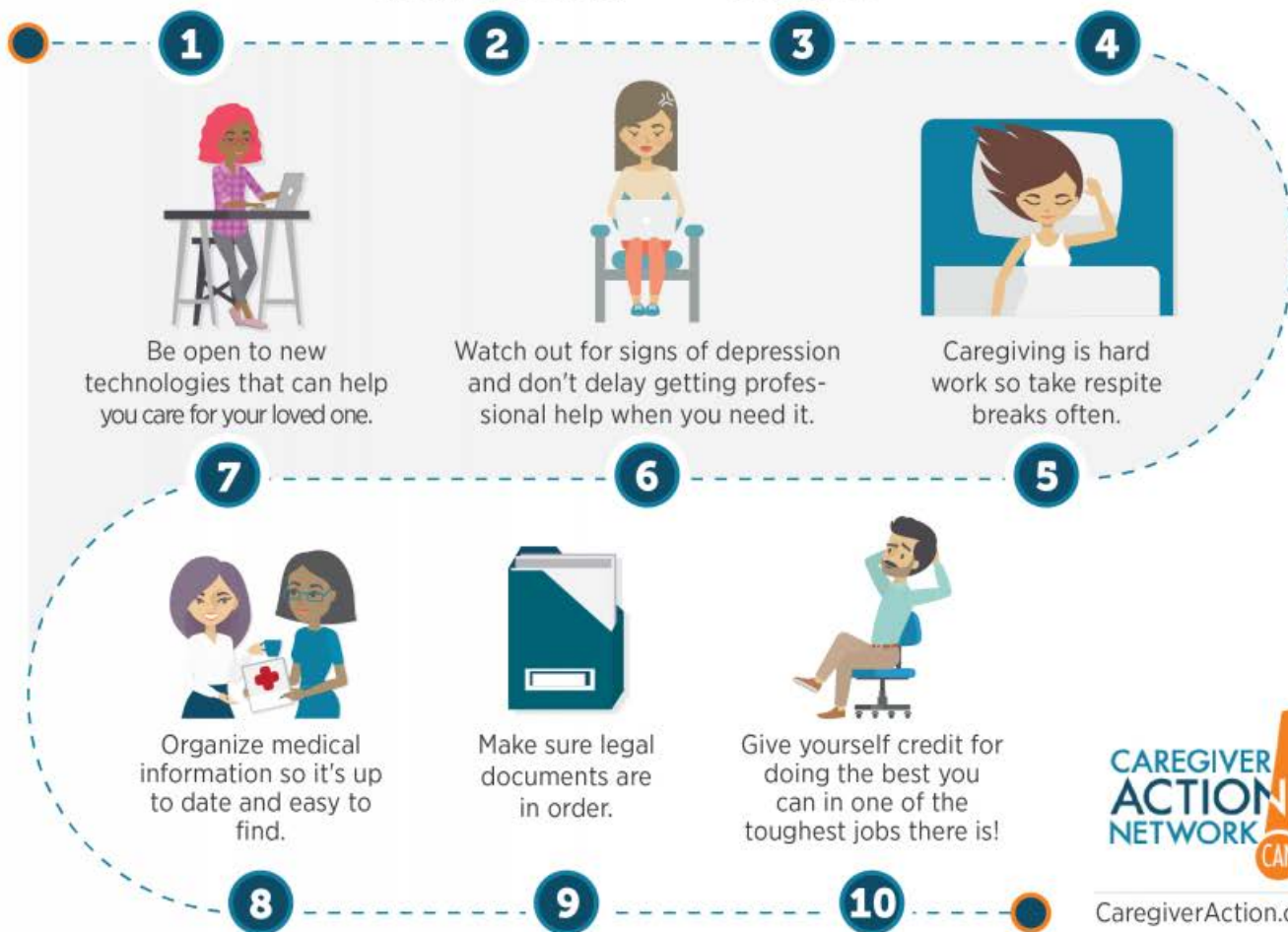
Take care of your own health so that you can be strong enough to take care of your loved one.



Accept offers of help and suggest specific things people can do to help you.



Learn how to communicate effectively with doctors.



CaregiverAction.org

A Caregiver's Bill of Rights

By Jo Horne

I HAVE THE RIGHT:

To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.



To seek help from others even though my loved ones may object.
I recognize the limits of my own endurance and strength.



To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.



To get angry, be depressed, and express other difficult feelings occasionally.



To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and /or depression.



To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return.



To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.



To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.



To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

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**DEMENTIA
ALLIANCE**

of North Carolina

A STATE OF CARING

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Warning Signs of Caregiver Stress

1. Denial about the disease and its effects on the person who's been diagnosed. *"I know Mom is going to get better."*
2. Anger at your loved one or others, or that no effective treatments or cures currently exist and that people don't understand what's going on. *"If he asks me that question one more time, I'll scream."*
3. Social withdrawal from friends and activities that once brought pleasure. *"I don't care about getting together with the neighbors anymore."*
4. Anxiety about facing another day and what the future holds. *"What happens when he needs more care than I can provide?"*
5. Depression begins to affect your ability to cope. *"I don't care anymore."*
6. Exhaustion makes it nearly impossible to do necessary daily tasks. *"I'm too tired for this."*
7. Sleeplessness caused by a never-ending list of concerns. *"What if she wanders out of the house or falls and hurts herself?"*
8. Irritability leads to moodiness and triggers negative responses and reactions. *"Leave me alone!"*
9. Lack of concentration makes it difficult to perform familiar tasks. *"I was so busy, I forgot we had an appointment."*
10. Health problems begin to take their toll, both mentally and physically. *"I can't remember the last time I felt good."*

Courtesy of: Duke Family Support Program

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- **Sit quietly** in calm surroundings with soft lights and pleasant scents
- **Aromatherapy** – lavender, citrus, vanilla, cinnamon, peppermint, fresh cut grass
- **Breathe deeply** – rest your mind & oxygenate
- **Soak** - in a warm bath, or just your hands or feet
- **Read** - Spiritual readings, poetry, inspirational readings, or one chapter of what you like
- **Laugh and smile** - Watch comedians, America's Funniest Home Videos, look at kid or animal photos
- **Stretch** – front to back, side to side, & across
- **Garden** – work with plants
- **Beanbag heat therapy** - Fill a sock with dry beans and sew or tie closed. Heat bag and beans in a microwave for 30 seconds at a time. Place on tight muscles and massage gently; relax for ten minutes
- **Remember the good times** - Record oral memories - scrapbooks, photo journals, keepsake memory picture frames
- Do a little on a favorite **hobby**
- Have a **cup of decaffeinated tea or coffee**
- Play a **brain game** – crosswords, jigsaws, jeopardy, jumbles
- Look through the **hymnal** and find a favorite – hum it all the way through
- **Books on Tape** - Rest your eyes and read
- **Soothing sounds:**
 - Music you love
 - Music especially for stress relief
 - Recorded sounds of nature
- Listen to **coached relaxation recordings**
- **Pamper Yourself** – think of what you LOVE and give yourself permission to do it for 10 minutes
- **Neck rubs or back rubs** – use the “just right” pressure
- **Hand Massages** – with lotion or without – it's up to you...
- **Take a walk**
- **Sit** in the sun
- **Rock** on the porch
- **Pray** or read a passage from scripture
- **Journal** - Take the opportunity to “tell it like it is”
- Cuddle and stroke a **pet**
- Have that cup of coffee or tea with a **special friend** who listens well
- Pay attention to **your personality:**
 - If you rejuvenate being alone, then seek solitude
 - If you rejuvenate by being with others, seek company

Is It Time to Get Help?

Just like the ten warning signs of dementia, warning signs that a loved one living independently might need more help may not be a single bold sign. Instead, there may be a combination of things or smaller “red flags” adding up to the fact that more help, or a move, is needed.



Often, just asking the question, “when is my loved one no longer safe to live alone?” can indicate that it is time to get in-home help or look at a move to a care community.

There is no simple answer as each person and situation is individual. However, we have shared below some points to keep in mind.

1. Safety
 - a. Do you worry about her all of the time? How often are you checking in, calling, or not going out because you cannot leave her alone?
 - b. Have there been many falls, medication challenges or wandering episodes that stress you daily?
 - c. Does she feel safe at home? Does she have concerns that keep her up at night?
2. Caregiver Burnout
 - a. Are you and/or other caregivers exhausted? Do you find yourself being short, easily angered, with low patience?
 - b. Are you sleep deprived? Missing a lot of work?
 - c. Is your health at risk?
3. Increased healthcare needs
 - a. Is his/her health more at risk by being alone or are the needs beyond your abilities as the caregiver?
 - b. Have doctor visits and/hospital visits been increasing due to increased care needs?
4. Socialization
 - a. Is your loved one isolated? Would they benefit from being around others on a daily basis?
 - b. Do they have a fear of being alone? Are they paranoid or suspicious for seemingly unfound reasons?
5. Have there been unexplained physical changes?
 - a. When you hug your loved one can you tell there has been significant weight change?
 - b. Are there changes in posture, difficulty with balance, movement or how they get around?
 - c. Are there signs of recent falls such as unexplained bruising?
6. Hygiene
 - a. Have you noticed changes in hygiene such as body odor, wearing out of season clothing, wearing clothing inappropriately or wearing the same thing repeatedly?
 - b. Have shaving or mouth care habits changed?

7. Money

- a. Have there been changes in finances, warnings of late or no payment for bills? Have there been changes in purchasing habits or money given away that is out of the ordinary?
- b. Is your loved one uncharacteristically buying multiples of items and either not remembering they already have the item or saving just in case where they would not have done this before?

8. Living Conditions

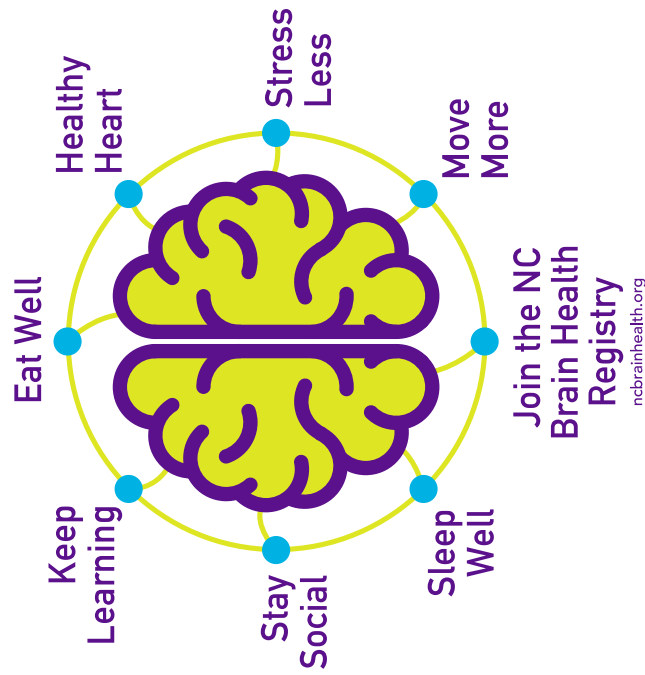
- a. Have you seen signs of staining, mold, or burns (kitchen towels singed)? Water damage where sinks might have overflowed? Laundry not being done or getting clean?
 - b. Are you noticing food that has passed its expiration dates? Moldy foods?
 - c. Are there expired medications that have gone unnoticed?
9. Are they still as organized as they have always been, or are things slipping?
10. Would they benefit from 24-hour supervision?
11. Are they experiencing aggression, wandering or “sun downing”?
12. In the event of an emergency, would your loved one be able to follow appropriate emergency procedures such as calling 9-1-1 and evacuating to somewhere safe?

If you decide it might be time to explore your options, call Dementia Alliance of North Carolina for resources and support. You may also want to speak with your regional Long-term Care Ombudsman, a geriatric care manager, ask support group members, research online, talk to friends about their experiences, visit local care communities and learn about alternate options that may enable your loved one to live at home as long as possible.



www.DementaNC.org
919.832.3732

WHAT IS BETTER BRAIN HEALTH?



Dementia starts with small, unnoticeable changes in the brain that can begin 20 years or more before symptoms appear. While there is no cure in sight, there is strong evidence that you can potentially prevent or reverse those changes by taking steps towards better health today:

EAT WELL focusing on vegetables, fruits and lean protein, particularly protein sources containing omega-3 fatty acids.

HEALTHY HEART lifestyle to reduce vascular risk factors, high blood pressure, high cholesterol and diabetes.

STRESS LESS to calm blood pressure, lower cortisol levels and maintain positive mental health.

MOVE MORE every day including some aerobic exercise

SLEEP WELL to aid your body in flushing toxic beta-amyloid proteins from the brain

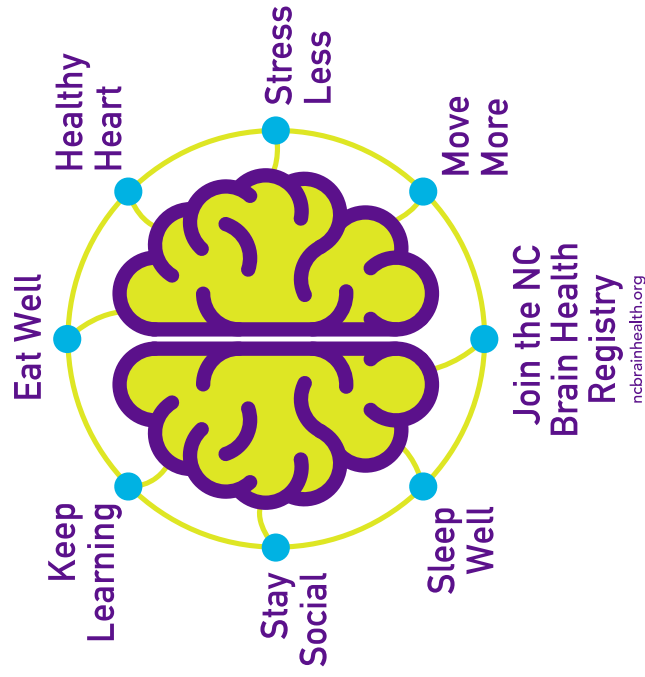
STAY SOCIAL and engaged with family, friends & community.

KEEP LEARNING and developing cognitive skills throughout entire lifetime



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2020 DEMENTIA STATISTICS

The World Health Organization estimated the number of people living with dementia worldwide was **47.47 million** in 2015, will reach **75.63 million** in 2030 and **135.46 million in 2050.**

Alzheimer's is the **6th leading cause** of death in the USA, and **1/2** of those aged 85 and over are living with dementia

There are currently **180,000** North Carolinians living with Alzheimer's Disease and dementia. That number is projected to increase by 16.7% to **210,000** by 2025.

DEMENTIA CAREGIVERS ARE:

- Over **60%** are women over age 55
- Over **50%** are caring for parents
- Nearly **60%** are employed and report that they miss work; **8%** turned down promotion opportunities; and **31%** had to give up work to attend to caregiving responsibilities.

In North Carolina, there are

479,000 caregivers providing

545,000,000 hours of unpaid care, valued at **\$7,151,000,000** million dollars per year.

Sources:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/>

2020 North Carolina Alzheimer's Disease Facts and Figures; Alzheimer's Association

https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf

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I JOINED A SUPPORT GROUP AND ...

- *Learned that I could share my challenges and learn from others who understand in a safe and confidential environment.*
- *Learned approaches to caregiving and creative coping strategies.*
 - *Exchanged helpful resources.*
 - *Was reminded to take care of myself.*
- *Learned that humor and laughter are essential in the caregiving journey.*
 - *Worked towards understanding and acceptance of the many emotions involved with dementia.*
 - *Gained education about dementia, research, and advocacy.*
 - *Was able to support others by sharing my own experiences.*
 - *Learned to accept that my loved-one's ways were real and to stop correcting and reasoning.*
- *Became friends with others that were going through similar experiences.*
 - *Realized it was ok if I wanted to remain quiet.*

To find a local Support Group, visit
<https://dementianc.org/family-services-support/supportgroups/>
or call Dementia Alliance of NC at 919.832.3732



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ADDITIONAL CAREGIVER RESOURCES:

National Institute of Health has an excellent resource library of articles and tip sheets:

<https://www.nia.nih.gov/health/alzheimers/caregiving#behaviors>

We recommend sharing this source with caregivers in your group

For resources regarding sexual activity please see the following articles/websites:

The last taboo: A guide to dementia, sexuality, intimacy
and sexual behavior in care homes

https://ilcuk.org.uk/wp-content/uploads/2018/10/pdf_pdf_184.pdf

Sex and dementia

www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=129

Dementia, Intimacy and Sexuality - Alzheimer Society Canada

**[https://alzheimer.ca/sites/default/files/files/national/brochures-conversations/
conversations_intimacy-and-sexuality.pdf](https://alzheimer.ca/sites/default/files/files/national/brochures-conversations/conversations_intimacy-and-sexuality.pdf)**

ACTIVITIES FOR DAILY LIVING



TIPS TO HELP WITH DRESSING

Clean out closets to limit choices and offer only seasonal clothing (best done without your loved one).

1. Offer limited appropriate choices and favorite colors.
2. Lay clothes out on a light solid colored surface to provide contrast to the clothing and make it easier to see.
3. Lay out clothes in the order they should be put on, underwear on top to be put on first.
4. Make sure the room is warm, well-lit and private.
5. Limit distractions.
6. Offer clothing they can manage (buttons, zippers, Velcro, slip on).
7. If a person wants to wear something frequently, get duplicates.
8. Choose easy care clothes in case of spills or accidents.
9. Avoid tight fitting clothing, panty hose, high heels, tight socks, etc.
10. Use soft music to set the tone – music they personally enjoy, more upbeat to get them going in the morning and more relaxing to help them unwind in the evening.

Help as needed but allow them to do as much as they can. Perhaps verbal (here is your shoe) or tactile cues (touch their hand holding the shoe) can help them do something instead of you taking over.



TIPS TO HELP WITH TOILETING

Have patience, if you are upset they will be, too. They are doing the best they can.

1. Use signs for visual cuing
2. Leave lights on and doors open so the restroom and toilet are easily found. At night use motion activated lights.
3. Choosing contrasting colors in the restroom can help with depth perception and finding the toilet. Colored toilet seats help show the difference between the white floor, white toilet, and white walls.
4. Install grab bars for safety and a sense of security.
5. Follow their schedule. It may be every 2-3 hours, but it may be shorter during some parts of the day and longer during others.
6. Give privacy whenever it is safe to do so.
7. Provide easy on and off clothing for success.

For someone more advanced with their dementia, simply asking if they need the bathroom may not be enough. They may not understand what you are asking. Showing them the bathroom when you ask will be helpful.

Issues leading to accidents might include:

- Urinary tract infections
- Medications
- Dehydration
- Constipation

Watch for signs that might mean they have to go:

- Pulling on clothing
- Increased wandering, restlessness, or agitation

Limiting fluids before bed may be helpful. Fresh fruit can be a good alternative if someone needs hydration later in the evening.

(continued)



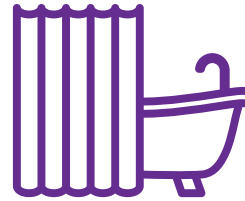
TIPS TO HELP WITH MOUTHCARE

Show them how to brush their teeth.

1. Brush yours at the same time
2. Go step by step
3. Use hand under hand assistance until they can take over the task
4. Follow their past routines and habits as much as possible
5. Ask them to rinse with water after each meal; rinsing with mouthwash at least once a day
6. Go to the dentist, they can help with cleaning and offer suggestions for other ways to make oral hygiene effective
7. Use two toothbrushes, if necessary, they can hold one and you can hold one for them
8. Consider having the person sit while brushing – be sure they can still look in a mirror for cuing
9. Add a rubber grip to the toothbrush to make it easier to grasp
10. Try a 3-sided toothbrush – cleans all sides of teeth at one time for less actual brushing time

Keep in mind:

- Mouthwash with alcohol may burn and discourage use
- It may be better to brush without toothpaste than not brush, it may be better to rinse with water than do nothing at all
- If he/she will not/cannot spit or rinse you may want to use toothpaste that is OK to swallow
- Daily care establishes routines and habits



TIPS TO HELP WITH BATHING

Follow a regular routine and rely on preferred habits and routines of the past.

Keep in mind:

- Focus more on the person than the task
- Be flexible – you must adapt, they cannot
- Adapt the environment to make it comfortable for the person
- Padded shower chair, warm room, cover the seat with a towel, reduce noise, try soothing music
- Use persuasion not coercion – give choices within the task, respond to requests, support remaining abilities, help the person feel in control as much as possible.
- Be prepared, have everything you need before you begin
- Stop- when the person is distressed, stop and re-assess the situation

Types of Bathing:

- Shower
- Bath
- Whirlpool
- Walk-in tub
- Sponge Bath

Equipment that might be helpful:

- Limited hand function? Bath mitt, soap on a rope
- Limited reach? Bath sponge, hand held shower head



- Limited balance or endurance? Bath chair or bench, stool, grab bars, shorter chair for shorter people (no dangling feet = better balance), slip resistance surface on shower floor
- Limited understanding of what is happening? Warm space, privacy, limited distractions, slow pace, cover for modesty (can keep on gown or boxers if need be), use hand under hand assistance to support remaining skills, start at the “edges”, wash what is most needed first, keep checking temperature, have everything you need with you, bring extra towels

Sample bathing:

- Know what you are going to do, what your goal is – but meet the needs of the person first
- Gather all supplies
- Give the person acceptable choices (not “Do you want to take a bath”, instead try “It’s time to get washed up, do you want to help get the towels together?”)
- Stay calm, relaxed, be gentle and respectful
- Keep the room very warm (people with dementia have trouble regulating their own body temp)
- Get the water temperature right for the person – let them test the temperature



- Help them to undress in the bathing location.
- Assist or transfer them into the bathing location
- Keep the person warm (a warm, wet towel on their back or on the back of the shower chair might help)
- Help them do as much of the washing as they can, even if they are simply holding a washcloth and you are actually doing the majority of the bathing
- Start at the edges but complete the most important tasks first. Remember that areas like the feet, face and genitals may be extra sensitive
- Use hand under hand assistance to give more control and reduce resistance
- Give positive reinforcement. Praise and reassure often.
- Apologize and acknowledge the person’s concerns.
- Use distraction as needed (treats, singing)
- Help the person dry off and stay warm (pat dry instead of rubbing)
- Cover with a robe (can help with getting dry, too)
- Help them dress

Common issues:

- Gender of the caregiver – would the person needing help be more comfortable with someone of the same or opposite sex?
- BM while showering
- Moving too fast
- Too cold
- Feeling exposed, scared and out of control
- Caregiver doing too many things at one time
- Pain

(continued)

- Be sure the foot surface is non-slip. Have grab bars. Don’t use slippery oils.

Ideas:

- Bathe upper body at one time and lower body at another
- Make the room comfortable, warm, inviting, no shiny floors (they look wet), no slippery rugs
- Use dry shampoo
- Get hair washed at the beauty parlor or barber shop if it is an issue at home
- Soak feet outside of the shower, when seated, as a separate and enjoyable activity
- Find ways to offer contrast in the bathroom. A white floor, white walls and a white seat make it hard to distinguish one from the next; draping a colored towel on the shower chair can be an easy fix



Myths:

- It takes a lot of water to get people clean: *Careful washing is more important than the amount of water*
- A shortened bath means someone is not doing a good job at getting someone clean: *This is about the person taking the bath, adjusting how and when things are cleaned is good when it works better for the person being bathed*
- Someone has to take a shower or bath to get clean: *There are many ways to get clean without getting in the shower or tub*
- People always feel better after a bath or shower: *If it is forced, no one feels better after a task. They may feel attacked or fearful and may remain upset for long after the event.*

- They will forget about it later so just go ahead and do what you have to do: *They may forget the experience but they will not forget the emotion and how they feel. They may also remember bathing as a negative experience overall, even if they don't know why.*
- It takes more time to go slow and be thoughtful and gentle in your approach: *It actually takes more time and creates more stress if the person is resistant.*

Keep in mind:

Some resistance may be due to pain. Bathing provides a lot of opportunity for painful stimulation. The person may not be able to communicate the pain to you and may simply not want to bathe.

Frequent causes of pain may include: *arthritis, back pain, constipation, contractures, dental problems, headaches, diabetic nerve pain, old fracture or injury sites, infections, bruised areas.*

Know the signs to watch for and learn how your person with dementia expresses themselves both verbally and non-verbally. Signs may include, but are not limited to: *calling out, frowning, crying or closing eyes, wincing, hitting, pushing you away, guarding a particular body part, jerking motions, restlessness, or rapid eye blinking.*

Treat pain before bathing whenever possible.

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