

Finding the Flow of the Day for People Living with Dementia

Melanie Bunn, RN, MS
melanie.bunn@yahoo.com

Helping people living with dementia (PLWD) find meaning in their days takes creativity and organization, 2 skills that don't often go together naturally.

- When done well, the day ebbs and flows, with time spent alone and with others, active and relaxing, doing things one needs to do and things one wants to do.
- When done well, the day is predictable and interesting.
- When done well, PLWD experience joy and fun, fulfillment and success, and positive relationships with the people around them.
- So, investing time in finding the flow with a flexible structure is worth the time and energy. developing a schedule is worth the time and energy.

There are 4 components to put together when organizing the day:

- What you know about the person
- 4 ways we spend time (self-care, leisure, rest, work)
- Daily energy levels and patterns
- History of usual day

WHAT YOU KNOW ABOUT THE PERSON

This is what you know about the person, or think you know about the person. But may or may not have been real, could have been part of "public" face versus "private" face. Plus, these characteristics may or may not be changed by dementia.

- Introvert/Extrovert: where does the person get energy? alone or with others?
- Likes to be in control or go with the flow
- Organized and structured or flexible
- Coping skills
- Likes and dislikes

4 WAYS WE SPEND TIME

Self-care: What you do to meet your basic needs, eating/drinking, bathing and grooming...

Leisure: Activities you do just because you enjoy them, fun, interesting, enjoyable

Rest: Things you do to reenergize and restore yourself, build yourself back up

Work: Activities that make you feel worthy, accomplished, important, (paid or not)

Principles

- Not all activities fit in the same category for all people
- Some activities can fit into more than one category for the same person
- Rest is ACTIVE not PASSIVE, doing with intent, not doing anything is WAITING
- Balance is the KEY! PLWD need each of these, every day!

DAILY ENERGY LEVELS AND PATTERNS

Think about these critical questions

- What was the person's usual energy level earlier in life?
 - Busy person?
 - Still person?
- What is the person's energy level now?
 - Busy person?
 - Still person?
- Morning person? Evening person?
 - When was/is the person's high energy level time/s of the day?
 - When was/is the person's low energy level time/s of the day?

HISTORY OF USUAL DAY

What was a usual day like, in the past? recently?

- Time get up and routine
- Work: Home or away? Type of work?
- Bathing: Bath or shower or sink? Time of day? Frequency?
- Bathroom schedule
- Meals: Times? Alone or group? Formal or informal? Table?
- Time to go to bed and routine

Who was around? Lots of people? Family or strangers? Or more time alone?

Was this the person's choice or just what happened?

What do you know about other times of life and routines?

- Young child
- Young adult
- Working life
- Early retirement

What happened on weekends? Holidays?

Did this person like and use routines or prefer a more loosely structured day?

PUT IT TOGETHER

Take the information you've collected and put it together. The goal is to develop a daily routine that is consistent and predictable, but flexible and responsive. This requires pulling together the 4 ways we spend time, daily energy levels and patterns, history of usual day.

- Start developing your schedule by putting in the less flexible pieces. This might include leaving at a specific time for an adult day program, meals that are served at a specific time, getting up/going to bed times that work best for the person.
- Block in most important patterns from usual day. Sometimes it's helpful to start with the morning routine, because most people have one (usual time and order of activities)
- Color code times of high and low energy. (maybe red-high, yellow-moderate, blue low)
- Match energy level with activities from 4 ways we spend time. So a high energy time might match up with a work activity and a low energy time match up with a rest activity.
- For example, before breakfast, you might want to ask the PLWD to help you wipe down then set the table (moderate energy, work activity consistent with previous routine.) During the meal, the person might eat and engage in social conversation and remembering (low energy, leisure and self-care activity.) After the meal, the person can move to the living room to watch the weather (low energy, rest activity) followed by a walk to the mailbox (high energy, self-care and leisure activity).

Movement through the day: The pattern of movement through the environment is important for some people; it gives the day predictability and meaning. Think about how the person literally moves through the day. Where does the day start, where do we go next, then where do we go? This consistency helps with creating "muscle memory."

Structured flexibility or flexible structure: The idea is that each day will have the same flow, meaning the order of types of activities and location of activity will be consistent, the same every day, with variation occurring from the specific activity. So every day has the same PATTERN regarding ORDER and LOCATION with variation within the SPECIFIC ACTIVITY.

Example:

Morning: bathroom-toilet and grooming, hand washing, meal prep, breakfast, clean up, bathroom, outdoor activity (gardening, walking, exercise) bathroom hand washing, table activity (craft, cooking, seasonal/multisensory experience)

Midday: meal prep activities, lunch, clean up, quiet rest time, movement activity (balloon tennis, dance), outside activity, table activity

Evening: meal prep activities, supper, clean up, activity box, bed time routine

Using the day to reduce distress

The flow of the day can be the answer to many challenges. Realize that when the person becomes distressed, your response makes a difference and using your skills in approach and communication can make the difference in both process and outcome. But that response is only the beginning. The critical action is what follows, understanding what happened and how to reduce risk! The first step is understanding what happened by describing, not diagnosing because when we label, we limit! Look at the person's day, what was different? What was the same? What were the early signs? What were the later signs?

Progressively lowered stress threshold is a theory developed by Geri Richards Hall and Kathleen Buckwalter that offers tremendous insight into distress, especially that occurring late afternoon or early evening. The following is adapted from their work. They identify 3 levels of behavior; normal, anxious and dysfunctional. Normal is baseline behavior. Anxious can be either restless or withdrawn. Dysfunctional includes an element of risk. Unmet needs or a poor fit between ability and expectation can create situations where people living with dementia experience and express distress. Common issues can be physical (pain, fatigue, shortness of breath), emotional (fear, worry, anger, frustration), social (lonely or not the right fit or people or roles), environmental (sound, sights, familiar, safe), stimulation (too much to do, too little to do). Too often life for people living with dementia is either too much (the summer camp approach) or too little (if not troubled don't trouble). The usual expectation of the day can become overwhelming for a person living with dementia unless carefully monitored. For example, just getting up and getting ready for the day may be too many steps and decisions and create distress. Not having enough to do can be. By creating a day that considers this approach, understanding of personality and personal coping skills (need for time alone and together) we can reduce distress and improve quality of life. Strategies can include breaking up complex series of activities into several sessions, doing the hardest activities at the person's best time of day, and watching for early signs of anxiety and distress.

Organizing the day means finding a flow that creates gentle waves of energy instead of an upward spiral by using what you know about the person, 4 ways we spend time (self-care, leisure, rest, work), daily energy levels and patterns and history of usual day.

When you're organizing the schedules of multiple people:

- **First** look at individuals (identify the most important individual components of schedule)
- **Next** look for patterns of the group (between the individuals, time of high energy/low energy)
- **Add** fixed components (meals, meds)
- **Then** make a group schedule (include common patterns)
- **Lastly** adapt to individuals (when an individual needs a modification)