

# **After a Move: Maintaining Meaningful Relationships and Letting Go of Guilt**

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Merrill Gardens Burien***



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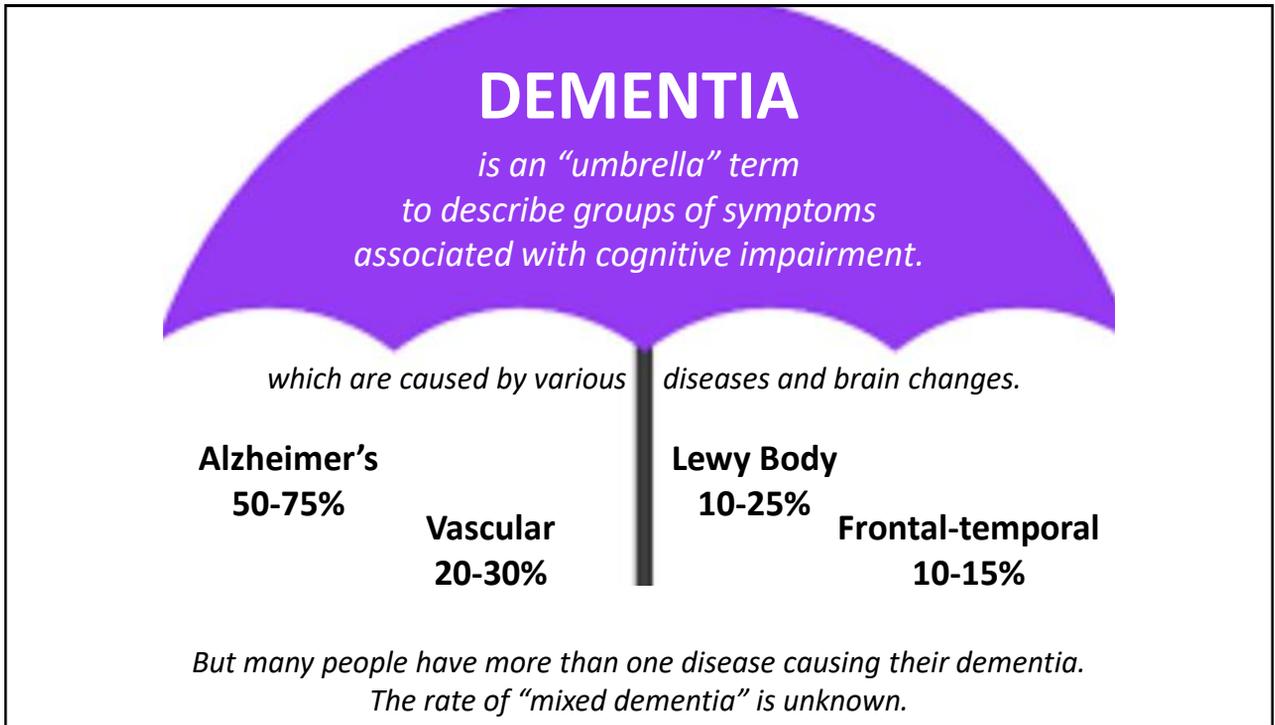
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**I help older adults and families figure things out.**

***These slides are on my website at <https://agingcareconsult.com>***

*In the menu, click on “For Older Adults/Families”  
then click on “Download Resources” and go to the bottom of the page.*



## Dementia stages

- Chronic, progressive, and irreversible.
- No set timeline for how someone moves through dementia stages.
- General dementia stages: Early, Middle, and Late.



## Maintaining Meaningful Relationships

- Maintaining Connections
- Tips for Spouses, Adult Children and Grandchildren
- Less-Stress Celebrations
- Resolving the Guilt
- Work-In-Progress

## Relationship changes in dementia

- Partners or spouses
- Adult children with parents
- Younger children or grandchildren
- Each relationship is different. Everyone deals with their unique relationship changes in their own way.

## Grief, anger, sadness are all normal feelings.

- It is normal to feel enormous grief over the changes in your relationship.
- You are not selfish or unfaithful for experiencing these feelings.
- Support groups, especially ones for spouses and partners, can be extremely helpful – you are not alone in your experience.

## How to treat your loved one with dementia?

- With the same respect and love you always have.

*"Don't underestimate me.  
I know more than I say, think more than I speak  
and notice more than you realize."*

## Partners: how to stay connected

- Find enjoyable activities to share during visits.
- Even if your partner moves into residential care, most places can provide overnight private accommodation for you to be alone.
- Whether it's a cuddle on the sofa or much more than that, physical intimacy can still bring comfort, support and pleasure for many years to come – for both of you.

## Parents with dementia: tips for “kids”

- Relationships change, but we still need love, affection, and respect.
- Honor their place in your life.
- Respect their life experience – even if they can't all they used to do.
- You may be their main support, as they were once yours.
- You will need other support to confide in about worries or fears.

## Parents with dementia: boundaries

- Set appropriate boundaries with your parent.
- You may need to do things for them, but they deserve respect and dignity.
- They may treat you as a child, but you do not deserve disrespect or abuse.
- Be clear about what you can or cannot do, and what you will or will not accept – but in a loving, respectful way.

## Dealing with parents with dementia

- Get support from care providers around how to handle challenges.
- Difficult conversations may be easier with someone else involved.
- Grief, anger, sadness, resentment – these are all normal feelings.
- Support groups for people caring for parents can be extremely helpful – you are not alone in your experience.

## Talking about dementia with kids and teens

- There are lots of resources to help kids understand dementia.
  - Consider your child's age and emotional development when deciding how much information to share.
- Talk to kids ahead of time about:**
- what they might see,
  - how the person may not remember them,
  - how the person might behave in surprising ways, and
  - how kids might feel when they see the person = normal and OK.

## For kids and teens: ways to connect

- Ask questions and ask them to tell you stories, about things like:
  - Family history – their parents, grandparents, ancestry.
  - What growing up was like – their home, pets, siblings, neighborhood.
  - Describe a typical school day, or a favorite memory or subject
  - Where they went to elementary school, high school
  - Their first job, first home away from their parents, first romance
- Kids can write up what they learned for a school project and to share with other family members.

## Tap into technology

- Share grandkids' photos by giving them a digital photo frame that you can update over time.
- Schedule video conference or Facetime when they can share a song that they like, wish the kids a happy birthday, read a story, or just say good night to their grandkids.
- They'll see that even with dementia, they can still share happy moments with those who mean the world to them.

## Less-Stress Celebrations:

- What to expect in order to make special occasions manageable for the person with dementia and less stressful for you
- Birthdays
- Weddings
- Graduations
- Reunions
- Faith services

## Adjust expectations

- For people living with dementia, holidays and special events can be challenging.. Festivities can agitate, confuse, and overstimulate them. Changes in routine, large and noisy groups, and the general chaos in the air can be anxiety-provoking.
- Each holiday after this one will likely be harder on them, with them being able to enjoy things less and less.

## Adjust expectations

- It's common to feel compelled to “pull out all the stops” because it could be the last holiday their loved one may remember...

*“That, ironically, will usually make it the worst holiday anybody will remember... In spite of the best intentions, many caregivers’ own behavior sometimes triggers negative emotions in the person with dementia: anger, aggression and sadness.  
**[Holiday stress] may amplify those triggers.”***

## Adjust expectations, cont'd

- Dementia varies from person to person, so don't have any expectations of how an activity or experience will pan out.
- Often the holiday or event overall might not go completely to plan, but some aspects of it will be enjoyed -- these special moments will make the experience meaningful and worthwhile.
- It's okay to spend time preparing for and enjoying all of the "things" that make up the holiday or event, but putting feelings ahead of the festivities may end up being the best way to celebrate.
- Remember, the holidays at their best are a time for enjoying one another's company and sharing gratitude for each other.

## Adjust expectations, cont'd

- It's very common for family and caregivers to feel anxious, frustrated, and lonely.
- To minimize the anxiety and encourage a happy holiday season for the entire family, a little advanced thought and planning can go a long way in ensuring everyone has a wonderful time.
- Think about what activities will be the most difficult, socially and emotionally.

## Adjust expectations, cont'd

- Focus on making more moments that really matter by identifying what is most important to you.
  - This may help you feel better about saying “no” to things that might take you away from what is most impactful for you both.
  - Maybe this year you skip getting cookies delivered to everyone, but instead spend time cuddling on the couch and feeling truly connected.

## Planning is key

- Maintain normal routines as much as possible
- Strategize and prepare before the holiday or event
- Educate others about your loved one's dementia
- Build in support for them to be successful

## Plan to keep to normal routines

- This helps keep holidays from becoming disruptive or confusing.
- Stick to daily routines as much as possible. Respect their routines and make it clear that they are not inconveniencing you.
- Give them plenty of time to rest. Don't force them to stay up and join in the activities.

## Plan to lead into the event with music

- Condition them to enjoy happier celebrations by starting their day with some singing of their favorite songs.
  - Before Christmas, sing carols.
  - Before a wedding, sing old favorites like “Going to the chapel” or songs from their own wedding.
  - Choose songs that make them smile or laugh, or that have special meaning to them.
- After the holiday or event, replace these with other happy songs. Help them choose which ones are their favorites.

## Plan with the person with dementia

- In the early stage, some people may withdraw and be less comfortable socializing while others may relish seeing family and friends as before.
  - Check in with each other and discuss options.
  - Ask them if they would like to contribute. Even if they can no longer cook, perhaps they can stir or or add ingredients.
  - Involve them in planning what to do or whom to invite.
  - Focus on the things that bring happiness and let go of activities that seem overwhelming or stressful.

## Plan and consider their needs

- For people in the middle or late stages, rethink your usual holiday plans in light of what they enjoy and what they find difficult.
- Ask caregiver staff and professionals for advice.
- Everyone is unique and finding a plan that works can involve trial and error.

## Planning: YOU be the judge

- It's okay to say NO to family requests, if you feel that it is not in the best interest of your loved one with dementia.
- Explain to family, nicely but firmly, that for your loved one's well being keeping things simple and maintaining normal routines is important.
- If your family does not understand, accept and support you setting limits, then it is really their problem, not yours.

## Plan to educate others

- In the early stage, relatives and friends might not notice any changes.
- But people with dementia may have trouble following conversation or tend to repeat themselves.
- Family can help with communication by being patient, not interrupting or correcting, and giving them time to finish their thoughts.

## Plan to educate others, cont'd

- In the middle or late stages, there may be significant changes in cognitive abilities since the last time a guest visited.
- These changes can be hard for others to see and accept.
- Make sure visitors understand that changes in behavior and memory are caused by the disease and not the person.

## Plan to educate others, cont'd

- It may be easier to share changes in a group letter or email.
- Give honest info on their current condition, as well as limitations or needs, such as keeping a daily routine, or making modifications to plans to minimize holiday stress – emphasize the goal here is time together.
- Describe any usual behaviors or conditions the person with dementia may exhibit. Ask family members not to chastise or try to correct them for these behaviors.
- Encourage family to read about dementia in advance – especially young kids and teens.

## Plan for others' presence

- Remind friends and relatives to re-introduce themselves and make quiet times for one-on-one visits.
- Encourage them to be patient, stay calm, speak slowly in a relaxed tone, avoid criticism, use their name, and do not argue or correct.
- Ask them to put aside any conflict. Someone with dementia will pick up on mood and tension very quickly and may cause them to become upset.

## Plan for others' communication

- Let them know that “quizzing” your loved one may be stressful.
  - “It’s a lovely holiday season” is better than asking them, “What have you been doing over the holidays?”
- Ask them to keep the conversation “failure free” by making general observations as opposed to asking questions that require specific answers.
- Ask everyone to avoid speaking in condescending tones or using “baby” talk.

## Plan for timing

- To avoid your loved one feeling overwhelmed and wanting to go home, plan the celebration during their best hours.
- Plan rest periods, especially at times when they may be irritable or uneasy, and be sure to keep their bedtime the same.
- Limit timeframes. Generally, after being away for two to three hours, people may feel the need to return home. During a hectic holiday visit, they may even want to leave earlier.
  - Do not take this as a failure – a short and good visit is better than a longer, more stressful visit..

## Bring the holidays to them

- A holiday is still a holiday whether it is celebrated at your home or at your loved one's new home.
- Consider joining in any facility-planned holiday activities
- Bring a favorite holiday food to share
- Sing holiday songs and ask if other residents can join in
- Read a favorite holiday story or poem out loud
- Look over old pictures and reminisce

## Tweak when you celebrate

- Celebrate the holiday with your loved one on a day that is not so hectic – they may not realize the actual day of the holiday.
- The spirit of each holiday season can be enjoyed by bringing your loved one home the day after the holiday. You may be less distracted and able to truly enjoy the time with your loved one.

## Plan how much to talk it up

- Providing lots of notice that there is a large gathering may intimidate and overwhelm your loved one, inadvertently adding more pressure to perform socially.
- You can certainly coordinate your day with your loved one's caregiver or care community, but it might be best to not tell your loved one repeatedly about an upcoming gathering.
- Without talking about the big event, prep them for it by talking about and looking at photos of people who will be there, play familiar music and serve familiar foods.

## Build in support: decorate carefully

- Ensure that holiday decorations – including family heirlooms displayed for generations – don't endanger your loved one.
- Make sure that holiday throw rugs and electrical cords do not become trip hazards.
- Don't place large displays in areas that may confuse them.
- If they help with decorating, ensure items get where needed and aren't accidentally hidden.
- Blinking lights may confuse or scare them, and
- Decorations that look like food could be mistaken as edible.

## Build in support: consider a schedule

- Prepare a schedule for the day in advance – not too detailed:
  - 11am: Arrive for tea/coffee and chat/activity before lunch.
  - 12pm: Sit down for lunch.
  - 1pm: A game with the children.
  - 1:30pm: Gift giving with tea/coffee and chat.
  - 2pm: Quiet time, kids watching TV and adults relaxing or having a nap.
  - 3pm: Afternoon tea and a casual activity (optional).
  - 4pm: Head home for dinner.
- When they get there, go through it with them so they will be prepared and can refer back to the schedule for the order of events.

## During the event or celebration

- Keep them comfortable
- Involve them in conversation and activity
- Give them a purpose or role
- Be emotionally supportive

## During: keep them comfortable

- Avoid confusion, frustration and wandering by having a “buddy” assigned:
  - someone close who can understand the disease,
  - to sit calmly with your loved one, and
  - to keep an eye on them for signs of distress or anxiety
  - to help identify other family members and help navigate conversations.  
“Here comes your niece, Pam” may reduce frustration at not being able to remember faces.
- Also designate a driver – someone who can take your loved one home early if needed, and knows how to handle the return (e.g. check in).

## During: keep them comfortable – and safe

- Keep walkways open for wheelchairs and walkers.
- Limit access to stairs and kitchen
- Check temperature of food and drinks.
- Supervise meds and keep emergency info handy.
- Make sure to have favorites at the ready: holiday music, movies, clothing and food – these can bring comfort and build enjoyment into a holiday celebration.

## During: keep them comfortable and included

- Designate a quiet zone -- near the festivities, but not in the center of the action – for your loved one and the companion to sit. This will lessen the impact of noise and activity.
- Make quiet times for one-on-one visits or rests.
- Lower key, one-on-one activities, such as looking through a photo album together or playing cards, are less stressful than noisy activities with several people, even for someone who used to enjoy that type of activity.
- Regularly check on their comfort. Don't overdo it, but be aware if they are starting to feel overwhelmed, so you can take action quickly and diffuse any stress before it becomes an issue.

## During: help them participate

- Know whether they might require additional help.
- For example, they may struggle to cut their food or eat large pieces. To avoid embarrassment during the meal, you can prepare their plate accordingly and serve it to them without calling extra attention to it.
- Get programs, hymnals, prayer books, bibles, etc. in large print.
- Check if they need help turning pages or holding onto reading material during an event or service and offer to help them as needed.

## During: family can involve them in...

- Decorating a paper garland and helping to drape it across a mantelpiece or window.
- Asking for their help with easy activities
- Including them in conversations
- In later stages, simply offering a gentle touch or reassuring word

## During: emphasize gratitude

- Holidays can be much more meaningful if people say what they're thankful for each day. For people with dementia, it will help them to stay positive and connected with the entire family.
- The rest of the family should join in to maximize the effect of being positive. Everybody will feel more hopeful for what's still to come.

## During: involve them in activities

- Build on past traditions and memories. Focus on activities that are meaningful to the them.
- They may find comfort in singing old holiday songs, watching favorite holiday movies, or looking through old photo albums.
- Involve the person in holiday preparation. As the person's abilities allow, invite him or her to help you prepare food, wrap packages, help decorate or set the table. This could be as simple as having the person measure an ingredient or hand decorations to you as you put them up.

## During: give them a role or purpose

- For someone with dementia, a good way of feeling connected to an environment is having a role or purpose. Give them something straightforward to do to help them feel more included.
  - Passing around the matzah during the Passover meal,
  - Folding napkins or programs for a service
  - Starting off the singing
- Read or retell the story of the holiday or festival you're celebrating.

## During: help them create a central piece

- Let them pick the flowers and arrange them in a vase while you cut the stems for them.
- Make a wreath where you can both pick fallen leaves or add holly, pinecones, or whatever you can think of that would add a holiday cheer on your wreath.
- Both of you will smile whenever you see the finished product and they can show off the creative family handiwork.

## During: encourage reminiscing

- Break out the family scrapbooks or photo albums, especially of older pictures. Ask who people are and for funny stories.
- Patience is key: Let them reminisce about stories and things they remember from the past, but don't make it feel as though you're quizzing them.
- Make sure to film the interactions for everyone to share later – can be helpful for the grandkids to do this

## During: avoid alcohol

- Generally, it's best for persons with dementia to avoid alcohol consumption.
- If possible, substitute nonalcoholic beverages. Their sense of taste is weaker and they are unlikely to notice any difference.
- However, if they do drink alcohol, remember this may affect the quality of their sleep. Be prepared for them to awaken at odd hours.
- With alcohol often prevalent at holiday parties, watch their intake, as they may easily lose track.

## During: support their perspective

- Celebrating an event can bring feelings of joy or sadness.
- If a celebration reminds them of events they participated in in the past, they may think that the event being celebrated is from another era. They may speak of people and activities from the past as if they were taking place in the present.
- Rather than trying to reorient them to the present, talk about their memories of similar occasions. Enjoy revisiting the incident through conversation and laughter.
- If they experience sadness, empathize with them, remind them that they are valued; then redirect their thoughts to other things.

## Making events less stressful for you

- Looking at current and future events, it's important to remember the good and to hold onto joyful past memories in the wake of holiday stress.
- Emphasize the positive, rather than being overwhelmed by the negative – this will help you cope and celebrate, and also encourage your loved one to enjoy such a special time.
- Focus on your love for your family and try to maintain happy holiday traditions with your loved ones. Your kids and grandkids will benefit from that later on.

## Lessen your stress with help

- Consider passing on hosting responsibilities and enjoy the hospitality of friends or family.
- Consider hiring help or asking other family members and friends to help, perhaps by bringing food, or coming early to help set up.
- Arrange for respite care so you can enjoy a movie or lunch with a friend.

## Lessen your stress by planning

- Try to keep celebrations small.
- Avoid over-stimulation and over-tiring by eating earlier in the day, and steer clear of long travel
- Use the buddy system and assign someone familiar to the individual with dementia to shield them from distress and give a break to the primary caregiver

## Lessen stress by tailoring traditions.

- Holiday family outings, such as outdoor ice-skating, caroling, or seeing “The Nutcracker” at a local playhouse, hold fond memories, but may not be possible now. Instead, take a snowy-day walk, light a fire and listen to holiday music, or find a version of “The Nutcracker” on DVD.
- If evening confusion and agitation are a problem, consider changing a holiday dinner into a holiday lunch or brunch. If you do keep the celebration at night, keep the room well-lit and try to avoid any known triggers.
- Making cookies can be easier by pre-mixing the dough and focus the fun on cutting out and decorating the cookies.

## Birthdays

- If birthday parties are usually a big event, consider having a separate smaller celebration, or multiple smaller ones.
  - For a son, have just the birthday boy and their siblings.
  - For a grandchild, have just their immediate family members.
  - For friends, celebrate with just two or three of the group at a time.
- Smaller and more intimate events will be easier for them to enjoy.

## For their celebrations

- To honor their birthday or anniversary, hold the activity at a time of day when they are most able to participate.
- Whenever possible, involve them in preparing for the occasion. Much of the pleasure of an event is getting ready and the anticipation of the special day.
- Plan for fewer guests, or stagger the times guests arrive so it's easier for them to interact with people one-on-one.
- Choose a familiar place for the event to reduce stress.

## Weddings

- If your dad is sensitive to too much stimulation, include him in the part of an event that would be the most meaningful. Take him to the wedding ceremony, then arrange for someone to stay with him during the busy reception, or to take him home.
- If your mom is unable to attend the wedding, bring the event to her. Arrange a special visit from the bride and groom. Plan for opportunities where other family members can visit individually or in small groups to avoid overwhelming her.

## Graduations

- Being surrounded by many people that they don't know and have little in common with at a child or grandchild's graduation ceremony can be very stressful.
- Consider having the person with dementia write a formal card or letter wishing their younger relative the best for their future.
- Then have the graduate visit afterward with a highlights video or photos.

## Reunions

- Again, it would be stressful being surrounded by so many people that they don't recognize or can't remember.
- Consider having the person with dementia write a statement or letter to be read at the event, or record a video greeting to play.
- Have a group photo taken and a framed mat that everyone can sign.
- Make a copy of the photo and label people's names and relationships.
- Visit after the event to give them the framed and signed photo, and share a highlights video or other photos.

## Faith services

- Every person is different – someone who went to services every week may want to continue this, or they might not want to if they don't feel as comfortable or able to participate fully.
- Someone who joined a congregation or faith later in life may have more difficulty following the service.
- Some places have “quiet rooms” for crying babies – these might be useful to access if needed.
- Some congregations are actually starting dementia-friendly services that are shorter and tailored to the audience.

## Support their gift giving

- People feel a sense of self-worth when they are able to give to others.
- Shop from home online or through a catalogue. They can still choose gifts for others but avoid the overwhelming shopping trip.
- If they are able and interested, involve them in wrapping, or better yet, use gift bags.

## Celebrate from a distance

- Send video messages: seeing you “in person” is more special than a call. Have family, friends, or staff set up a computer, phone, or tablet to share video messages or facetime.
- Send cards and letters: people enjoy receiving mail and having something to look forward to reading. If they are more traditional, you could send a formal holiday card and letter full of all the latest news and goings on in yours and your family’s lives.
- Send thoughtful gifts: a photo album of some favorite shared memories or a care package of luxury essential items

## Resolving the guilt

- Be forgiving... of yourself, your family, and your loved one.
- No one is perfect. Mistakes are going to happen. Things may have been said or done by your loved one or other family members that caused stress.
- But your ability to move past that and set it aside can only support a happier celebration, and relationship, for all of you.
- Let go of past hurts – if not forever, at least for now.

## Guilt and shame

**Brene Brown and other writers encourage us to examine these feelings and transform them into strengths:**

- “Shame is the most powerful, master emotion. It’s the fear that we’re not good enough.”
- “Shame corrodes the very part of us that believes we are capable of change.”
- “If we can share our story with someone who responds with empathy and understanding, shame can’t survive.”

## Guilt vs shame

**Brene Brown:**

- “Guilt is just as powerful, but its influence is positive, while shame’s is destructive.”
- “Guilt helps us stay on track because it’s about our behavior. It occurs when we compare something we’ve done – or failed to do – with our personal values.”
- “Shame erodes our courage and fuels disengagement.”

## Emotional connection

### **Brene Brown:**

- “We cannot selectively numb emotions, when we numb the painful emotions, we also numb the positive emotions.”
- “I define connection as the energy that exists between people when they feel seen, heard, and valued; when they can give and receive without judgment; and when they derive sustenance and strength from the relationship.”
- “You are imperfect, you are wired for struggle, but you are worthy of love and belonging.”

## Work-in-progress

- Dementia will continue to progress and change your loved one.
- Likewise, you will need to continue to evolve in your responses to them and to find new solutions.
- It’s always a moving target – once you figure out something that works, things will change and you will need to figure it out and adjust.
- You’re going to need ongoing support as your situation changes and the challenges you face are different.

## Support groups

- Support groups can be very valuable to helping you remember that you are not alone, that other people understand what you are going through.
- Support group members can also be sources of advice and knowledge, tips and tricks, to make life easier.
- If possible, find a group focused on your role (partners, adult children, long distance, etc.)

## What's most important?

- Accept where your person with dementia is at, right now, and what is important to them.
- Focus on what is important to them.
- Treat them with care, respect, and dignity.
- Help them have the best quality of life possible.

***Professionals and care providers can help handle sticky situations.***

## What's most important – for you?

- Allow yourself to feel however you feel. Remember any feelings are normal and ok.
- Get support for yourself – know that you are not alone.
- Take care of your own health and wellbeing.

## Feel free to contact me with any questions:



### **Aging Care Consultation Services**

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