

Summertime has been a traditional time to take a break, to get away, to not go to work, and to enjoy ourselves for at least a little while. The concept of a vacation first started in the US with the closing of schools in the summer and having the teachers and students vacate the premises. By the mid-1800s taking a break and getting away from the daily grind of work and chores became a much sought after change and an indicator of having achieved middle class or higher social status. For the first time, people other than the wealthy could take their family and go somewhere. With the completion of railroads, families could go from home to a destination and hotels and spas quickly became available to house those who took vacations.

In 2016, our options for travel and vacationing are almost endless. Based on income, interests, time availability, abilities, and finances you will almost certainly be able to find whatever floats your boat (or whatever type of activity you're looking for). One reality, however, is always a part of the puzzle when someone in the family is living with dementia. It isn't exactly like it used to be. Traveling is more complex and being somewhere different doesn't always create joyful moments. Being around unfamiliar people or being around familiar people who are doing unusual or unexpected things can cause distress and surprise for everyone with the challenges that can pop up.

For people living in the early stages of dementia or care partners who are totally stressed out, vacations can be absolutely terrific or major disasters. Brain changes can trigger emotional reactions as well as limit thinking and communication, which is why we need to increase our awareness and have a Plan B. Creating a vacation that has built-in flexibility and tolerance of last minute modifications can make all the difference for success. Getting from Point A to Point B can cause more strain than ever before, as complex signage, overhead auditory information, and the constant movement of people and luggage make comprehension and direction following more difficult and complex.

For individuals in mid-stages of dementia, changing abilities and modified schedules, travel plans, and engagement expectations can either make or break the vacation for everyone involved. Smaller, shorter, simpler, closer, and more predictable vacations or breaks can really create a more enjoyable and relaxing experience for all participating. The idea of one last BIG and SPECIAL vacation, tends to wear both the planner and the doer out long before the vacation is over. By mid-stage dementia, new and different takes an enormous amount of effort to cope with day after day after day. When the person is having difficulty getting through a typical day in a familiar setting without steady direction and much guidance, adding on the challenge of a new place and different food, drink, activities, and routines can start off as a great adventure, then rapidly deteriorate into a dangerous and frightening situation due to stimulation overload. If you are wanting to take a trip or outing at this point in the brain change journey, consider possible trial runs first with shorter visits or jaunts to gauge how the person does. Experiencing an overnight at a local hotel with the pool and breakfast on

site can help determine whether or not a longer trip makes sense. Making sure car keys are secured and that there is a portable alarm for the door, so that you would be alerted, should the person become wakeful or confused at night and try to leave or head home. A simple peel-and-stick battery operated unit is available at local DYI centers, and are great to have along when traveling.

For someone in the later stages of dementia, a much needed refreshing vacation for family members or primary care partners can be much improved for the person left at home. This happens more frequently if there is advance planning and rehearsal so that the routine and patterns that make up that person's life can be sustained and supported. Ensuring that a different care person can use techniques and rhythms that match what typically happens can bolster security for the person and relax the care partners who are taking the vacation. It is surely possible a person in the later stages of dementia could enjoy simple changes and breaks in routine, sitting outside in the sunshine, feeling the air rushing by through an open car or van window, or smelling the fresh cut grass while swinging on the porch can be a vacation from the inside of the house or building. Going swimming rather than taking a bath might create a moment of joy or bring back a summer of long, long ago. Swaying to a hummed song or listening to crickets may allow the person to take a vacation we can only imagine, back in time or to a magic place.

When considering travel with someone living with dementia, there are a number of simple strategies that can help, but only if they are employed.

- As hokey as it sounds, wearing brightly colored and matching outfits with hats, if possible, serves multiple purposes. If the person living with dementia becomes separated from you, it is much easier to describe what they are wearing, if you are wearing the same thing. It is also makes you more likely to be noticed by others, increasing the possibility that someone would notice you. Additionally, hats are generally easier to spot in crowded spaces and open areas.
- Making sure both of you have identification tags on that are readily visible can help if something were to happen. Care partners are notorious for thinking only the person living with dementia would have an accident or illness, and never considering the importance of having themselves labelled as a care partner with information about their person as well as who to contact and how if they were incapacitated.
- Consider traveling on lighter traffic times and days. Many airlines and railways can provide you with info about less popular or busy flights or routes. Sometimes space and quiet trumps speed and bargains.
- Make use of family restrooms. What typically is not problematic at home or in a routine setting can become frustrating and confusing when in busy public restroom with a variety of automatic, combined with traditional, fixtures and devices such as soap dispensers, faucets, toilets, hand drying systems, and paper towel dispensers. It can be so overwhelming that the person may go in and

come right back out, forgetting to do one or more of the vital functions. It is easier by far to take turns in the family space or even share it, for added security.

- Carrying refillable water bottles that hook on or snap onto a fanny pack or backpack can provide ready hydration. The snap on bottle can also be used for other drinks that you get along the way, keeping hands free and bags at a minimum, yet providing sips when you want them.
- Loading up an iPod with favorite tunes and bringing along an iPad with various visually engaging apps can help both parties fill the waiting time up with something a little more engaging and enjoyable than just sitting. Road trips are once again opportunities for noticing things and game playing, although the duration might be shorter and more forwardly directed.
- Carrying along an extra set of clothing from the inside out (perhaps for both of you), a container of wipes, hand sanitizer, a set of gloves, and a couple large sealable garbage bags can make all the difference in the world when stress or distress surprises a digestive system and unexpected outcomes result in a need for a rapid and effective response. It is hard enough to manage problematic body functions at home, but in public settings or unfamiliar places, the challenge is much greater, and in my experience it is much better to have a set of clothes you don't use than not have a set you need.
- Airport chapels or pray spaces may provide a quiet place for recharging batteries and finding an oasis in the busy flow of people, noise, and action.

If the care partners or family members are going on vacation but the person living with dementia is not participating, consider carefully and thoughtfully the value and importance of sharing the details of the plan or even knowledge of the trip itself. If the person is a worrier, then make sure to keep in regular contact and affirm that everyone is fine and enjoying their summer. This may be much more beneficial than trying to help the person understand that the train, plane, or cruise ship you are on is not the one in the news and that no one is in harm's way. This also minimizes the need to rush home when the person has a panic attack because they think you have been gone for a month when it has really only been three days. If, on the other hand, the person has always enjoyed traveling, it is possible that daily video calls (Skype, FaceTime, Zoom) may help the person feel actively involved and part of the vacation. Your loved one can feel connected without having to deal with all the drama and trauma of the actual trip or travel as health conditions or mobility issues would make for a negative experience instead of a positive one.

So one final thought about this season of vacationing. The difference between a vacation and being unemployed is sometimes in the eye of the beholder. Do I have something to go back to that offers me value and purpose? Is this time away from my life and routine refreshing me or is it enforced because I am not actually being allowed to do that which I feel is important? Do I feel like my time away from work is providing moments of joy and energy or do I long for my routine and structure? Being on vacation

can be empowering while being unemployed can create a sense of being powerless. Maybe when someone is living with dementia they need a vacation from being cared for and instead get a chance to be the person who offers something of value and importance. Maybe they need a vacation from us and our view of the world, so they can find enjoyment in their moments of travel where we cannot go. And maybe, just maybe, the person living with dementia needs to be meaningfully *employed/occupied* on a regular basis, doing something of value and purpose with recognition, so that a *vacation* makes sense. Next month we will dig into this topic.