Memory Moment By Shannon Nosbisch, CDP, DCS

There are many helpful articles on the internet about dementia caregiving. I often share these articles from www.dailycaring.com on Effingham Area Alzheimer's Awareness' Facebook page. Here is an article I shared this week.

KEEPING A DEMENTIA JOURNAL MAKES CAREGIVING EASIER: 7 THINGS TO TRACK

Feel more in control by taking notes on dementia symptoms

Caring for someone with <u>Alzheimer's</u> or <u>dementia</u> can feel like riding a rollercoaster.

When symptoms and problems seem random and uncontrollable, caregiving becomes very stressful.

But having accurate information and being able to find patterns or triggers helps you feel more in control and less stressed.

You'll also be better equipped to solve difficult behaviors or health problems.

This is why a dementia journal is a key caregiving tool.

Writing quick notes throughout the day in a dedicated journal means that you'll have accurate information about what happens and when it happens.

Any note-keeping method will do – a simple notebook, a binder with some lined paper, on your computer or smartphone, or whatever works best for you.

Plus, having notes makes it easier to share important information with doctors, family, and other caregivers.

We describe 7 top things to track in a dementia journal and share real-life examples of how this could help solve problems and make caregiving easier.

7 things to track in a dementia journal

1. Dementia symptoms and care needs

Tracking new or existing dementia symptoms helps you see the bigger picture and reduce worry from uncertainty.

Jotting notes about level of confusion, behaviors, or ability to do everyday tasks helps you know if your older adult's cognitive function is declining or staying the same.

It also gives perspective on the severity and frequency of symptoms and helps you figure out what kind of help they need on a regular basis.

For example, your notes could show that they need help with meals, but can shower and dress on their own.

Or, your notes might reveal that they need a lot more care than you thought – they're quite disoriented and regularly need help with all tasks of daily living.

Sometimes, the amount of care can add up slowly so you don't even realize how many additional responsibilities you've taken on since you started caregiving.

Taking notes helps us realize when care needs are increasing so we'll know that we need to <u>ask family to help</u>, <u>hire help</u>, or find volunteers and other resources.

2. Challenging behaviors – anger, anxiety, hallucinations, etc.

Difficult behaviors are especially stressful when it seems like they happen at random.

But sometimes, you can find patterns or solutions by taking notes about what happened, when it happened, and what happened before or after.

For example, after taking notes for a week, you realize that your mom's anger at a certain time of day could be caused by being hungry, thirsty, and a little tired.

The next day, you try an experiment. About an hour before her usual outburst, you give her a small snack, encourage her to drink some water, and then encourage her to use the toilet.

After having those physical needs met, she looks more relaxed, is in a better mood, gets interested in a <u>fun activity</u>, and doesn't have an angry outburst.

Because of the dementia, she didn't realize she had those needs or know how to ask for what she needed.

Taking notes and looking for patterns and possible triggers helped you figure out what could be causing the problem and test a possible solution.

3. Eating and nutrition

Eating habits can change when someone has dementia.

If you're concerned that your older adult isn't getting good nutrition, it may help to track what they're eating, when they're more or less interested in food, and what foods they seem to like or dislike.

Those notes help you figure out what types of food to offer at what time of day.

Plus, they also tell you how much your older adult is actually eating.

Maybe they only eat small amounts so you worry that they're not getting enough. But the notes show that they eat 6 good-sized, nutritious snacks during the day.

Seeing the facts helps you worry less about nutrition.

Tracking the amount of liquids your older adult drinks is a similar idea.

If you're worried that they're <u>dehydrated</u> or if they need a certain amount of liquids for a medication to be effective, take notes on how much they drink and which beverages work best.

4. Toileting and incontinence

People with dementia typically become <u>incontinent</u> at some point.

If it starts to become a concern and the doctor doesn't have any suggestions, use the dementia journal to keep your older adult on a regular toileting schedule.

And if there are accidents, your notes could help you figure out if something triggered it and if it's something that could be modified.

For example, you may notice that if you encourage your older adult to use the toilet every 2 hours, there are no problems. But going to the bathroom every 3 hours sometimes causes an accident.

Now you know that the ideal time for bathroom breaks is every 2 hours.

Or, your notes might reveal that certain foods or beverages are more likely to cause an accident so you remove them from their regular diet.

5. Safety issues

Safety can become a big issue when someone has dementia.

One symptom is to not know what a particular object is or what it's used for.

So they may think that cleaning fluid is a sports drink or that shaving cream should be used to brush teeth.

They could also get confused when handling sharp objects like knives, razors, or scissors and seriously injure themselves.

It's a fine line to walk between keeping someone safe and letting them be as independent as possible – especially in the <u>earlier stages</u>.

It can be tough to know when it's necessary to put safety locks on the stove or lock away all sharp objects.

Tracking behavior and symptoms over time helps you see when they're making certain types of mistakes and gives hints as to when greater supervision or added safety measures are needed.

6. Medication effectiveness and side effects

With medication, a notebook is an essential tool.

Writing things down helps you know if a medication is working well or if there are side effects that a doctor needs to know about ASAP.

Taking notes about symptoms and changes in behavior are especially helpful when your older adult starts a new medication, you're suspicious about an existing medication causing problems, or there's a change in medication dose or timing.

In case there are problems, you'll be able to give the doctor the details they need to improve the situation.

7. Information for medical appointments

Keeping a dementia notebook also makes visits to the doctor more productive.

When you're concerned about certain issues, your notes will have the specific information that the doctor needs in order to help.

Without those accurate details, they might need to ask you to go home, observe the behavior for 2 weeks, take notes, and come back for another visit.

Symptoms that <u>doctors typically ask caregivers to track</u> include falls, sleep problems, pain, fatigue, and incontinence.

They'll usually want to know how often it happens, how severe it is, if there seems to be any trigger or pattern, and anything unusual.

When you prepare for a doctor's appointment. look through your dementia journal to find the things that have been worrying you.

Put them into one list of questions and concerns. Then, choose your top 3 questions/concerns and bring the entire list and the journal with you.

At the appointment, take notes on what the doctor says. This gives an accurate record of the issues discussed and the doctor's specific instructions.

There's often so much covered during an appointment that it's very difficult to remember it accurately in your head.

Effingham Area Alzheimer's Awareness (EAAA) is a volunteer-run, not-for-profit organization founded to provide education and support to all families, caregivers, and people with Alzheimer's disease and related

dementia in Effingham County and the surrounding area. For more information about Effingham Area Alzheimer's Awareness, check out the website at www.effinghamalz.org. If you are a caregiver & have specific questions or situations you would like information on, please feel free to call Shannon Nosbisch at 217-663-0010 or Amy Sobrino at 618-363-8372.