The Caregiver's Journey®

Finally! Practical Tips and Candid Conversations
for Alzheimer's and Dementia Family Caregivers

Managing Incontinence

A Guide for Dementia Family Caregivers

SUE RYAN & NANCY TREASTER

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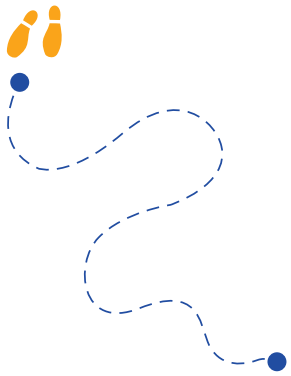
This guide brings our years of experience in a variety of family caregiving roles. We are sharing our personal experiences, not medical advice, to help prepare you to navigate your caregiving journey.

Introduction: You're Not Alone on This Journey



If you're reading this guide, you're likely navigating one of the more challenging aspects of caring for someone with dementia: incontinence. First and foremost, take a deep breath and know countless caregivers have walked this path before you. Experienced caregivers Nancy Treaster and Sue Ryan often say "We both wish we knew more about incontinence before it began." That's exactly why this guide exists—to provide you with the knowledge, practical tips, and emotional support you'll need for the journey ahead.

Incontinence is a natural progression in the dementia journey, typically beginning around 3 to 5 years after diagnosis. It starts gradually with early warning signs and continues throughout the remainder of your caregiving journey. While it undoubtedly presents real challenges—physically, mentally, and emotionally—with proper preparation and the right approach, you can navigate this journey with compassion, dignity, and confidence.

Remember: This isn't something anyone learned in school! It's okay to feel overwhelmed, uncertain, or even resistant at first. Give yourself permission to acknowledge these feelings while also recognizing that with the right tools and support, you absolutely can handle this aspect of caregiving. As you read through this guide, you'll find practical advice drawn from real experiences, helpful strategies that have worked for others, and reassurance that you're more capable than you might currently feel.

As Nancy and Sue would remind you: "We're all on this journey together."

The Reality of Incontinence in Dementia Care

Before diving into specific strategies, it's important to understand what's happening and why. Incontinence in dementia isn't just about physical changes—it's tied to cognitive changes that affect awareness, recognition, communication, and motor skills.

As dementia progresses, your loved one may experience:

- Difficulty recognizing the need to use the bathroom
- Problems communicating their needs
- Inability to find or recognize the bathroom
- Difficulty managing clothing in time
- Loss of awareness of social norms around toileting
- Eventual loss of physical control of bladder and bowels.

Understanding these underlying factors helps you approach the situation with greater empathy and less frustration. This isn't happening because they're being difficult—it's happening because their brain is changing in ways beyond their control.

Before Incontinence Begins: Preparing Yourself

Watch ***The Caregiver's Journey Podcast Episode 9: Preparing for Incontinence***

SCAN TO WATCH

Recognizing the Early Signs

Incontinence doesn't typically start suddenly. Being alert to early warning signs gives you valuable time to prepare both practically and emotionally. Here are key indicators that incontinence may be approaching:

- Not flushing the toilet: They might forget this step after using the bathroom
- Putting toilet paper in unusual places: Such as the trash can instead of the toilet
- Looking confused about where the bathroom is: Even in familiar environments
- Having difficulty finding the bathroom when you're out in public
- Struggling with clothing: Taking too long to manage zippers, buttons, or belts
- Resisting drinking fluids: Because they don't want to deal with using the bathroom
- Expressing urgency: Suddenly announcing they need to go "right now"
- Standing up and looking around: As if searching for something
- Holding themselves: Either in the front or back
- Having occasional "accidents": Small amounts of urine in underwear.

Nancy recalls: "For my husband, I would say the early signs started about four and a half years after his diagnosis." Sue's experience with her father: "I'd say about three, three and half years."

Tips for Preparing

1. Have an Open Conversation While You Still Can

If your loved one is in the early stages of dementia and still able to have meaningful conversations, consider talking openly about what's coming. This approach allows for collaboration rather than simply managing the situation later.

Sue suggests: "Talk with your loved one before it's coming. They've been diagnosed, but you can still have great conversations with them. If there are any areas of discomfort, you can get through that and you can talk with them about how you feel about it and you can have them talk about how they feel about it."

This conversation creates an opportunity to:

- Acknowledge the reality of what's coming
- Express concerns and feelings from both perspectives
- Discuss preferences and comfort levels
- Try different products together before they're actually needed
- Establish language and routines that will feel familiar later.

Sue adds: "For example, having conversation that starts, 'Incontinence is going to come and we're going to have things that are going to help you with that. Let's experiment with them now to see what feels comfortable for you even before you need them.'"

Nancy reflects: "I highly recommend tip one," noting that her approach was different: "Talking about it would be a fabulous way to start. If you are in the situation where collaborating with your loved one is something you believe is a good idea and you can make it happen, this is way better than just quietly helping behind the scenes which is what I ended up doing."

2. Do Your Research and Prepare

Whether or not you've had an open conversation, you can begin preparing practically for what's ahead:

Research Adaptive Underwear Options:

- Look into washable urinary incontinence underwear that resembles regular underwear
- For men: Jockey styles and briefs (boxer shorts don't work well for incontinence)
- For women: various panty styles in different colors and designs
- Research different levels of absorbency (light and medium) for gradual transitions.

Nancy shares her proactive approach: "Start by simply changing their current underwear to look like the washable incontinence underwear you are planning to use. For example, my husband wore white jockey briefs and white briefs are not popular in incontinent underwear. Number one, you wouldn't want white because they're going to have urine stains in them. In the men's styles they are mostly black and gray, which also works out nicely because the Depend brand and Depend-like products are actually light gray and dark gray for men.

I just slipped black and gray Jockey underwear into his drawer. Slowly started taking the white underwear out and over the course of a very short period of time, we had only black and gray regular underwear. I did

this before we needed incontinence underwear to ease the transition when the time came."

She adds: "When my husband did have to transition to washable urinary incontinence underwear, he put on the light version. Yes, there's some padding in his underwear. He kind of patted it like something's not quite right. And then he continued putting on his clothes and that was the end of it."

Sue offers an alternative approach for the transition period: "Sometimes having the regular underwear and sometimes having the incontinence underwear in his drawer worked for us. When my husband asked where his underwear was I said 'the other ones were in the laundry, sorry about that, let's just use this today and I'll get the laundry washed' so that he was more receptive to wearing something that was different."

Research Cleaning Products and Equipment:

- Adult wipes (larger than baby wipes)
- Non-rinse cleansing products
- Mattress protectors and bed pads
- Furniture protectors
- Floor cleaning products designed for pet accidents (which work well for human accidents too)
- Odor neutralizers.

Modify Your Home Environment:

- Consider which areas might need protection
- Identify furniture that should be moved or covered
- Think about bathroom accessibility and visibility
- Prepare for nighttime needs with lighting and clear pathways.

3. Prepare Yourself Mentally, Physically, and Emotionally

Physical Preparation: Caring for someone with incontinence requires physical strength and stamina, especially for:

- Helping them stand and balance during changes
- Lifting or supporting them if mobility is limited
- Frequent cleaning of both the person and the environment
- Increased laundry and housekeeping demands.

Nancy shares her foresight: "I recognized several things started getting difficult about the same time in multiple areas with incontinence being one. I'm a runner but I didn't do any strength training whatsoever. And it was clear to me at this point, I needed to build some upper body strength so I started doing strength training specifically so that I could be a better caregiver."

Sue adds an important consideration: "There were people in support groups talking about when there's a big size and weight difference between caregiver and care receiver things can be challenging because a lot of what you're going to be doing is working with their balance. Ask yourself "Am I strong enough? Can I actually do this?"

Mental and Emotional Preparation:

- Acknowledge this will be challenging and uncomfortable at first
- Recognize feelings of reluctance, disgust, or resentment are normal and don't make you a bad caregiver
- Identify support resources before you need them (support groups, counseling, friends who understand)
- Practice self-compassion and setting boundaries.

Sue emphasizes: "This is not something we went to school for so it's reasonable we haven't talked about it. Find someone to share your feelings with. If you're uncomfortable with this, or this is something that's very emotional for you, don't keep it inside. Talk about it in your support group, or get counseling, or talk to a family member. Make sure before this becomes a bigger deal that you've already had a chance to mentally and emotionally prepare, so you're able to make the wisest choice when it does happen."

Nancy adds: "Give yourself some grace. This is where a lot of people just say, 'This is not something I can do' and that's okay."

4. Have Open Conversations with Family Members

Be upfront with family members who might be helping with care about the reality of incontinence. Not everyone will be comfortable helping with this aspect of care.

Nancy recalls an important lesson: "I relied on my oldest son, Merritt, several times before I had any caregivers to help me take care of my husband after he was no longer capable of being left alone. After incontinence started, I asked him if he could come stay with his dad for a few hours? . He had realized his dad was incontinent at this point. He said to me, 'Mom, I don't think I can do it.' And I said, 'Why not? He said, 'Because I don't think I could change him. I'm not comfortable with that.'"

Nancy reflects: "Number one, I now realize I shouldn't have put him in that position. Thankfully he was bold enough to say no. Lesson learned. Before you ask someone to take care of your care receiver, talk to them about incontinence and how they feel about handling it. This would have saved my son from having to be bold. He shouldn't have had to do that. I put him in an awkward position and that was unfair."

When Incontinence Begins: Managing the Early Stages

Watch ***The Caregiver's Journey Podcast Episode 10: Pre-Incontinence and When Incontinence First Begins***

SCAN TO WATCH

Understanding the Progression

Typically, incontinence follows a pattern:

- Pre-incontinence: Early warning signs appear, occasional accidents
- Early urinary incontinence: They don't get to the bathroom fast enough, regular accidents
- Complete urinary incontinence: No longer trying to use the toilet for urination
- Bowel incontinence: Usually comes later in the progression
- Complete incontinence: No awareness of bladder or bowel needs.

Nancy describes it as "reverse potty training": "Think of it as a two-year-old who's just been potty trained, and sometimes they get there fast enough and sometimes they don't. That's sort of the situation you'll be in in the very beginning."

Tips for the Early Stages

1. Make the Bathroom Easy to Find

As cognitive abilities decline, finding and recognizing the bathroom becomes increasingly challenging. Make it as obvious and accessible as possible:

- Keep lights on in the bathroom day and night - Create "a beacon to the bathroom"
- Remove obstacles in the path to the bathroom
- Use child proof door knob covers on other doors they might confuse with the bathroom
- Install tall pet gates to block off areas you don't want them to have access to
- Remove locks from bathroom doors to prevent accidental locking
- Consider removing the bathroom door entirely as the condition progresses
- Take off the toilet lid (not the seat) to make the toilet more visible
- Remove distractions from the counter that might confuse them
- Consider using night lights that create a path to the bathroom.

Nancy shares what she learned: "When my husband's dementia really got down to the point where the incontinence became a big part of what we were dealing with, he locked himself in the bathroom. If the toilet lid was down, to him, the toilet was unavailable. If the door to the bathroom was closed, he assumed the bathroom was unavailable, or didn't even know that was where the bathroom was, so he wouldn't go in."

She adds a practical tip: "I started encouraging him to sit down as much as possible on the toilet... because hitting the toilet was becoming quite the challenge and that's less of a mess to clean up. Secondly, I wasn't always sure when we went to the bathroom exactly what he needed to do, so sitting down was the safest option."

For public outings, Sue suggests a helpful strategy: "I would have Jack stand up before we went out to get a picture of his face and what he was wearing. When I was standing outside the public bathroom he was in and I was thinking "Maybe he should have been out by now", I'd show the next person who went in his picture and say, 'Excuse me, my husband has dementia. If you see him in there and it looks like everything's okay, great. But if not, could you please either let me know or steer him out this way?'"

She adds: "When we went to a restaurant, one of the other things I would do is call the restaurant ahead of time to ask if they had a family bathroom, so I could go into the bathroom with Jack. If they didn't, I would reach out to one of the guys we were going out to eat with and ask him to become a bathroom buddy. Part way through dinner they would say, 'I'm gonna go to the bathroom, Jack, do you want to go with me?'"

2. Schedule Regular Bathroom Breaks

- Being proactive with bathroom visits can significantly reduce accidents:
- Observe their natural patterns to identify optimal timing
- Create a consistent schedule for bathroom visits (every 2-3 hours during the day)

- Track and document patterns to identify foods, drinks, or medications that affect urgency
- Use gentle reminders and positive language when guiding them to the bathroom
- Watch for non-verbal cues that they might need to go (restlessness, tugging at clothes, looking around)
- Take them to the bathroom before leaving home and immediately upon arrival at destinations.

Sue advises: "Early in the diagnosis, start observing what their patterns are and getting very specific about bathroom times. Getting them on a routine while we still have the ability to have conversations with them can help get their body clocks on a schedule."

3. Transition to Appropriate Incontinence Products

As accidents become more frequent, you'll need to transition to products designed for incontinence:

For Early Stages:

- Washable incontinence underwear: Looks like regular underwear but offers light protection
- Protective pads: Used with regular underwear for light protection.

For Progressing Incontinence:

- Disposable pull-up style products (Depend products or similar brands)
- Different absorbency levels as needs change
- Consideration of style and color (matching previous preferences when possible).

For Overnight:

- Higher absorbency products specifically designed for nighttime
- Added absorbency inserts or "guards" for extra protection.

When making the transition, Sue offers this advice: "If there are any areas of discomfort, the earlier in the journey you talk about them the better. For example, in the case of incontinence, you can each talk together about how you feel about your supporting them and their having you care for them. A critical point both caregivers emphasize repeatedly: "These are underwear. Call them underwear.The consequences, if you call them diapers or pull-ups, is they are more likely to reject them. These are their underwear and we want that. This is part of maintaining their dignity."

4. Simplify Cleanup

Protect your home and make cleanup easier:

For Furniture:

- Use mattress pads over furniture
- Place disposable pet/pee pads on chairs
- Keep old towels handy for quick cleanups
- Consider replacing upholstered furniture with easier-to-clean options in key areas like breakfast room chairs.

Nancy suggests a practical approach: “If you have your grandma’s favorite antique chair, now’s the time to move it to a different room. I even jokingly have what I call the chair room. It’s got like six different chairs that were out in the main level that are no longer accessible.”

Sue shares her solution: “I went out to a resale shop and bought some chairs that didn’t have padding on them that I didn’t mind if anything happened to them. I still protected them. And yet they didn’t have either sentimental or financial value.”

For Floor Cleaning:

- Keep SwifferJet or similar mops easily accessible
- Use pet-specific cleaning products like Resolve Urine Destroyer
- Try Pooph or similar products for neutralizing odors
- Consider a Bissell Pet Carpet Cleaner for carpets.

Nancy shares: “In my husband’s bedroom he has carpet, and overnight, especially early on with incontinence, he wouldn’t always make it to the bathroom. Sometimes I was happy if the bathroom floor was the only thing that was wet, that was a win. But there came a time where he just wanted to get out of the bed and go to the bathroom and pretty much anywhere on the carpet was fair game. So I bought a Bissell Pet Carpet Cleaner focused on pets and then Resolve has carpet cleaner that also is focused on pets. And I was cleaning the carpet three times a week at least for quite a period of time.”

She adds: “Once my husband started going in the same spots each time, I bought washable jumbo pet pee pads off of Chewy.com. I also want to note here that at first I bought a white one but because of his depth perception when we would take him to bed at night he’d get confused with the white of the pad and mistake it for the bed and literally start to get on the floor, so I ended up buying a brown one. It works much better. We don’t have that problem anymore. Probably twice a week I have to wash it. But it’s now no longer the entire carpet. It’s just that one spot and it’s much more manageable with the pet pee pad.”

Sue adds a creative solution: “I couldn’t get one pet pee pad that was quite the size we needed, so thank goodness for Duct Tape. I would flip two over on the backside and I would duct tape them together.”

5. Maintain a Positive Attitude

Your attitude makes a tremendous difference to your loved one’s experience. They’re likely embarrassed and ashamed about what’s happening, and your response can either increase or decrease their distress.

Nancy shares an important observation: “When I hired a part-time caregiver, one of the first things I noticed was that she was so positive about everything. It seemed like she said ‘Great job’ about everything! I could see the change in my husband’s face and in his confidence because of her tone, her comfort. When incontinence issues occurred she’d say things like ‘It’s okay, it’s not a big deal.’ She made him feel so much better when things went wrong and it helped him maintain his dignity in these very undignified situations. I quickly adopted her approach because I realized how much of a difference it made.”

Sue adds: “It validated him and he felt better because he wasn’t sure how he should feel. And again, this is like a two year old. They’re not really sure if they did the right thing or not. So with your loved one, validate them and try to make them feel comfortable. Even if they’ve just pooped all over the floor, which is probably gonna happen at some point in time, be positive. If you train yourself to have a positive attitude and use positive reinforcement it helps both of you stay calmer.”

Nancy emphasizes the importance of empathy: “Please give your care receiver grace. I’m positive that they would rather have gone to the bathroom in the toilet than either soil themselves, soil their chair, or wherever it is they’ve done. Try your very best to remember that they’re ashamed and embarrassed. Getting mad and upset just raises the emotions of everyone and will increase their angst and how upset they are. We want to protect their dignity as much as we can”

Adaptive Clothing: Making Changes Easier

As incontinence progresses, adaptive clothing becomes increasingly important for simplifying changes and maintaining dignity.

What Is Adaptive Clothing?

Adaptive clothing is specially designed to be easier to put on and take off. Features include:

- Side openings with snaps, Velcro, or magnets
- Elastic waistbands
- Simplified closures.

These design elements make changing your care receiver’s clothes much easier for both of you.

Types of Adaptive Clothing

Pants and Shorts:

- Side-opening pants with snaps all the way up the side
- Pull-on pants with elastic waistbands

Nancy shares an important insight: “All my husband wears now is snap up the side shorts or snap up the side long pants. Once you’re completely using Depend-like products it’s a life saver. It’s not worth trying to get their clothes off to change them. It just creates more drama and makes a bigger deal out of something that you’re trying not to make a big deal about.”

She adds a crucial tip: “One of the things I learned is to be very careful because some of the adaptive clothing, for some reason, might snap all the way up the side to the waistband, and then the waistband doesn’t come apart. So I’m sure if you had a broken leg or something, that would be fine, but if you’re trying to change soiled underwear, you need to be able to snap them all the way off, including the waistband.”

Where to Find Adaptive Clothing

Several companies now specialize in adaptive clothing that’s both functional and attractive:

- Silvert’s
- Buck & Buck
- Adaptive Clothing Showroom
- Amazon’s adaptive clothing section
- Target’s adaptive clothing line
- Zappos Adaptive

Cleaning Your Care Receiver

Watch ***The Caregiver's Journey Podcast Episode 11: Cleaning Your Care Receiver***

SCAN TO WATCH

Essential Supplies to Have Ready

- **Adult washcloths or wipes:** Don't use baby wipes – they're too small. Adult wipes are found next to Depend-like products in the grocery store. These are not flushable, so dispose of them with the soiled Depend-like product.
- **Warm water and gentle soap:** Keep wipes warm if possible.
- **Non-rinse bathing wipes** like Scrubzz or HYGIENJOY: You wet them in warm water and they become soapy and there is no rinsing required. As soon as you get them all cleaned up, you take a towel, you dry them off and you're done.
- **Scissors:** For cutting Depend-like products when changing (often easier than tearing).
- **Disposable gloves:** Keep these handy when changing bowel movements.
- **Disposable incontinence pads:** To place under them during changes.
- **Towels for drying:** Keep these readily available.
- **Trash bags:** Preferably scented for containing odors.
- **Spare clothing:** Keep extra sets within easy reach.

How to Change a Wet Depend-like product

Prepare the area:

- Have a disposable pad underneath them while sitting
- Ensure all supplies are within reach
- Use positive, clear language to explain what you're doing.

Remove adaptive clothing:

- Either while standing or sitting, depending on what's easier
- If using adaptive clothing with snaps, unsnap along the sides
- For regular clothing, carefully remove pants or bottoms.

Prepare the new Depend-like product before removing the old one:

- Open the new Depend-like product and pull it up to their knees while they're seated
- This preparation ensures they only need to stand once during the change.

Take off the wet Depend-like product:

- For pull-ups, cut up the sides (scissors are often easier than tearing).

Nancy advises: "When you get an experienced caregiver in your home, they'll tear the sides like it's nothing. What happens when you're not experienced is you are pulling and struggling and ripping and it's ripping up this way and that way and now you've created a more uncomfortable situation for your loved one. They're embarrassed. They're ashamed. We're trying to make it okay. 'Have a seat. We're going to change your underwear.' We're trying to make it no big deal and now we're making it a big deal because we're ripping and tearing."

Her solution: "I use kitchen scissors. If that seems a little bit risky, get some round tip medical scissors. I just snip up one side and snip up the other. There's not much drama involved in that."

Help them stand:

- Ask them to stand (offer physical support if needed)
- Remove the wet Depend-like product from behind
- Pull up the new Depend-like product that's already positioned at their knees.

Nancy notes: "You do not have to clean them every single time that you change their underwear. You do need to give them a good cleaning in the morning and you clean them really thoroughly when they have a bowel movement."

Throughout the process, maintain calm, supportive communication:

- Tell them what you're doing each step of the way
- Use simple, clear instructions one at a time
- Offer praise and reassurance
- Thank them for their cooperation
- Keep your body language and facial expressions positive.

Changing After Bowel Movements

Watch ***The Caregiver's Journey Podcast Episode 12: Bowel and Bedbound Incontinence***

SCAN TO WATCH

This can be more challenging, but with practice, it becomes manageable:

Get to the bathroom quickly:

- Don't let them sit down if they're standing
- Use calm, positive language: "Let's go get you some clean underwear. Let's go get you cleaned up."
- Guide them to the bathroom where cleanup will be easier

Create a calm environment:

- Check your body language and words
- Speak calmly and reassuringly
- Remember they're likely embarrassed and ashamed.

Prepare the area thoroughly:

- Put disposable pads on the floor to catch anything that falls
- Turn on warm water to have it ready
- Lay out all supplies within easy reach
- Put on disposable gloves.

Remove the Depend-like product carefully:

Watch video of changing a Depend-like product with a bowel movement here.

SCAN TO WATCH

- Cut up one side of the Depend-like product
- Fold it inside toward the other side (cradle the bowel movement)
- Cut the other side nearly through
- Grab both front corners for control
- Finish cutting and take the Depend-like product down between their legs from behind
- Guide it into a trash can positioned nearby.

Nancy explains the technique: "Tell them what you're doing the whole time. 'I'm going to take your underwear off,'

It's easiest to understand how to do this if you watch the video Sue and I made here.

SCAN TO WATCH

"Stand behind your care receiver and cut up one side of the Depend-like product and then take that side and fold it into the other side of the underwear so you're sort of cradled the bowel movement. Use your scissors on the other side and cut almost all the way through. With the same hand, grab that front of that side of the Depend-like product as well. Finish cutting it all the way through. The back is pulled together like an envelope and you're still holding the front. Take your free hand, grab the front of the underwear and separate the sides and then just slide the underwear down between their legs and take it off behind them."

Clean thoroughly:

- Use adult wipes or non-rinse bathing wipes
- For women, wipe front to back to prevent infection.

Nancy explains why: "If it's a woman, you want to wipe front to back because you don't want to risk getting any stool inside of them. It can create yeast infections and urinary tract infections."

- Ensure all areas are clean
- Dry completely with a towel.

Put on a fresh Depend-like product quickly:

- Be aware they might need to urinate after cleaning with warm cloths
- Have the new Depend-like product ready
- Help them step into it and pull it up
- Assist with putting clothes back on.

Dispose of waste properly:

- Use scented trash bags if desired.

Nancy suggests: “I use a lemon scented small trash bag. I tie it up and then place it in an adult disposable incontinence can that is in my garage. We take all of the dirty Depend-like products with bowel movements and put those in the garage incontinence can. Since we take our garbage out of the house every night, I don’t find the urinary ones smell too much inside, but the bowel movement ones definitely do so you want them out of your house as soon as possible preferably.”

Nancy reassures: “You’ll probably be a nervous wreck the first bunch of times that you do this, you’ll think, ‘my goodness, I don’t have it, I can’t do this, it’s going to be a big mess’ and it might be. Just like anything, once you get comfortable with it and get good at it, and once your care receiver knows what’s happening and is more cooperative, then it really won’t be a big deal. You can do this!”

She adds: “At the beginning, your care receiver may resist. Put yourself in their shoes. Someone’s coming at you. They’re pulling off your pants or whatever clothes you have on. They’re coming at you trying to take your underwear off, you’re gonna feel like you need to defend yourself, at least at the beginning, until they understand what’s going on here, and it starts to become more routine. Don’t be surprised if there’s some battling going on early on. That passes for what that’s worth. They do get comfortable, more comfortable, at least in my experience with the routine, and it’s not such a big deal. Remember to be calm and use positive body language.”

Managing Overnight Incontinence

Watch ***The Caregiver's Journey Podcast Episode 13: Incontinence Overnight***

SCAN TO WATCH

Nighttime presents unique challenges. As Nancy puts it: "You may need to let the chips fall where they may."

Understanding the Challenge

Managing overnight incontinence involves balancing several factors:

- Your need for sleep
- Their comfort through the night
- Safety concerns if they get up unassisted
- The reality that accidents will happen.

Practical Strategies for Overnight Management

1. Transition to Nighttime Underwear

Even if your loved one doesn't normally wear underwear to bed, they'll need to start wearing absorbent products at night.

Sue notes a particular challenge: “The challenge I had is my husband was used to putting on his underwear in the morning and wearing it for the day and he did not want to put on a clean pair of underwear before he went to bed. He usually took them off when he went to bed. So that was a little bit of an adjustment.”

Nancy adds: “A lot of people don’t wear underwear under their pajamas. So for example, my mother had to convince my dad that he had to wear nighttime underwear. He looked at her kind of funny, but he did it. That was the end of that discussion. It was a Depend-like product.”

2. Create Multiple Layers of Protection for the Bed

Overnight accidents are inevitable. Prepare the bed thoroughly:

Use waterproof allergy-proof mattress encasements

Sue notes: “The best waterproof mattress cover we both found was the allergy proof mattress bags. They say they’re waterproof as well and they are. Most of the rest of the mattress covers say they’re waterproof, they might be waterproof if you’re two years old, but they’re not waterproof for a grown adult who might completely go to the bathroom in bed.”

Use multiple layers of protection:

- Mattress encasement as the base layer
- Mattress cover
- Absorbent bed pad on top of that (I found large pet pee pads worked best after much trial and error)
- Fitted sheet over everything.

Nancy emphasizes: “Whatever it is you want multiple layers because you’re going to need to massively protect the mattress. I have two layers of mattress covers and then there’s loose mattress covers that aren’t necessarily fitted that I have even in between the two layers of mattress covers. Some days we take one mattress cover off and wash it, some days it’s the mattress cover and the loose one in between and some days it’s all three of those.”

Use large washable pads:

- Large pet pads (72” long) are perfect for queen or king beds
- Position them in strategic locations on the floor as well as in the bed.

Nancy shares: “I bought washable jumbo pee pads off of Chewy. The one I have right now is 72 inches long, which is the length of a king size bed. I keep those next to the bed as well. At night there’s not as much walking around the room and going in the wrong place as there used to be, but there is some standing up and going next to the bed. We’re down to one spot. I keep a jumbo pet pee pad in that one spot and we wash it when it’s wet.”

Sue adds: “All of your bedding needs to be washable, including your comforter, everything needs to be washable. You probably want to have two of all of it. If you don’t have a washable comforter or bedspread, it’s time to get one, you need something washable.”

Consider splitting a king bed into twins:

- Use two extra-long twin mattresses
- Use separate sheets for each side
- This way, you only need to change half the bedding when accidents occur.

3. Make the Bathroom "a Beacon"

Making the bathroom easy to find at night is crucial for reducing accidents: .

Keep lights on in the bathroom and pathway

- Use night lights to mark the path
- Ensure the bathroom itself is well-lit
- Avoid shadows which can be confusing or frightening.

Sue explains: "We call it making it a beacon to the bathroom. You want to make it really easy to find the bathroom. There are a couple things that you do. One is you leave a light on in the bathroom."

Remove distractions in the bathroom

- Keep the bathroom counter clear
- Remove anything that might confuse them.

Sue shares: "I would leave the lights on into the bathroom. I took everything away that could be distracting to him so that there was less confusion."

Take the lid off the toilet

- This makes the toilet more recognizable
- Keeps it visibly available.

Use childproof locks on other doors

- Prevent them from going into the wrong rooms
- Keep them from wandering into unsafe areas.

Sue advises: "If you've got the bathroom connected to your bedroom, then use a child proof door knob cover to ensure they stay in the bedroom/bathroom and can't wander out into the rest of the house. If they have to leave the bedroom to go to the bathroom use the tips below."

Block off other areas

- Use tall pet gates to cut off hallways and to create a path to the bathroom.

Consider installing cameras

- Allows you to monitor without getting up every time they do
- Helps you determine when intervention is necessary.

Nancy shares: “I installed cameras that allow me to see on my phone what was happening. This way I can keep an eye on things without having to get out of bed.”

4. Maximize Absorption at Night

As sleep is essential for you both, maximizing absorbency at night is crucial:

Use overnight-specific incontinence products

- These have higher absorbance than daytime products
- Add absorbency inserts or “guards” for extra protection.

Add “guards” for extra absorbency

Nancy explains: “Later in the journey I found that a Depend-like product on its own, even the ones with the nighttime strips in them, don’t hold enough urine for someone to be comfortable all night. You find guards in the grocery store next to the Depend-like products. They are another level of padding for extra absorbency.”

She adds: “We got to a point where we’d put two guards inside the Depend-like product now. That was fine for a while, but over time I found that wasn’t even enough. My aunt put four guards on her husband’s Depend-like product.”

Consider creative solutions for maximum absorbency

Sue shares: “One of my friends would cut off the inside of the Depend-like product out and put the inside of the second Depend-like product in the first one. So that’s an option as well.”

Consider nighttime changes if possible

- This can dramatically increase comfort and reduce skin issues.

Nancy shares a valuable insight: “When I was on a tour of a care community, they talked about how, in the memory care unit, they would change them in the middle of the night. Well, duh, never crossed my mind that we should change him in the middle of the night, honestly. Not everybody can do this. Some people have to sleep straight through the night, eight hours, and this is not even an option. But for me, it was a wake up call.”

She explains her approach: “I’m a light enough sleeper and I sleep for a good four hours and then I wake up pretty refreshed and then I go back to sleep for another four hours. Well, guess what I do now when I wake up in the middle of the night? I go down, I change his Depend-like product, I go back to bed, he goes back to bed. I know he’s more comfortable and honestly, it’s a pretty easy process for me.”

Manage hydration strategically

- Ensure adequate hydration throughout the day
- Consider reducing fluids in the evening.

Sue advises: “One of the things you can do is if you can help them get that water earlier throughout the day and then stop it earlier in the evening, then they’ll have much less need to void in the middle of the night. Don’t cut back on the amount of water. That is where urinary tract infections come from. Dehydration is not a good thing.”

Nancy adds: “My father had Parkinson’s and so he’d want to get up all night and go to the bathroom. Unfortunately for people with Parkinson’s getting up in the middle of the night is a big struggle because they have massive balance issues. His doctor suggested that he not drink after 6 p.m. so that it would minimize the amount of times he needed to get up. If you choose that strategy then, as Sue suggests, you need to push a lot of water earlier in the day to keep them from being dehydrated.”

Be prepared for a thorough morning cleaning

Nancy notes: “When your care receiver gets up in the morning, they have likely been sleeping in wet incontinence underwear. So the first thing that happens when my husband gets up in the morning is a bath from the waist down.”

Balance Between Assistance and Self-Care

Nancy shares a reality check about overnight care: “By default it can be very stressful because you don’t know what you’re going to wake up to. In the wandering episode, we talk about at night you should be minimizing the areas that your loved one can go to. They need access to a bedroom and a bathroom.”

She continues with an important perspective: “If you’re not getting up with them in the middle of the night, give yourself some grace - you can’t manage things 24/7. Realize you’re often going to wake up to a mess and that’s stressful.”

Nancy emphasizes compassion: “You got to give everybody some grace, yourself and your loved one. It adds no value to get mad at them for whatever mess happened during the night. You’ll only be taking a very difficult situation and adding embarrassment, shame and frustration to it. You will only make things worse.

Think - how would you want someone to treat you if you were confused and made a mess during the night?”

Cleaning and Changing Your Bedbound Care Receiver

Watch ***The Caregiver's Journey Podcast Episode 12: Bowel and Bedbound Incontinence***

SCAN TO WATCH

Cleaning and changing your bedbound care receiver requires specific techniques and considerations.

Sue's Experience: "I've had experience with loved ones both at home and in a care community. When I was at home and changing my loved ones alone, it was quite challenging in the beginning. I began writing the steps of this complex task to share with you and realized it would be much easier for you if I could find a video showing the process. We are all fortunate because there is one!

SCAN TO WATCH

I wish I'd had this video, Changing an Absorbent Brief for a Bed bound Patient, by two hospice and palliative care nurses, Brenda Kazir and Nancy Hyerman, on their YouTube channel 'The Hospice Care Plan'. Their video provides excellent, detailed instructions on changing a bedbound individual.

I highly recommend you have a professional caregiver demonstrate these techniques and help support you when you're first learning. I was actually afraid the first few times I put on and changed my loved one's disposable incontinence underwear. I was afraid I might hurt them and also somewhat afraid of what they might do if they felt I was trying to harm them. It would have been much less stressful to have had someone with me to teach me and to be a reassuring presence if something went wrong.

Additional Tips

- Get all your supplies ready and within your reach.
- Give one instruction at a time.
- Maintain a positive, calm demeanor.
- Keep moving, but don't rush through the process.
- Continuously check on your care receiver's comfort and condition.
- Check the integrity of their skin every time to prevent bed sores.
- Depending on the size of your loved one, a pillow may not be enough to support them on their side. I recommend an actual wedge pillow to keep your care receiver stable.
- Consider using a bed with rails for added support and safety.

Nancy's Experience: It's important to note that bedbound situations can be temporary. When my husband had COVID, he was immobile for a few days. I had no idea what to do or how to change him. Even if you don't need this information now, it's good to save it for future use.

When You Need Additional Support

Recognizing Your Limits

Incontinence management can be a significant turning point in your caregiving journey. It's completely okay to recognize when you need help or when this crosses a boundary for you.

Sue emphasizes: "This is really an important inflection point for whether or not this is something that you have the capacity to do. You've had a very full day caring for your loved one. Can you manage the nights as well?"

Nancy adds: "This is another inflection point. We've mentioned this in the earlier episodes - when you get to urinary incontinence, some people realize that they've reached a line they're not comfortable crossing. That's okay - give yourself some grace. Some people look into care communities at that point, or they bring in professional caregivers. Some people make it through urinary incontinence and cleaning their care receiver but when we get to bowel incontinence, that is a boundary they don't feel comfortable crossing."

Sue points out physical limitations as well: "It's not just that you're uncomfortable with it. You physically may not be able to." This is especially true for caregivers who are older themselves , have physical limitations, or have a loved one who is much larger than they are.

Options to Consider

Bring in professional caregivers to learn techniques

Even if you plan to continue as the primary caregiver, having a professional show you proper techniques can be invaluable.

Sue suggests: "In the very beginning when you're kind of flustered and trying to figure this all out, bring in a professional caregiver and have them work with you."

Part-time help:

- Consider bringing in help specifically for tasks you find most challenging
- Overnight assistance can be particularly valuable for preserving your sleep
- Weekend help can give you a break to recharge.

Full-time in-home care:

- Professional caregivers who come to your home
- Can be adjusted to the level of support needed
- Allows your loved one to remain in familiar surroundings.

Care communities

For some, this may be the point where a memory care community becomes the best option.

Sue notes: "There are many people I've talked with where this became the pivot point because they recognized they could not navigate all of the other care and incontinence 24/7. They either needed to bring care into the home or find a community. This had just gotten too much for them to handle."

Nancy adds a valuable insight about care communities: "I always keep abreast of what's going on in the care communities that are around me. I want to make sure if the day comes that I need a care community, I'm not caught at ground zero trying to figure out places I would be interested in. I tour care communities periodically."

Final Thoughts: You've Got This

Incontinence management is challenging, but it does become more manageable with time, practice, and the right approach.

What Matters Most

Through this challenging aspect of care, keep these principles in mind:

- Dignity matters: Your approach and attitude can preserve their sense of dignity
- Relationship matters: This is still the person you love, despite the challenges
- Self-care matters: You cannot provide good care if you're depleted
- Grace matters: Give it generously to both yourself and your loved one.

Sue summarizes it well: "Give yourself a tremendous amount of grace. Check in with yourself. Is this something that you are feeling okay with or do you need to bring in someone to help support you or potentially consider moving your loved one into a care community?"

You're Not Alone

Throughout this journey, remember that countless caregivers have walked this path before. Connect with others through:

- Support groups (in-person or online)
- Caregiver forums
- Professional resources and advice
- Friends and family who understand.

As Sue and Nancy say: *"We're all on this journey together."*

Listen to The Caregiver's Journey Incontinence podcast playlist:

PODCAST EPISODE 9

Preparing for Incontinence

WATCH EPISODE

PODCAST EPISODE 10

Pre-Incontinence and When Incontinence First Begins

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PODCAST EPISODE 11

Cleaning Your Care Receiver

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PODCAST EPISODE 12

Bowel and Bedbound Incontinence

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