

How do we continue to feel that we have a place at the table, a voice that matters, something we offer, or a way to feel we still have talents or skills when dementia enters our lives?

Humans are born to do things and to gain skill at doing things. As infants and toddlers, we are in a constant state of exploration and experimentation. For children play is WORK! When they *get it* they feel the intrinsic value of achievement and the thrill of success and mastery. And those of us who support and care for them love to see and hear them do it. We CHEER them on and model the sounds, actions, and connections that guide them into the world of self-sufficiency and competence. We use phrases and comments such as, “Can you help mommy?”, “Can you give daddy the spoon?”, “Show me your toes!”. We applaud and celebrate efforts and attempts, not just the successes.

As our babies and toddlers become children, we begin to sort out responsibilities and activities into ones that are more work-like and some that are more play-like. They certainly cross over, but there are different expectations for participation in many situations. Thus we have classes and recess, chores and games, and rules and goals or objectives to be achieved. When a child is successful at work there is almost always some pay-off or reward that occurs in addition to an internalized system of acknowledgment.

Time passes and schooling and training happens and we become adults. At some point along the journey, we find our work or career path. It may change multiple times over our lifetime, but if we are lucky we figure out how to be monetarily or socially rewarded for doing things, creating things, organizing things, saying things, looking at things, smelling things, or tasting things. If we get paid, it is frequently called a job or work. If it is done without financial reward it is called volunteering or community or family service provider. Both have value, and for some, one is more internally valued than the other, although both may play an important role in life satisfaction and sense of self-worth and value.

One unique aspect of work versus play or being productive versus having fun, is that when we are **at work**, we anticipate and accept that there will be unpleasant, uncomfortable, and possibly painful parts of the effort. We seem to expect it and tolerate it, often delaying gratification for extended periods of time, in order to *find the cheese*, to win the gold medal, to succeed where there had been failure or where others were unable to do so.

So what happens when someone develops one of the various forms of dementia, and has to learn to live with changes in the brain and in abilities that may or may not be evident to the person. If those who surround and support the person are not tuned in and careful, loss of ability to work or volunteer, as had been a life-long pattern, can be devastating and crushing.

How can we help in a more productive and effective way rather than simply being sympathetic or creating *make-work* opportunities that may feel both childish and *stupid* to someone who, although unable to complete the task, is still aware of the level of skill or ability needed to do so, due to long-term, old, emotional memories. It really is a combination of:

- a. Knowing the person – their life story, their personality, their preferences and beliefs – and how those are changing or staying the same as dementia finds its way into all the bits and pieces of life
- b. Being aware of other conditions and health factors – mental and psychological status, physical health and illness status, and sensory system status (vision, hearing, movement, touch, smell, taste perception)
- c. Appreciation of brain changes – both acute and the ever-changing ones that happen with dementia
- d. Ability to set up and create an environment that provides the just right cueing and support to foster successful completion of interesting and challenging opportunities
- e. Structure and flexibility in creating a schedule that promotes work or purpose-driven activities and engagement, on a regular basis, that matches the person's desire for and need of a sense of value and meaning.

So now for the hard part; how do we provide opportunities for feeling competent, valued, fulfilled, empowered, significant, and purposeful when how the person has traditionally done this is no longer possible? It is **hard work!**

We must take what we know and can find out about who and how the person was and what they did that gave them a sense of value and purpose. Then we need to know how they evaluated and rated their own performance and success AND compare it to present interests, abilities, and sense of self in order to create the space and time to do them as well as support these kinds of interactions and events.

Here are some examples of productive or purposeful activities. It is however, important to always recall that it is not just the doing of the activity that gives it value; it is the feelings, emotions, and interactions it triggers that makes the difference. How we respond to efforts to engage, to the person's doing of the activity will be key. Whether the doing of the activity is physical engagement (motoric), social or supervisory engagement (opinion-giving), or visual engagement (observational), reinforcement and appreciation of the effort is vital.

For each activity, the next step is to figure out how to modify it or grade it to match current abilities and compensate for missing skills. The following is a table that lists some possible ways in which to do this for two very different productive opportunities. One is related to managing funds and paying bills and the other is related to cooking and meals management.

To figure out what might provide a sense of value and purpose, consider this list of possible things with which to interact. Almost all humans have an innate desire to nurture, to connect to some thing or someone else and find value in that connection and relationship. Not everyone is person-oriented. This list may help us to expand our frame of reference when we are trying to figure out how to provide the right support.

Using the [GEMS® model](#) can help in providing some guidance and help in this effort. The following table provides an example of pet care activities that can be modified and used for someone who loves animals and finds value in nurturing an animal of some variety.

Creating Meaningful Activities for People with Different GEMS® States

If you feel totally overwhelmed or are unable to think of *anything* the person can still do, it may be time to seek out more support and help. There are health care professionals who are trained to provide support in this area, and there are many resources on-line if you know what to look for. One more thought in closing, as always, it is important to look in the mirror and check out your own sense of having value and purpose in what you are doing. Ensuring you feel a sense of fulfillment during the care support you provide is vital to your health and well-being, as well. Seeking support for yourself, may be the first step in successful change for both of you.