

One of the most challenging aspects of supporting someone who is living with a dementing illness is to develop daily routines and activities that are interesting, meaningful, do-able, and valued by the person who is experiencing so many changes due to the condition. Helping to ensure there are a mix of activities to meet social, physical, mental, and spiritual needs for another human being is a complex and ever-changing task. As the disease progresses, changes will repeatedly need to be made based on changing abilities and skills, while retaining the characteristics of the activities that make them meaningful to the person. Families and communities must work together to successfully create options and programs that work to make moments count and fill the day.

There are essentially four categories of activities that fill our lives. They are work, self-care, leisure, and rest activities. Maintaining a healthy balance among these activities helps us manage stress and optimize our positive sense of self and control in our lives. Anyone who has ever worked an 80 hour week, been without sleep for days on end, been on an extended vacation away from home, or been unemployed, is aware of the negative impact of imbalance on life and your dissatisfaction with it. This balance must be maintained even in the presence of dementia. Caregivers will find that the affective health of the clients will be much improved if this balance is respected.

The types of activities that are generally most valued by adults are work activities. Work activities are those that we use to show ourselves and others we are competent, skilled, valued, and talented members of our families and communities. Work tasks may be "job-related" or they may be volunteer or home care tasks. They typically include job actions and activities. For instance, a businessman may consider greeting and socializing with others, making phone calls, sorting through papers, paying bills, making visits, and supervising others as part of his "job". A housewife may view baking, cleaning, laundry, bed making, and sweeping as part of her work routine. Getting dementia does NOT eliminate the need to be needed and to be seen by others as a productive and vital member of one's community. It does, however, make it more difficult to make sure the person can perform tasks successfully. It is essential that work opportunities be offered on a regular and frequent basis. It will help the person integrate into their new life and develop a strong feeling of belonging and membership in this new community.

Self-care activities are those tasks that we do in order to take care of ourselves, our bodies, and our homes. Our ability to *take care of ourselves* marks our transition from childhood to adulthood. We learn to care for our own bodies first. We feed ourselves, groom ourselves, dress ourselves, toilet ourselves, and bathe ourselves. Then we learn to fix our food, care for our homes, manage our money and medicines, transport ourselves, and care for our clothes. We exercise our bodies and our brains in an effort to keep in shape, or gain a sense of wellness. When people with dementia start to

experience problems with successful completion of these tasks, it clearly signals a decline in function and lessening of the person's independent status. Encouraging a person to participate actively in these tasks, and providing the support needed, will ensure the person maintains dignity and a sense of adulthood. Trying to just get these tasks done, so that the person can *go to activities* not only doesn't make sense, it creates problems. There are often episodes of resistance to care and emotional or physical outbursts from being pushed too hard or by having caregivers trying to take over. These situations of *over-helping* can result in injuries, refusals to do anything, calls to family members about dissatisfaction, or attempts to leave home or the community due to a sense of being disrespected or 'attacked'.

Leisure activities are frequently seen as the highlight and most fun part of our day. These are the activities we engage in just because we want to. These are the activities we do in our free time or when work is done and time permits. It is important to note, however, that many of the older generation we are now serving did not view leisure activities as a routine part of life or may in fact see them as wicked or worthless. If this is the case, great care will need to be taken to provide leisure activities that are acceptable and mature, and perhaps old-fashioned. Some people may actually find *working* leisure activities fun and rewarding. Tasks such as setting up for, or cleaning up after parties, participating in exercise groups, helping someone else complete a project or a faith-based endeavor, or care for a pet may be viewed as valuable uses of time and much more vital than being entertained.

Finally, activities that promote re-energizing and revitalization are rest activities. Although sleep provides the majority of needed rest, it is not the only way to recharge. As the disease progresses, it is important to look at other restful activities such as rocking, quiet and slow walking, listening to music, or watching or petting animals. Sleep cycle disturbances are very common with dementia and acceptable substitutes will help to ensure the person is able to perform optimally in other areas of function.

Category	Meaning	Examples
Work	Activities that make us feel valued and appreciated for our skills and abilities	helping others, supervising others, completing jobs, doing tasks that are part of the work roles the person has had before in their life
Self-care	Activities that we do to keep our bodies functioning, ourselves clean and neat, our adult independent selves	AM care, bathing, eating, toileting, dressing, taking medicines, shopping, managing money, paying bills, fixing food, tidying up
Leisure	Activities we do because we like them, get pleasure from them, and enjoy them or enjoy doing them with others	Socializing or visiting, singing, reading, playing cards or games, doing puzzles, walking, dancing, exercising, gardening, crafts, art, music, movies, photo albums
Rest	Activities we do to re-energize ourselves, to find our inner peace, to relax, and to feel better	Sleeping, napping, praying, listening to music, holding hands and sitting with someone you like, taking a quiet walk, rocking, watching birds or fish, petting a dog or cat

Once you recognize the need for each type of activity, you will then want to individualize them for them to be effective. Each person's background, work history, leisure interests, social preferences, personal care habits and routines, and wake and sleep patterns will be vital in determining what sorts of activities might help them continue to be who they have always been. Knowing the key features of jobs people have done, what they liked about what they did in their free time, what their preferences were in terms of grooming, dressing, and bathing, and what they did to manage their stress and to rest will allow family and staff to propose tasks and activities that will be familiar and beneficial to each person. Talking with family members and friends in obtaining this information will encourage them to remember who their loved one has been and what special talents, skills, and values they held. It will allow staff members to really get to know the people they are caring for, and will help them to better understand behaviors that occur as something more than just a challenge, but rather an expression of some unmet want or need. As family members identify preferred activities and historic jobs and roles, the care team has opportunities to share with all involved some possibilities and develop a plan to have a balanced activity schedule. Those not immediately involved in the day to day routine will benefit from appreciating the reason behind having the person completing work tasks such as sweeping, dusting, moving furniture, or helping with laundry. They can better understand that the care provider is encouraging the person to do these *menial* tasks, not as free labor but rather as a critical opportunity for that person to experience positive self-regard and get appreciation and feedback from others.

The final and most important part of planning meaningful activities for people with dementia is to modify the desired and preferred activity so that the person will be able to engage in them. In order to be successful at matching specific tasks to an individual, you must know their state of cognitive change, what skills and abilities are remaining, and what cues or environmental aids can help the person. Some critical points to assess are to –

- determine the person's ability to initiate a task or steps within the task - if not, be aware that the person will need one-on-one help to do an activity
- decide what types and intensities of cues are useful in helping the person to perform, so that you can give the *just-right* amount of help
- figure out the ability of the person to use their hands and to use tools or utensils in task completion - if they can only do gross movements and can no longer manipulate small objects, use both hands together
- identify typical attention spans and what factors increase or decrease it, make sure activities are about the right length of time for the different types of activities
- determine what environmental features (visual, auditory, tactile, spatial) are important in helping the person recognize and complete activities
- determine the person's interest and enjoyment of being alone, with 1-2 other people, or in large groups
- try to identify what words, objects, sounds, places encourage participation and optimal behavior as well as what has the opposite effect
- look at what times of day are best for what types of activities (most people with dementia do better in the first 1/3 of the day, but there are certainly exceptions – so you may want to schedule challenging or difficulty activities earlier and more mellow and relaxing activities later in the day)

- figure out if the person values talking about doing something or getting something all the way done when you are thinking about what to have them do

Once you have selected individualized activities and graded them for each participant, you will want to implement the program throughout the community. The goal is not to occupy every second of every day, but to make sure that there are a variety of meaningful activities for each person each day. Some of the activities may occur individually, while others may happen in dyads or small groups. Activities should occur, as much as possible, in a setting or space that looks like the right kind of place for that activity. For instance, meals in either a dining room or a kitchen while games or cards would be in a den or living room type area. Grooming would be done in a bathroom or vanity area. Which setting is selected should be based on the history and preferences of the individual as well as the space and work surface demands of the tasks. Staff and family interest and involvement is critical for success. Activities do not belong to any one department or service. The use of family members, friends, care personnel, and other volunteers or employees will determine how available activities will be and how well integrated the program is into the fabric of the community. It is generally recommended that schedules are predictable and regular, BUT that the family, staff, and programs need to be flexible based on day-to-day variations in function and interest. It is also possible to build in special events, as long as each person's interests, abilities, and schedules are kept as key deciding factors in selection and participation.

A well-designed and well-run activity program is the dream of most communities as well as family caregivers. It is not an easily achieved goal, but it is a much-valued one. It will take the support system to make the program work. There will be many stops and starts in developing and implementing such a program, but it will make your community much sought after and very successful. Creating meaningful days and meaningful moments is what it is all about as we try to help people living with dementia cope with this progressive and terminal illness that gradually steals a person's life, abilities, and memories away.

The following is a sample schedule for three persons on a special care unit. Note that there are some significant differences among people, as well as some similarities. Check the schedules for a balance of work, self-care, rest, and leisure activities. Do you have some idea about what these people may have valued and done in their lives? What is not addressed in this version of the schedule is the involvement and assignment of staff members, volunteers, or family members, or the actual details of task performance and amount of help or guidance needed. In a real scenario, these pieces of information should be documented and agreed upon in order to make sure the plan becomes a reality.

Time	John	Mary	Susie
5-5:30 am	Sleep	Get up – in robe	Sleep
5:30-6 am	Sleep	Get coffee & sit	Sleep
6-6:30 am	Sleep	More coffee & sit	Sleep
6:30-7 am	Sleep	Bathroom & dress	Get up & snack
7-7:30 am	Sleep	Hot breakfast	Bathroom & sit
7:30-8 am	Sleep	Listen to radio news	Wash up & dress
8-8:30 am	Sleep	Go to dayroom & sit	Eat cold breakfast
8:30-9 am	Sleep	Clean up breakfast dishes & wipe tables	Clean up breakfast dishes & wipe tables
9-9:30 am	Sleep	Sit, visit, and drink coffee	Sit, visit, & drink coffee
9:30-10 am	Sleep	Fix & serve snack	Help with birds
10-10:30 am	Wake-up & bathroom	Go to room and rest	Walk dog outside
10:30-11 am	Eat late cold breakfast	Listen to radio in room	Bathroom & in dayroom
11-11:30 am	Get dressed & shave	Bathroom & look at photo album	Help do load of laundry
11:30-12 noon	Go for a walk with a friend	Set up tables for lunch	Set up tables for lunch
12-12:30 pm	Eat lunch	Eat lunch	Eat lunch
12:30-1 pm	Get in recliner & rest	Clean up & wipe tables	Clean up & wipe tables
1-1:30 pm	Bathroom & coffee	Bathroom & room time	Bathroom & room time
1:30-2 pm	Songfest	Songfest	Songfest
2-2:30 pm	Songfest	Songfest	Go lie down in room
2:30-3 pm	Sit & visit & drink coffee	Sit & visit & drink coffee	Make snack
3-3:30 pm	Arrange room for cocktail hour later	Serve snack to others & eat	Eat snack & visit
3:30-4 pm	Rock on the porch	Rest in day room – music	Sweep the dining area
4-4:30 pm	Visit with daughter	Sleep	Help fold laundry
4:30-5 pm	Visit with daughter	Sleep	Bathroom & in room
5-5:30 pm	Serve snacks and drinks to others	Cocktail hour	Cocktail hour
5:30-6 pm	Eat dinner	Eat dinner	Eat dinner
6-6:30 pm	Go to dayroom & look at paper/news	Clear dishes	Clear dishes
6:30-7 pm	Sleep in recliner	Sit in dayroom & listen to music with a friend	Sit in dayroom & listen to music with a friend

Time	John	Mary	Susie
7-7:30 pm	Sleep in recliner	Get clothes together	Fold a basket of clothes
7:30-8 pm	Sleep in recliner	Take a bath	Go to room & wipe surfaces
8-8:30 pm	Sleep in recliner	Go to bed	Fix popcorn & drinks
8:30-9 pm	Eat snack & visit	Come back out to eat snack & visit	Eat snack & visit
9-9:30 pm	Get desk area set up	Go back to bed	Go to bed
9:30-10 pm	Pick up mail from several locations & take to desk	Sleep	Sleep
10-10:30 pm	Open junk mail & file it	Sleep	Sleep
10:30-11 pm	Open junk mail & file it	Sleep	Get up & rock a baby
11-11:30 pm	Clear the desk – put everything away	Bathroom & back to sleep	Go back to bed
11:30-12	Check all the common rooms and doors	Sleep	Sleep
12-12:30 am	Go to bed	Sleep	Sleep
12:30-1 am	Sleep	Sleep	Sleep
1-1:30 am	Sleep	Up & visit with staff	Sleep
1:30-2 am	Sleep	Back to bed after bathroom	Get up, bathroom & rock a baby
2-2:30 am	Get up work on jigsaw puzzle	Sleep	Back to bed
2:30-3 am	Check all doors & public spaces	Sleep	Sleep
3-3:30 am	Go back to bed after bathroom	Get up, sit in recliner, listen to scripture on tape	Sleep
3:30-4 am	Sleep	Sleep in recliner	Sleep
4-4:30 am	Sleep	Sleep in recliner	Sleep
4:30-5 am	Sleep	Sleep in recliner	Sleep