# Caregiving 101 Care Partnering 101

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Today we will take a 30,000 foot view of the principles of caring for a PLWD and then come in to explore how to actually implement these in your everyday needs.



# Important factors for take off in flight. Critical knowledge that must be understood.

- \* Dementia is a progressive brain condition that, as of now, has no cure. The PLWD is in brain failure.
- \* Depending on the type of dementia and the individual, the symptoms will be somewhat different.
- \* There are around 100 different types of dementia and some of the techniques may need to be modified depending upon your PLWD.

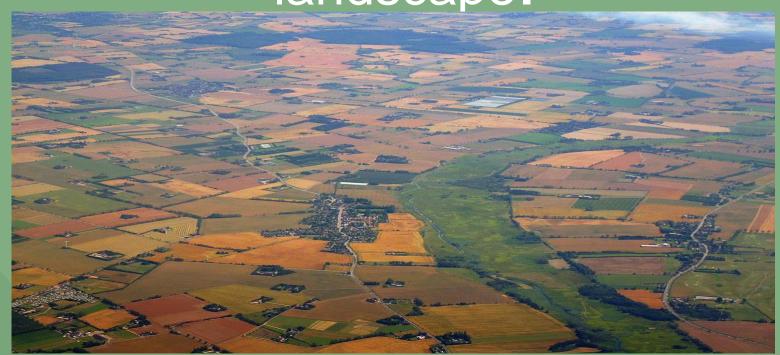
# Principles of understanding basic communication skills when working with the PLWD

- Work <u>WITH</u> the PLWD do not do <u>TO</u> them. It might take a little longer up front, but the outcome will be better, and actually take less time overall.
- You must truly believe that the PLWD is doing the best they can.
- We must change as they change.
- Relationships are more important than tasks to be accomplished.

## Self Care – It is for the PLWD as well

- \* Start early in the journey, do not wait until it gets too much. Find a helper.
- \* Put something in your appointment schedule and stick with it. (hair appointment) This makes it a routine, even if you do not really have a hair appointment. Routine is important.
- \* Get connected. Support Groups, Alzheimer's Assn etc...
- Stop comparing or worrying about what others think or about perfection.
- Take little moments when you get them, dishes be dammed.
- Breathe, it is more than a catch phrase.
- Have FUN with your PLWD Music, dance, ice cream.

# Now we are have reached cruising altitude, let's take a good look at the landscape.



# You can only do what you have permission to do, anything else the PLWD will feel violated.

- Relationship is everything
- They may not remember what you did that upset them but they will remember the feeling they got when we force our will on them, however well meaning it was.
- Take your time and breath, look at the whole picture, the whole person and be a bit of a detective.
- Think about maslow's hierarchy of needs

# Maslow's Hierarchy of Needs

home= connections and control / hallucinations, not feeling safe? Let's get out of here



- Focus on what they can do and not on what they cannot do.
- Our actions, however well meaning, often are the cause of their frustrations.
- Learning how to hide your agenda and understanding what really needs to be addressed and what just needs to be let go is crucial. Ask your self, is this really important right now?
- Teepa Snow teaches that it is all in our approach: vision loss, along with the inability to swiftly process spoken language places a great importance to learning the skill of approach, visual, verbal, touch in that order.

## Break tasks down to little steps

Simplify the environment. Example: If brushing teeth, have nothing on the sink top except what will be used. When getting dressed only have 1 item in view at a time.

- \* Use Nonverbal communication hand gestures etc.. Say less motion more help me do...?
- Start with the first step and wait, help with hand under hand when needed. Then move the 2<sup>nd</sup>. How much assistance depends on what stage the PLWD is in.
- Steps have to be very small not put on your pants putting on pants have about 6 8 steps. Think about where you are positioned and how you are motioning, using just a few words. Praise them but be careful not to do it in a way that makes them feel belittled. This is very important.
- Blame the item. Example: "That's ok, happens to me all the time; these darn toothpaste tubes are just difficult, you'd think someone would come up with a better design"
- Templates can be very helpful. These can be used for activities or for self care, or tasks around the home.

## Tips

- Hide your agenda there are 2 agenda's yours and theirs your job is to make them match as much as possible. Do not force your agenda Do not use task words too early.
- Use Nonverbal communication hand gestures etc.. Say less motion more help me do...?
- Do not use tasks words until you are in the room where it happens. Maybe do a little task before that
  is not so difficult for the PLWD.
- Be careful of your tone, to not sound as though you are assigning blame or speaking to them as a child or a boss or as if they are stupid.
- When giving choices make it only 1 or 2 at the most especially if it is something they might say no to. Beware of yes, no questions, they will say no 90% of the time.
- Sometimes it is easier to change the environment than change the person. Example, coffee table or plant.
- Schedule appointments, difficult or stressful tasks at their best time of day.
- Example: We've been sitting a long time my bones are aching... I need your help.

# Coming in for the Landing



# Coming in for the landing. Where the rubber meets the road.

- Examples and putting the skills to work.
- Marie Montessori said: Everything to you for me you take away from me.
- Do not do too much. Let the PLWD dementia be the guide for this. Only assist as is truly needed.
- Assistive or modified devices are great way to keep as much independence as possible.

# Care-partnering 101 Top Difficult Tasks

- Bathing I rarely ever use the words bath or shower Cozy
   Wash Up
- Eating Sit down meals to finger foods while on the go
- Walking Put rhythm to the walk hand underhand
- Oral hygiene Brush teeth
- Toileting Personal hygiene
- Dressing / Undressing

# Bathing / Showering

- Bathing I rarely ever use the words bath or shower –I use 'Cozy Wash Up'
- For \$3- 5.00 you can transform the way you approach personal hygiene.
- The cozy wash up can be used in a tub or shower or if bathing has become a real issue for the PLWD use it right in their room or anywhere they feel safe and comfortable with a modified commode.
- Do it at their best time of the day. If done when they get up and they have night clothes on it might be easier.
- Start this early in the dementia process. It will be even more helpful later.
- With the cozy wash up they are always covered, never naked or exposed.
   No worry if the draped towel will fall off. They will feel less vulnerable, and cold.

### Steps

- Show the PLWD the cozy wash up, make sure it is in their field of vision. Show
  them the hole and motion that it goes over their head. Maybe model it for them.
  Then if needed assist in putting it on. Maybe have one of your own, this creates a
  we not just a you.
- You can do this while they are still in bed or even on the sofa or wherever, you do
  not have to wait until you are at the shower or commode.
- Take the clothes off (and put back on) underneath the cozy wash up. Only take off what they are comfortable with.
- Have 2 basins of warm water and at least 3 wash cloths, and some disposable wipes (warm), 1 towel, no rinse or mild soap. 1 basin Will work but 2 is nice. Tip: save time running around gathering items. Make a cozy wash-up pack to always have on hand ready to go.

### Steps

- NEVER start with the face or anywhere on the head!
- Consider using salon or 'beauty operator' for hair.
- Give the PLWD a warm wet washcloth. Let them start... wait, then assist. This helps them know what is going on and puts them in charge.
- Do the places that are not as threatening feeling first. Then move to other areas. Use hand under hand as much as possible. When they are comfortable get the next washcloth and with their permission do areas they cannot reach. The back has less nerve endings than the front.
- If you have a 2<sup>nd</sup> basin you can use it to put the feet in and wash and feet and legs and might be relaxing and more like a spa.
- Cleaning the Face and the peri-area go only with permission and let them do as much as
  possible and do hand underhand if they cannot do it alone. If I touch your face it is weird,
  but you can touch your own face just fine.

# Eating and Drinking

- This will change dramatically as the PLWD changes.
- They may not like foods they did before or like foods they didn't be open to that.
- Only do what you need to do when you need to do it.
- Messes are OK. Instead of the bib looking item try the big Italian napkin.
- Assistive devices
- The color of the tablecloth, plate and food matters.
- Put one item at a time in front of them.
- Make sure the food and the drink are in tier field of vision in bright or contrasting colors

#### Assistance Levels

- Set up open packaged food, cut food into small bite sizes before bringing to the table and position the PLWD so they are sitting as upright as possible.
- Cueing
- Mirror or eat with them.
- Chaining
- Hand under hand try assistive devices first
- Full assist understanding that the inability to swallow or the desire to take in food/fluid is part of the end process. When to say when. Is there a plan for that?

# Eating

#### • <u>Texture</u>

- Regular to texture as tolerated
- Soft think mashed potatoes, macaroni, ice cream Puree? Try forms or molds
- Have meat already cut up before bringing to the table. Ready-made meals, or have them help.
- Swallowing can become an issue work with a speech pathologist (therapist) small bites followed by small drinks. Mirror swallowing in their field of vision. If allowed, touch the cheek or throat.
- Problem foods hard to maneuver and handle.
- Spaghetti some soups
- Foods that are hard to chew or swallow i.e., steak or large amounts of peanut butter
- Other things to consider
- We lose around 50% of our taste buds as we age. Especially sweet and salty.
- We lose the ability to recognize thirst as we age.
- Straws can help but can be tricky with swallowing issues Aspiration Decisions

# Adaptive Devices



# Food on the go

- There may be a time when the PLWD just will not sit for a meal. If sitting for a meal gives stress, then try food on the go. Think about foods you can easily eat with one hand.
- Cheese Sticks or cubes or cheese crackers
- Fish Sticks Chicken strips not too hot
- ½ or even quarter sandwich
- Protein shakes Sips add up
- French toast sticks
- Boiled egg
- If mealtime is not working then work food into everything else throughout the day.

# Walking

- Again, depending on where they are in the dementia process, and what type of dementia they have will greatly change how much assistance the PLWD will need.
- Start by watching Is there a list to one side more than the other? Is this driven by vision or balance? How far do they stoop over? Do they reach out to hold on to things? Have they always been a risk taker or a safety seeker? Do they push back or are they ridged?

# Safety in Walking

- Make clear well-lit paths, with items they can hold on to.
- If they cannot remember their walker even after placing it in their field of vision with a big note on it, try having furniture or grab bars placed around where they can hold on as they ambulate.
- Move items that are trip hazards and confusing such as throw rugs especially if they have a
  different colored border.
- Remove furniture that is not in their field of vision that can cause trips or falls, stubbing toes
  or hitting their head.
- Areas you do not want them to go, keep dark and create a natural looking barrier.
- Shoes and gripper socks
- Incontinence products
- Gait belt?

# Assistance in walking

- Standing up: Approach in their field of vision (you may need to bend far over) Offer hand under hand Stand to their weaker side if they have one. Bend over and forward to signal what you want and with very few words signal with your motion for them to bend forward and then stand.
- Keep the hand under hand as a rudder to steer them, pumping the palm as you go.
- Walk with rhythm, even singing in rhythm as you go. (music is an important tool)
- When it is time to sit pump the palm as you motion, then lean a little forward and then sit.

# Oral Hygiene

- Brushing Teeth
- Warm water warm environment- towel or cozy wash up
- Good uplighting- color contrast
- Toothpaste that is not strong flavored (kids)
- Smallest and softest head on the toothbrush in a bright or contrasting color.
   Assist using their dominant side.
- Minimum Assistance Set up and environment, cueing
- Medium Assistance they hold toothbrush, and you guide as needed.
- Full assistance you do the fine motor skills with hand underhand. Use motions, gestures
  in their field of vision, ouch toothbrush to lips.

# Toileting - Incontinence

- This is very specific to the individual and the stage they are in.
- If using the bathroom the door must be open when you approach with the light already on and warm.
- Try the cozy wash up or the wrap around towel
- Use the words 'push down' rather than 'pull down'
- Use hand under hand.
- When all else has failed and they really need to change their brief /
  pants..... 'accidentally' spill something on them and then apologize,
  this almost always works if done right. But have everything set up and
  ready, warm wipes, clothes etc...

# Dressing - Undressing

- Use Cozy wash up to dress and undress Warmth and preserve dignity— Have several – Same color or different depends on your PLWD
- · Stretch, elastic, smooth fabric, Velcro, and just little big.
- Stay away from over the head that have small openings or do not stretch.
- When you find something that works really well, buy several.
- Modify clothing! When people ask Let me know if there is anything I can do to help.... Well yeas there is and give them specific items such as these to help. If they do not sew ask them to help you find someone.
- For front closure shirt Your hand through sleeve hold their hand and pull through -

## Steps

- · For front closure shirt, sweater, jacket or coat.
- Position yourself in their field of vision and show them the item.
- · Put your hand through sleeve hold their hand and pull through
- Keep it below their elbow go low across the back and put your hand/arm in the other sleeve, hold their hand and pull through.
- Pull the clothing up and around. Allowing them to assist.
- For over the head
- Repeat the 1<sup>st</sup> 2 steps
- Keep sleeves above the elbow as high as possible
- Motion head down and point to the hole for the head, pull over head

# For pants

- If you have trouble kneeling or bending far down. Get a quick folding low stool for you if needed.
- Push down Pull up
- Hands through leg of pants as in shirt
- Lean forward and stand
- Elastic waist bands and stretch fabric are your friends.

# Bring down anxiety and stress learn how to diffuse a situation.

- 1.) Repeat what they say with the same emotion.
- 2.) Validate their feelings-and to say sorry in a heartfelt way when needed.
- 3.) Be the hero come on, I will help you!
- 4.) Break the loop "tell me about it" Move away from the situation.
   (HUH pumping the palm as needed)
- 5.) Remember substitute do not subtract. Make a deal.
- 6.) Engage in meaningful activities boredom will restart the loop.