

When Someone Won't Use the Toilet: Dementia, Lost Cues, and the Missing "Steps"



A particular confusing part of dementia care for families is this: a person may shift constantly in their chair, stand up repeatedly, pace around the room, or look as if they are searching for something — yet when you guide them toward the bathroom, they either refuse, look blank, or wander away again as if they don't know what they're looking for. And if you ask, "Do you need the toilet?" you'll often get a firm "no". This is the dementia brain failing to recognise the signal and failing to complete the steps.

In a healthy brain, using the toilet is automatic. The body signals the need, the brain translates it, the person acts, and the routine completes itself. In dementia, that chain can break at multiple points. The bladder may still be working exactly as it always has — but the brain can no longer interpret the cue properly or move the person through the process. So the person feels unsettled... but they don't know why. They feel pressure, discomfort, restlessness, confusion, urgency, or "something isn't right" — but the brain doesn't label it as toilet. Instead, the feeling comes out as movement. They shift, stand, pace, search, hover by doors, fidget with clothing, or repeatedly get up and sit down again. The behaviour becomes the message — because the words and the clarity are no longer accessible.

But there is another layer families often don't realise is happening at the same time: even if the person does recognise the need to go, the brain may not be able to complete the journey of finding the right place and knowing what to do once they arrive. Toilet use is not one task. It is a full sequence. And dementia breaks sequence. That sequence includes recognising where to go, recognising what the toilet looks like, recognising the door, turning the correct way, stepping inside, knowing what to remove first and how, knowing how to sit down safely, knowing what happens after, remembering whether to flush, recognising what an incontinence aid is called and what to do with it, knowing whether something is flushed or binned, and recognising the

correct bin, the correct place, the correct action. So what families see as “refusing to go” is often the person standing at the edge of a system that has become too complex for the brain to finish without support.

This is why a person might search for a place and still walk straight past the bathroom. They may not recognise it. Or they may recognise it too late. Or they may know they need something, but not know what that something is. Or they may be afraid of getting it wrong. And when people feel confused and exposed, they protect themselves the only way they can: they resist. This is why a simple environmental change can suddenly transform everything. Sometimes the difference is the bathroom door being clearly visible. Sometimes it’s the light being on. Sometimes it’s a picture on the door. Sometimes it’s removing clutter and making the toilet the most obvious object in the space. And sometimes it’s the bin.

Families often don’t think about the bin until it becomes a problem — but a dementia brain needs the clearly marked with an image bin to “make sense” in the same way it needs the toilet to make sense. If a person is wearing an incontinence aid, and they don’t know what it’s called, or whether it gets flushed, or where it goes, they can freeze. Or they can hide it. Or they can try to flush it. Not because they are being careless — but because the brain cannot complete the logic. So the question families really need to stop asking is not “Why won’t they go?” The better question is: “Which part of the sequence is failing today — recognition, location, steps, privacy, or confusion about what comes next?” This is why toileting support in dementia is about protecting their dignity when the brain’s automatic systems are no longer working properly. And when we stop missing the breakdowns the person living with dementia is experiencing and start supporting the brain, accidents reduce, distress reduces, and trust increases — because the person feels safer and a little bit more in control of themselves and their experienced situation.

If you’re supporting someone through this, you are not failing. You are doing something most people are never taught how to do: you are learning how to interpret a brain that can no longer explain itself.

To learn more about behaviours, the language they speak, and how to implement helpful tools and gestures, you’re welcome to join our *Dementia Care & Understanding* course on our website: <https://launexltd.com>



