Adapting your Expectations for Dementia

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In our August 2020 edition of Caregiver Tips & Tools, we discussed the importance of knowing when to step-in and take control of finances, medical decisions, and other important areas. In this article, we’ll focus more on expectations of interpersonal relationships and how shifting these can help loved ones maintain a connection with the person with dementia.

You can find our August 2020 article and all our other editions here: alz.org/CACentral.

Adapting Your Expectations in Dementia

When you are caring for a loved one with dementia, it can be hard to leave behind all of the expectations that you had for your present and future with that person. You’ve spent decades with them – as a spouse, child, or friend – and now they’re behaving and speaking in a way that is not at all how they used to.

These changes can be distressing, and often take caregivers by surprise. It’s not uncommon for a caregiver to make assumptions about the person’s abilities based on how they’ve always been, but it’s important that you change these expectations as the disease progresses.

Understanding the Disease

Every person’s experience of dementia will be different, but there are some symptoms that are consistent. Memory loss is common, with short-term memories usually fading first. This means that the person will not be able to remember things like social plans, doctor’s appointments, or answers to questions that they may have just asked.

Another common symptom is decreased judgment and reasoning. This can result in the person making poor decisions, like insisting that they can drive safely even though they’ve had multiple accidents, or spending impulsively on items they don’t need.

Many people with dementia also experience aphasia – or the inability to use spoken language to communicate. This can make it difficult for a person to understand instructions, even when they’ve been given clearly or multiple times. It can also affect the person’s ability to express their wants and needs.

All of these symptoms – along with the many others that a person with dementia may experience – are the result of physical changes that are occurring in the brain. The plaques and tangles that are the hallmarks of Alzheimer’s disease, for example, make it difficult or even impossible for the person to retain information, comprehend language, and make good decisions. It has nothing to do with choices that the person is making and has everything to do with how this disease is affecting their brain.

Assessing your Expectations and Assumptions

As the person without cognitive impairment, it is up to the caregiver to adjust their...
expectations about the person’s abilities. In order to do that, take a step back and think about what assumptions you’re making and what you expect of the person. Here are some examples that might require reevaluation:

- **Finances** – do they still have everything under control?
- **Medical Issues** – are they able to remember and report back what advice their doctor provided?
- **Social Obligations** – are you relying on them to keep track of birthdays, etc.?
- **Household Duties** – are they staying on top of their laundry, the dishes, and other household chores?

It is common for caregivers and other loved ones of people with dementia to assume that all of these things are being handled by the person. When you’ve known someone for decades – especially if you’ve known them as a responsible person fully capable of living independently – it can be difficult to adjust your expectations of their abilities. But as a caregiver, it is important to make those adjustments in order to promote the person’s safety (both physical and financial), health, and wellbeing.

**Changing your Expectations**

Do you feel slighted when your loved one with dementia doesn’t notice you’re upset? Or when they go to the kitchen to get a snack and don’t ask if you’d like something? Does it feel like your emotional needs are no longer something? Does it feel like your emotional needs are no longer being fulfilled? Do you resent them for being self-centered, rude, or dismissive?

These are all common experiences for caregivers. As discussed above, dementia has a tremendous effect on a person’s brain. One of the most disheartening effects is that it can narrow a person’s world – meaning that they are only capable of thinking of themselves. For a spouse, child, or friend this can be very distressing, especially if your relationship with that person had been fulfilling and equitable up to now.

If you find yourself taking these things personally, it’s important to remember that these behaviors are not a choice for your person – they are the result of a necessary narrowing of their world to what their diminishing cognition can handle.

In the past they may have been able to order your favorite meal at a restaurant for you, or plan a surprise vacation, or give a thoughtful gift on your birthday. But now, they quite literally do not have the room for anything other than their own needs. It has nothing to do with how much they love you. It has everything to do with how this disease is affecting their brain.