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Illusion of Choice: How to help our loved ones still feel in control of their day to day lives

By Teresa Valko, Board member and Caregiver

Alzheimer's disease takes away so much from a person. Not only does it take away memory; it eventually takes away the ability to make decisions about how one lives. Knowing this can leave a person with Alzheimer's feeling they are losing control. This can contribute to frustration, anxiety, fear and depression. However, there are



measures that can be taken and activities to engage in that can help. These include learning about the disease, treatment options and opportunities for participating in clinical trials, along with developing a multi-pronged care plan and addressing legal and financial issues. These activities are essential and allowing your loved one with Alzheimer's to participate in them will contribute to their feeling of control. There are many ways to engage your loved one to help them feel in control in their everyday life as well. Together - big and small - these measures can help someone living with Alzheimer's feel more empowered and confident as they travel along their unfamiliar journey.

Learning about the Disease

The first step towards feeling in control after a diagnosis is to learn about Alzhei-

mer's disease. It's important to understand what to expect at each stage of the disease. Learning about the changes and limitations that arise as Alzheimer's progresses allows a person living with Alzheimer's and their loved ones to manage their expectations and plan accordingly. After learning about the disease, becoming educated about various treatment options, including clinical trials, is imperative. Making decisions regarding treatment may be the first major decisions after being diagnosed. This is a key moment in giving your loved one a voice in this new role as someone living with Alzheimer's.

Comprehensive Care Plan

Next, a comprehensive care plan will be the roadmap for your loved one's journey. It is the most meaningful way to involve your loved one with Alzheimer's and create something that is a reflection of their thoughts, feelings, and preferences. The care plan should include intentions and strategies for maintaining overall health. Your loved one should be the master of this plan because it is their opportunity to have control of their present and their future.

Daily or periodic activities will be part of the details of the plan. These activities give your loved one a way to feel empowered in their everyday life. He or she can first decide which activities to include in the plan and the frequency. Then develop a daily or weekly schedule, perform the scheduled activities, and finally, record completion of their activities within their care plan. The schedule is key; it provides your loved one with multiple points of involvement. It will



Keep the person's skills and abilities in mind.

A person with dementia may be able to play simple songs learned on the piano years ago. Bring these types of skills into daily activities.

Pay special attention to what the person enjoys.

Take note when the person seems happy, anxious, distracted or irritable.

Be aware of physical problems.

Does he or she get tired quickly or have difficulty seeing, hearing or performing simple movements?

Focus on enjoyment, not achievement.

Find activities that build on remaining skills and talents.

Encourage involvement in daily life.

Activities that help the individual feel like a valued part of the household.

Relate to past work life.

A former office worker might enjoy activities that involve organizing, like putting coins in a holder or making a to-do list.

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be their source for information, accountability and even security. Having a posted schedule of daily activities gives your loved one a place to go for guidance, answers and reassurance. Even when he or she is no longer able to write out or construct the schedule themselves, a visible, posted daily or weekly schedule can be a great comfort to someone living with Alzheimer's.

What kind of activities should be considered for a daily care plan? Ones that contribute to overall healthy living derived from lifestyle choices. One area to consider is diet. For instance, servings of healthy foods can be incorporated into the daily schedule or checklist. Also, because it is important to stay hydrated, a count of glasses of water may be included. Another area that should be included is exercise. Perhaps your loved one likes to dance, walk, or play basketball. Social engagement is also part of a complete care plan. Social engagement includes a bridge club, knitting groups, book clubs, church activities, or playing board games. Activities that provide mental stimulation should also be included. These might include attending classes, computer or word games, reading, and arts and crafts. Other activities that may not be as obvious to include are those that reduce stress and ensure proper rest. Stress relief can be scheduled in the form of yoga, meditation, spending time with loved ones, and attending support groups. Rest is vital to good health and setting a bed time can be very helpful in assuring adequate rest. One last item that may be included in your loved one's routine is journaling. Journaling not only provides mental stimulation, it also allows your loved one to explore and express their feelings. It serves as both mental exercise and therapy. It can be a powerful tool of engagement.

While a care plan schedule or checklist has immense value for both overall health and engagement on a daily basis, it also provides a routine. People with Alzheimer's



function best in a structured environment with regular times for meals, activities, and sleep. Routine reduces confusion and helps to ensure that a person with Alzheimer's is active and engaged, giving them a sense of choice and control. A good care plan schedule includes activities your loved one enjoys balanced by allowance for spontaneity and down time.

The encouragement and patience of care partners are essential in the success of these strategies. Creation of schedules and adherence to routines will become more and more challenging for your loved one with Alzheimer's. Gentle reminders of the care plan and assistance in activities from the caregiver will help maintain success. Beyond the care plan, a caregiver can present many opportunities throughout the day to give a sense of engagement and contribution to their loved one. A normal day includes plenty- for example, asking for their help to prepare a meal, or asking them to assist with household chores, such as laundry.

It is important to remember that there are measures that can be taken and activities to be done that can help your loved one exercise choice in their lives. Alzheimer's may take away so much, but you can be instrumental in helping your loved one live life to the fullest and feel engaged on a day to day basis by using some of these simple ideas.

Learn more at alz.org/care