

Peas on Earth

ALZHEIMER'S AND DEMENTIA OVER THE HOLIDAYS



Presented by Sandy O'Brien RN MN ACM CL

-HOLIDAYS CAN BE EXTRA CHALLENGING WHEN YOU HAVE A LOVED ONE WITH DEMENTIA.

-KNOWING WHERE THEY ARE IN THE DISEASE PROCESS CAN BE VERY HELPFUL FOR ALL INVOLVED.

-THIS ALONG WITH PLANNING AND SELF-CARE CAN MAKE THE HOLIDAY EXPERIENCE LESS STRESSFUL AND MORE ENJOYABLE.

Lets Start with Planning

- ▶ CHANCES ARE THE HOLIDAYS WILL NOT LOOK THE WAY THEY USED TO. NOT EVERYONE HAS A HALLMARK HOLIDAY TO BEGIN WITH, BUT WHATEVER YOUR PAST EXPERIENCE HAS BEEN, SOMETHING WILL CHANGE. IT EXPERIENCE WILL BE DIFFERENT.
- ▶ UNDERSTANDING THIS AND ENCOURAGING OTHERS TO UNDERSTAND IT WILL HELP WITH UNREALISTIC EXPECTATIONS.
- ▶ THE DEGREE TO WHICH YOUR LOVED ONE IS AFFECTED WILL DETERMINE THE DEGREE OF COORDINATION AND ENERGY (EMOTIONAL AS WELL AS PHYSICAL) REQUIRED OF YOU AND OTHERS, NEEDED TO INCLUDE THE PERSON WITH DEMENTIA IN GATHERINGS AND ACTIVITIES.

When Planning for the Holidays it is Important to Ask Yourself Some Key Questions

WHAT ARE THE GOALS OF THIS HOLIDAY SEASON BASED UPON WHAT EVERYONE WANTS?



START OFF GENERAL THEN BECOME MORE SPECIFIC WHILE USING:
THE RULE OF THREE

-WHAT ARE THREE THINGS YOU THINK **OTHERS** (FRIENDS, FAMILY) EXPECT AND MAY WANT? (TRADITIONS, ACTIVITIES, ETC.)

-WHAT ARE THREE THINGS YOUR **LOVED ONE** HAS EITHER TOLD YOU THEY WANT OR YOU BELIEVE THEY WOULD WANT? (IF THEY HAVE OR COULD EXPRESS THEIR DESIRES TO YOU.)

-AND, WHAT ARE THREE THINGS **YOU** WANT?

Now what are the Goals based upon wants and expectations?

- ▶ **ARE THE REALISTIC? ARE THEY FAIR? ARE THEY FACTORING IN WHAT YOU NEED NOW AND WHAT YOUR LOVED ONE WITH DEMENTIA NEEDS NOW?**
- ▶ **WHAT IS NEGOTIABLE AND WHAT IS NOT.**
- ▶ **WHO WILL HELP YOU WITH THESE GOALS, WHO WILL DO YOU THINK IS DEPENDABLE. (BEHAVIORS AND ACTIONS DON'T NECESSARILY CHANGE EVEN IF THE SITUATION IS DIFFERENT, IF THEY DID NOT COME AROUND BEFORE THEY MAY NOT NOW).**
- ▶ **ARE YOU WILLING TO ASK FOR HELP (WAS YOUR ROLE IN THE PAST TO BE THE ONE TO ORGANIZE AND MAKE THINGS HAPPEN, OR HOST GET TOGETHERS, BE SUPER GRANDMA OR GRANDPA, MAKE THE PEACE, ETC).**
- ▶ **CAN YOU BE AN ADVOCATE?**

Once you have decided on the Goals for the Holidays

- ▶ **DEVELOP A PLAN FOR REACHING THEM, (BEFORE YOU INCLUDED SOME DEGREE OF FUN FACTOR)**
- ▶ **MAKE SURE YOU DEVELOP STRATEGIES TO REALIZE YOUR THREE GOALS (AT LEAST ONE SHOULD BE PERSONAL) . IT IS ESSENTIAL THAT YOU FIND RELIEF AND JOY, MAKE THAT A PRIORITY. YOU CANNOT PROVIDE FOR OTHERS IF YOU DON'T PROVIDE CARE AND SUPPORT FOR YOURSELF FIRST**
 - ▶ **WHAT DOES THAT LOOK LIKE?**
 - ▶ **COMMUNICATE WITH OTHERS AND YOURSELF**
 - ▶ **SELF TALK, HONOR YOUR EMOTIONS AND FEELINGS, AND THOSE OF OTHERS**
 - ▶ **YOU MAY BE SURPRISED, DISAPPOINTED, FRUSTRATED. ALL OF THEM.**
 - ▶ **PRACTICE SELF COMPASSION**
 - ▶ **FOLLOW-THROUGH – HOLD PEOPLE TO PROMISES IF YOU CAN TO GIVE YOU A BREAK AND DO THINGS YOU USED TO DO.**
 - ▶ **BE FLEXIBLE (OK TO HAVE NEW TRADITIONS OR CHANGE) PRACTICE CELEBRATE – THANK OTHERS AND YOURSELF, SAY YAY ME(s)**

Communication with Others that may apply to some or all Stages Prior to Holidays or Get-togethers

IF YOU CAN, DISCUSS PLANS FOR THE HOLIDAY EARLY AND WHAT TO EXPECT. SOME WAYS TO DO THIS ARE:

CALL A FACE-TO-FACE MEETING

ARRANGE A CONFERENCE CALL

SEND AN EMAIL OR LETTERS



EXAMPLE OF WHAT TO PUT IN WRITTEN MESSAGE:

- ▶ I'm writing this letter to let you know how things are going at our house. While we're looking forward to your visit, we thought it might be helpful if you understood our current situation before you arrive. "You may notice that ____ has changed since you last saw him/her. Among the changes you may notice are _____. I've enclosed a picture so you know how ____ looks now. "Because ____ sometimes has problems remembering and thinking clearly, his/her behavior is a little unpredictable. Please understand that ____ may not remember who you are and may confuse you with someone else. Please don't feel offended by this. He/she appreciates your being with us and so do I. Please treat ____ as you would any person. A warm smile and a gentle touch on ____'s shoulder or hand will be appreciated more than you can know. "I would ask that you call before you come to visit or when you're nearby so we can prepare for your arrival. Caregiving is a tough job, and I'm doing the very best I can. With your help and support, we can create a holiday memory that we'll treasure. www.alz.org/midlands

The Stages of Alzheimer's/Dementia and the Holidays

- ▶ **MANY VARIABLES CAN IMPACT HOW FAST OR SLOW SOMEONE PROGRESSES THROUGH THESE STAGES, THE FOLLOWING ARE SOME IDEAS TO HELP YOU WITH DECREASING HOLIDAY STRESS BASED UPON THE IDEA THAT IT NEEDS, FUNCTIONS AND EMOTIONS CAN AND WILL CHANGE. IT IS BETTER FOR ALL THAT YOU GO TO WHERE YOUR LOVED ONE IS ...**
- ▶ **IN THE INTEREST OF SIMPLIFICATION I HAVE REDUCED THE 7 STAGES OF THE DISEASE, AS DESCRIBED BY THE ALZHEIMER'S ASSOCIATION INTO THREE STAGES:**
 - ▶ **EARLY, MIDDLE, AND LATE**
 - ▶ **(PLEASE REFER TO YOUR GUIDE TO DESCRIBE EACH)**

Early Stages

- ▶ THEY ARE AWARE, BUT MAY OR MAY NOT BE AWARE OF LIMITATIONS, BUT NEED INTERACTIONS AND EXPERIENCES THAT HELP SUPPORT THEIR REMAINING ABILITIES.
- ▶ BE SURE TO INVOLVE THEM IN DECISION MAKING
- ▶ AVOID QUESTIONS LIKE; DO YOU REMEMBER WHEN? TRY NOT TO PUT THEM ON THE SPOT OR WHERE THEY MAY FEEL EMBARRASSED.
- ▶ YOU MAY FEEL VERY SAD EVEN ANGRY DURING THESE TIMES, YOU MAY BOTH BE GRIEVING, IT IS UNCOMFORTABLE BUT A NATURAL REACTION.

GIFT IDEAS:

- ▶ THINGS THAT ENCOURAGE PLEASANT MEMORIES, SOCIALIZATION, AND ACTIVITY, MUSIC. SOFT OBJECTS, PILLOWS, ROBES, COLORFUL MOBILES, WINDOW PRISMS TO CATCH THE SUNLIGHT. A VISIT FROM A SMALL PET AMONG OTHERS. MEDIC ALERT BRACELETS IF THEY WILL WEAR THEM, APPLIANCES THAT HAVE AUTO SHUT OFF. LARGE CALENDARS AND CLOCKS. MEDICATION REMINDER/CONTAINER. BOOKS SPECIFICALLY FOR DEMENTIA (AMAZON HAS A VARIETY OF OPTIONS)

ACTIVITIES:

- ▶ SHOULD BE ABLE TO TAKE PART IN MOST ACTIVITIES, LET THEM TELL YOU WHAT THEY WANT, BUT AVOID THEY'RE BECOMING OVER TIRED. (LIKE MOST OF US)

TRAVEL:

- ▶ WOULD DEPEND ON ADVANCED THE DISEASE IS, BEST NOT TO TRAVEL LONG DISTANCES IF CAN BE AVOIDED. BUT IF STILL EARLY-A JOINT DECISION. DIFFERENT ENVIRONMENTS CAN BE VERY CONFUSING, MAKE SURE THEY ARE NOT EXHIBITING ANY SIGNS OR INDICATIONS THAT THEY ARE SICK OR GETTING SICK. DON'T LEAVE ALONE FOR VERY LONG, CHECK IN WITH THEM. HAVE SOMEONE WITH THEM IF YOU CAN. HAVE A DESIGNATED QUIET ROOM FOR A NAP AND A PLACE TO GET AWAY FROM STIMULATION. TRY TO STAY ON SCHEDULE WITH BEDTIMES BACK HOME.

SAFETY:

- ▶ PUT KEYS TO CAR WHERE THEY ARE NOT EASILY FOUND. AVOID OR MINIMIZE ALCOHOL IF YOU CAN.
- ▶ THEY MAY DECLINE IN THE EVENING AS WITH ALL STAGES, BE MINDFUL THIS MAY HAPPEN.



Middle Stages

- ▶ MORE DIFFICULTY WITH DAILY ACTIVITIES ALONG WITH COMMUNICATION AND ATTENTION SPAN. (INCREASE YOUR SELF CARE AND SUPPORT WHEN YOU CAN)
- ▶ TRY DOING THINGS EARLIER IN THE DAY, AND PERHAPS AT A DIFFERENT LOCATION. (YOU MAY WANT TWO EPISODES OF CELEBRATION; ONE WITH THE YOUR LOVED ONE AND ONE WITH FAMILY ON ANOTHER DAY OR LATER THE SAME DAY.)
- ▶ TRY TO VISIT IN SMALL GROUPS EARLY IN THE DAY INSTEAD OF A LARGE ONE.
- ▶ YOUR LOVED ONE MAY NO LONGER LIKE OR ENJOY WHAT THEY USED TO, THEY MAY LIKE OTHER THINGS THAT SURPRISE YOU. TRY TO GIVE THEM TWO CHOICES WHEN YOU CAN.

GIFT IDEAS:

- ▶ THINGS MAKE DAILY ACTIVITIES SIMPLE, THINGS LIKE EASY TO SLIP ON SOCKS, THINGS THAT MAKE GROOMING EASIER, EASY TO PUT ON CLOTHING. THINGS THAT THEY CAN LISTEN TO AND WATCH LIKE MUSIC, TAPES, VIDEOS, PICTURES, PHOTO ALBUMS OF FAMILY AND OTHER THINGS. ALSO THINGS, THAT MIGHT BRING NATURE TO THEM, BIRD FEEDERS, BIRD SONGS. CONSIDER ASKING FOR A "BABY MONITOR."

ACTIVITIES:

ENCOURAGE TO PARTICIPATE BUT, AVOID LOUD NOISES AND MUSIC. ENCOURAGE THEM TO TAKE PART IN THINGS LIKE BAKING, CAR RIDES TO SEE LIGHTS, ETC. AVOID HEAVILY CROWDED ENVIRONMENTS.

TRAVEL:

MAY NEED TO AVOID ALL TOGETHER, BRING FAMILY AND FRIENDS TO THEM.

SAFETY:

DON'T LEAVE ALONE, HAVE SOMEONE WITH THEM AT ALL TIME. PUT KEYS TO CAR WHERE THEY ARE NOT EASILY FOUND. PUT BELLS ON THE DOORS. KEEP PATHWAYS CLEAR OF TOYS, WRAPPING PAPER, CLOTHES, ETC. ESPECIALLY TO THE BATHROOM. OFFER BATHROOM AND TAKE OFTEN ASSIGN THEM THEIR OWN CHAIR AND KEEP IT AVAILABLE, PUT SOMETHING THAT IS THEIRS, THAT THEY CAN EASILY RECOGNIZE ON IT. AVOID FOODS THAT MAY CAUSE GASTRIC DISCOMFORT, OR DECORATIONS OR ORNAMENTS THAT LOOK LIKE FOOD. AND AVOID ALCOHOL. WITH INCREASE IN DON'T FORGET MEDICATIONS. PUT NAME ON LABEL OF CLOTHES.



Last Stages

- ▶ MORE DIFFICULTY WITH DAILY ACTIVITIES ALONG WITH COMMUNICATION AND VERY SHORT ATTENTION SPAN, POOR MOBILITY, POOR COMMUNICATION AND CANNOT PERFORM COMPLEX TO MOST TASKS.
- ▶ VISIT IN SMALL GROUPS EARLIER IN THE DAY, NOT LIKELY THEY CAN GO OUT.

GIFT IDEAS:

SHOULD GENTLY STIMULATE THE SENSES AND BRING THE INDIVIDUAL COMFORT AND SECURITY. TRY TO PROVIDE GENTLE MUSIC, GENTLE SMELLS AND GENTLE EXPOSURES.

ASK FOR GIFT CARDS THAT MAY PROVIDE RESOURCES FOR IN-HOME GROOMING AND RESPITE ALONG WITH FOOD DELIVERY FOR YOU AND SPECIALTY FOOD FOR YOUR LOVED ONE. GIFT CARDS CAN ALSO HELP PAY FOR TOILETING NEEDS/HYGIENE NEEDS. EQUIPMENT.

HAVE SOMEONE COME OVER AND READ TO THEM

THE GIFT OF TOUCH AND MUSIC ARE ESPECIALLY IMPORTANT.

ACTIVITIES:

MAY BE LIMITED BUT CAN GO ON AROUND THEM IF THEY ENJOY AND CAN TOLERATE.

TRAVEL: NOT RECOMMENDED.

SAFETY: NEED 24 HR. SUPERVISION

SELF CARE: ESSENTIAL ASK FOR RESPITE AND SUPPORT



REMEMBER

- ▶ AVOID UNREALISTIC EXPECTATIONS
- ▶ ASK FOR WHAT YOU NEED, MANAGE YOUR ENERGY.
- ▶ BE KIND TO YOU, USE SELF COMPASSION, KIND SELF TALK AND CELEBRATE. (BE AWARE YOU MAY EXPERIENCE POST HOLIDAY SADNESS.)
- ▶ FIND HUMOR WHERE YOU CAN
- ▶ BE OPEN TO NEW MEMORIES AND LETTING SOME TRADITIONS GO, BUT FLEXIBLE
- ▶ TAKE TIME OUT, EAT WELL, SLEEP
- ▶ USE POSITIVE MEANS FOR COPING
- ▶ IF YOU AND/OR YOUR LOVED ONE ARE PEOPLE OF FAITH KEEP PRACTICING AND MAKING IT A PART OF YOUR LIVES, REGARDLESS OF WHICH STAGE YOU LOVED ONE IS AT.



Activities

- ▶ Cards
- ▶ Smells
- ▶ Sights and Sounds
- ▶ Memory Books
- ▶ Mittens/Hats
- ▶ New Years Noises, Hats

Wishing You a Wonderful Holiday Season



► From: HARBOR TRANSITIONS LLC

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