

CHAPTER TWO

Delirium, Dementia, Depression, and Psychosis: The Importance of a Correct Diagnosis



SEPTEMBER 14, 2000

Glen and I were eating dinner when the telephone rang. I answered. It was my sister Jill, calling from the emergency room of a mid-Michigan hospital to say that Mom had been having bizarre and frightening hallucinations all day. Mom thought “they” were coming for her. She kept describing how “they” were outside the house, circling from window to window, and calling to her, “Alice, you have to come with us. It’s time for you to go.”

Jill said that Mom told her she’d told “them” they’d have to come back later, that she had her bridge club coming soon. However, Jill also learned that Mom had called her bridge group and told them not to come, that she couldn’t play cards today.

According to Jill, Mom had a urinary tract infection (UTI). I learned much later that hallucinations are a common symptom of a UTI with a fever in the elderly. The ER physician who diagnosed Mom told Jill that she could take Mom home, but that someone would have to stay with her to watch her.

Jill had just started back to work after a prolonged absence due to a recurrence of breast cancer. She explained that she could not stay home from work to care for Mom.

Betsy, our other sister, was caring for her critically ill husband, Mike, who had recently undergone heart surgery and who was struggling with lung cancer.

Jill said on the phone that the emergency room physician had explained he could admit Mom to a facility related to the hospital. He described it as a place for people with mental problems. He said that if Mom checked herself in, she would be able to discharge herself, but that if she refused to check herself in, he would admit her involuntarily. Then she would not be able to leave if she wanted to.

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Jill asked me if I agreed with a voluntary admission to a mental health facility. That was when I made my first mistake. I agreed that Jill should convince Mom to voluntarily admit herself. Now, when I Monday-morning quarterback, I realize that I should have jumped in the car and driven the three and a half hours to Mom's home. I should either have taken care of her there or brought her back to our house until she got better. A urinary tract infection, properly treated, goes away quickly. With one of the new wonder drugs, you can eliminate a UTI in a matter of two days.

Instead, Jill and Betsy drove Mom to Alpine Manor, the behavioral medicine unit of the facility associated with the hospital where the ER was.¹ It was nearly midnight by the time Mom was admitted and the paperwork completed.

A history was taken and a psychiatric evaluation was done. When questions were asked about prior episodes of "confusion" (a benign way of describing delirium often used in medical literature), one of my sisters answered that, yes, Mom had been confused in the past few weeks or months. She really meant that, as is common with the elderly, Mom would hear something or be told something but later, she would need to be told again. Forgetfulness ("confusion") is common in the elderly.

It was established that Mom had no prior history of mental illness and that there was no family history of mental illness. The initial psychiatric evaluation also said that Mom had demonstrated some memory deficits over the past two years. This record said that her hallucinations began two days earlier. Parkinson's disease and the urinary tract infection (UTI) were noted in the history, as well as the prescription of a powerful antibiotic for the UTI.

On September 15, the medical director, a psychiatrist who had never seen Mom before, diagnosed her not with delirium but instead with a psychotic disorder "possibly secondary to urinary tract infection and/or Parkinson's disease." He noted that it was necessary to "rule out" dementia. He prescribed 0.25 mg of an antianxiety medication to treat her extreme paranoid anxiety. An antipsychotic was prescribed on September 17 for her "acute anxiety that was accompanied by bizarre hallucinations."

I did not go down to see Mom the first two weeks she was in Alpine Manor. The visiting hours were from 6:00 p.m. until 7:00 p.m.; it seemed impossible to travel seven hours for a one-hour visiting period. Jill and Betsy were visiting with her daily and there was an 800 number I could call so that I could talk with her every day. Some days, I called her twice. The hope was that the infection would soon go away and she'd feel better and would be able to go home.

Each day that I talked with her, Mom would begin the telephone call with a long list of "news." The problem with the "news" was that it was one story after another of simply horrible things that had happened to a family member. Each

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time Mom would recount a story about how Michelle had had a bad accident with Mom's car, I'd say, "No, Mom, that was just a bad dream. It didn't happen. Everything is okay, Michelle and the car, too."

Mom would then tell me about Kathy's husband, Brian, a policeman (Kathy was one of Mom's granddaughters). "Did you know that Brian got shot yesterday and died?" Mom would ask.

"No, Mom, that was another bad dream. It really didn't happen," I would reply.

At the time, it was difficult for me to understand why Mom kept having all of these horrible thoughts. It was not until long after her death that I learned that hallucinations and paranoid thoughts are a common symptom of delirium and that many factors endemic to nursing homes contribute to delirium and/or confusion in elderly people. I learned that it is important to give emotional support to delirious patients, to acknowledge their concerns and reassure them that things are all right, rather than to deny their delusions. I also learned that when, as with Mom, delirium is undiagnosed, the result for the frail elderly patient may be imminent death.

Mom's hallucinations continued unabated and, according to the nursing notes that I eventually read, became more severe. Mom had slept during the night, according to the nursing notes, the first few days after her admission. However, between September 17 and 19, Mom slept very little; instead, she wandered the halls. At 6:45 a.m. on September 19, when she was encouraged by an elderly male patient who had befriended her to wave her cane at the monsters she was seeing and her cane struck a staff member, Mom was diagnosed as psychotic. Her medical records simply reflect that she "assaulted" a staff person. The antipsychotic was immediately doubled. There was nothing in her records to indicate that there had been any inquiry into the background of the incident—something that would have established that this was an isolated incident and was not evidence that Mom was dangerous to other people.

It was the beginning of the end. After the "assault," the staff transferred Mom to the intensive care section of the facility and took away her cane, which she used because of her Parkinson's disease. She was not given a walker, nor was Jill telephoned and asked to bring Mom's walker. At 5:30 p.m. on September 19, while trying to walk without her cane, Mom fell in the hallway and was taken to the hospital by ambulance. X-rays showed that she had suffered three broken ribs. After her return from the hospital, she slept through the night but the nursing notes show that Mom fell again at 6:00 a.m. on September 20, striking her head on the floor. Now her face was bruised along the entire left side and her left eye was swollen shut.

Another week went by. Though Mom had been given an antibiotic for her

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urinary tract infection, she continued to be delirious much of the time. About two and a half weeks after her admission, her records show that she was anemic, had an electrolyte imbalance, and was “thought,” because of her delirium, to have a continuing urinary tract infection. Her serum sodium levels were also elevated, indicating dehydration. None of these conditions was treated. The other profound and ultimately fatal medical conditions, all untreated, developed thereafter.

Critically, the diagnosis of psychosis and a few days later dementia with psychosis permitted the facility to give Mom an antipsychotic, even though the Omnibus Budget Reconciliation Act (OBRA) rules described later in this chapter were not followed. There was no documentation, for example, that the facility attempted to use any method to keep Mom from harming herself or a third party without using drugs. Nor was there any documentation that the facility had made an effort to determine whether Mom’s “assaultive behavior” was transitory or permanent. Despite OBRA requirements that psychotropic medications be tapered or discontinued, this did not happen either. Even when, on September 29, the discharge summary from the mental health unit stated that Mom was “considered to be significantly improved at the time of discharge as not reporting any overt psychotic symptoms,” the antipsychotic was not withdrawn. When, in fact, Mom became physically incapable of walking or raising her arms, when she’d lost her ability to talk, when the dystonic side effects of the antipsychotic twisted her neck muscles so much that her head was actually lying on her right shoulder, the facility still did not discontinue the drug.

Imagine my sorrow when I reviewed Mom’s medical records after her death and learned that she had asked to telephone me on the day she supposedly assaulted the staff member. Her records show that at 2:30 a.m. on September 19 she told a nurse, “I want to call my daughter in Traverse City. She’s a lawyer and she’ll get me out of here.”

Mom was refused a telephone. She was told that she’d be advised when she could use a telephone. This never happened. As usual, I called her that afternoon and her records show that we talked for 45 minutes. By then, her terror had abated. She was confused and rambling, but she did not ask me to come and get her.



Delirium: A Commonly Overlooked but Dangerous Problem

As a caregiver, you should be particularly alert to any sudden onset of confusion in your elderly loved one because delirium is often undiagnosed. As I will explain later in this chapter, when delirium is undiagnosed, then the critical conditions causing it are often untreated and can be fatal. Look at delirium as a kind of “fire alarm.” When you suspect delirium, you will want to sound the alarm and get the first responders on the scene. Because your loved one is probably not cared for by a geriatrician, use your special knowledge about delirium—what I’m going to teach you here—to advocate for a proper diagnosis and for diagnosis of its underlying cause.

A doctor or nurse trained in geriatric medicine will normally associate an unusual confused state in a sick elderly person with delirium and will naturally understand that treatment of the underlying condition will make the delirium subside. But because most doctors and nurses are not trained in geriatrics, many do not understand the sudden onset of confusion as delirium. This can lead to misdiagnosis. If, as occurred with my mother, the doctor misdiagnoses it as dementia and fails to detect and treat the underlying medical condition, a not infrequent result is the patient’s decline, or worse, her death.

Death May Result from Undiagnosed Delirium

15 to 26% of all nursing home residents who become delirious die, usually as a result of an untreated underlying disease process that is causing the delirium.

Once a diagnosis of delirium is made, it’s crucial to determine the cause of it. Many treatable diseases and conditions can cause delirium. Many medications commonly prescribed for the elderly also can cause delirium. Eliminating the medication or reducing the dosage may resolve the problem. Because 15 to 26% of all nursing home residents who become delirious die, usually as a result of an untreated underlying disease process that is causing the delirium, it is imperative that a correct diagnosis be made.² While it is not uncommon for the elderly to suffer from confusion or forgetfulness, it is important to note that *every medical journal article I have read* concerning the diagnosis and treatment of delirium states clearly and emphatically that any acute or sudden change in an elderly person’s perception and understanding of reality, consciousness, or both, *should be considered delirium until proved otherwise*. Delirium is a symptom that

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something is seriously wrong—that there is an underlying cause that can usually be resolved if prompt intervention occurs.

Unfortunately, dementia, delirium, and depression are the most commonly missed diagnoses in older adults with behavioral symptoms.³ The frequency with which delirium is missed is alarming! In 1994, Dr. P. T. Tzepacz found that doctors missed a diagnosis of delirium in 95% of patients! (They missed a diagnosis of dementia in 72% of patients and missed a diagnosis of depression in 85% of patients.) In another study of hospitalized elderly patients, he found that only 5% of the deliriums were detected by physicians, despite the fact that the nursing notes contained sufficient information to diagnose delirium 85% of the time. (Dr. Tzepacz found that physicians only used the nursing notes about 20% of the time.⁴) Thus, physicians were overlooking a key source of information about changes in their patient's behavior that might have helped them make a correct diagnosis.

A primary reason why doctors miss the diagnosis so often is that they see only a fraction of resident/patient behaviors. Since physicians typically have so little actual contact with patients, the best insight into behavioral symptoms that could trigger a diagnosis of delirium, dementia, or depression comes from the people—the nurses, aides, or family members—who have the greatest opportunity to see these behaviors.

Consequently, to protect your loved one from unnecessary or inappropriate treatment of what are viewed as problem behaviors or what may be written off as psychiatric illnesses or normal effects of aging (senility), is essential that you participate in the history-taking process and that you share your unique understanding of your loved one's usual mental status to make certain the physician and nursing home facility have adequately and accurately assessed your loved one's confusion.

Ask yourself the following questions:

Is your loved one suffering from:

delirium (confusion/hallucinations, usually due to an underlying medical condition),

dementia (a chronic, progressive illness characterized by loss of memory and a severe reduction in all aspects of mental functioning), or

psychosis (a psychiatric illness or disorder)?

Has her decline in normal cognitive ability been rapid or gradual?

Has her decline been acute or does it appear to be chronic and progressive?

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SUDDEN ONSET OF CONFUSION IS THE HALLMARK OF DELIRIUM

The abrupt change in mental status is a key to identifying delirium. The onset of delirium is so sudden, usually occurring in a matter of hours to days, that it is generally possible for a family caregiver to identify a precise date when it began. The intimate knowledge you have of your loved one's normal personality and demeanor makes you the most valuable member of the caregiving team because you will usually notice significant changes long before a nurse or an aide, and you can alert them that a physician should investigate the cause of these changes in status.

Differentiating between the mental state of the patient today and the normal mental state of the patient is crucial to the diagnosis of delirium. Ideally, of course, a patient will be seen and evaluated by a physician who is familiar with her. Once an abnormal mental state is noted, the lab tests showing a urinary tract infection or other medical complication may clearly indicate delirium as the cause for a patient's agitated mental condition.

COMMON CHARACTERISTICS OF DELIRIUM

In order to help your loved one's physicians detect delirium, you'll need to know what to look for. Delirium is characterized by a sudden change in mental status resulting in confusion and disorientation, especially as to time and sometimes as to identity. A delirious person acts very much like someone who is becoming increasingly intoxicated.

Incoherent thoughts and ramblings are also common symptoms of delirium. Delirious people often see strange and frightening hallucinations. Paranoia is often experienced in delirium, and a patient may think that strange things are happening either to them or to their loved ones.

Delirium can persist from hours to days or even longer, and its severity will depend on the underlying medical circumstances. It will also depend on whether any underlying condition is properly diagnosed and treated.

Typically, delirium is characterized by the following features:

- Confusion and disorientation. These conditions are readily apparent. Patients may, however, have periods of lucidity and their mental status may fluctuate throughout the day.
- Change in attention span. Patients are no longer functional but instead have extremely short attention spans.

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- Noticeable changes in patients' sleep-wake cycles. These may vary from hour to hour. Sometimes delirium is worse at night, a situation called "sundowning."
- Insomnia. This is also a common feature of delirium. In addition, some delirious people become very quiet and withdrawn, making it difficult to diagnose a problem. Other delirious people become agitated. These people may attempt to fight their hallucinations or delusions.⁵
- Drastic changes in patients' physical activities. Patients may either become lethargic and move very little or, in stark contrast, become hyperactive.⁶

MEDICAL CONDITIONS THAT COMMONLY CAUSE DELIRIUM

Knowing what can cause delirium can help you recognize it. The tests for common precipitators of delirium not only help in diagnosing delirium, but also in identifying and treating its underlying cause. Dr. Espino and his colleagues, writing for the *Journal of the American Family Physician*, recommend that when an acute change in mental status is observed, delirium should be suspected first and ruled out. Since delirium is so often caused by an underlying medical problem that, undetected, could lead to death, diagnostic tests should be undertaken to determine or to rule out an underlying medical condition as the cause of delirium. According to the *Merck Manual*, countless conditions or disorders can cause delirium, including readily treatable conditions such as an electrolyte imbalance, drug reactions, or serious infections.⁷

Some of the common causes of delirium in elderly people are as follows:⁸

- Urinary tract infections and the fever that persists
- Other types of infections, especially those accompanied by fever
- Side effects of many different types of medications commonly taken by elderly people for several different kinds of concurrent illnesses⁹
- Interactions between one medication and another
- A disorder of metabolism
- An electrolyte imbalance, even a minor one
- An imbalance in the levels of acids and bases in the body
- Dehydration
- Loss of the body's ability to maintain normal temperature (hypothermia)

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- Retention of urine
- Fecal impaction (constipation)
- Acute blood loss
- Congestive heart failure
- Kidney failure
- The change from a familiar environment such as home to a strange environment such as a nursing home
- Under-nutrition or malnutrition
- Acute grief such as that due to the loss of a spouse or other loved one
- Substance abuse, either active or in the past
- Poor heart or lung function that leads to decreased oxygen or increased CO₂ in the blood
- Poor or non-ambulatory status (wheelchair-bound or bed-bound)
- A history of serious brain trauma such as a subdural hematoma caused by a fall or disease
- A complication after surgery in the postoperative stage
- An overload of anticholinergic drugs

Anticholinergic Medications

Many of the prescription drugs used in the treatment of Parkinson's disease, depression, allergies, migraine, and irritable bowel syndrome are anticholinergic drugs, as are some pain relieving (analgesic) drugs. Non-prescription drugs of this type are becoming increasingly available, including cold and flu medicines, indigestion tablets, sleeping pills, and anti-diarrhea treatments. The risk of side effects from a dose of one of these might be very small, but many elderly patients take several kinds of medications at once, increasing the likelihood of an "anticholinergic load." The typical side effects of anticholinergics are dry mouth, constipation, urinary problems, dizziness, likelihood of falling, anxiety, rapid shallow breathing, and irregular or rapid heartbeat.

The lab tests physicians may order when ruling out delirium and identifying its cause include: (a) a complete blood count, (b) an electrolyte test, (c) metabolic screening tests, (d) thyroid function tests, (e) Vitamin B₁₂ and folate tests, (f) screening for drug toxicity, (g) tests for syphilis and HIV, (h) a urinalysis, (i) an electrocardiogram, and (j) a CT scan or MRI imaging study.¹⁰ Physicians will test for the most common causes first, and will only order expensive tests like CT scans or MRI imaging if the earlier

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tests do not reveal a cause or causes of the delirium. See Appendix C for a more complete description of the tests and conditions each test is intended to detect.

MEDICATIONS: THE SECOND MOST COMMON CAUSE OF DELIRIUM

Clinicians are equally adamant that, upon ruling out a medical problem as a cause of delirium, an adverse drug reaction should be suspected. In Mom's case, the delirium caused by her urinary tract infection was exacerbated soon thereafter by the prescription of an inappropriate drug.

As will be discussed later, an elderly patient frequently suffers from more than one disease or condition and typically takes several medications as a result. Sometimes one of those medications will interact with another. The onset of delirium may help alert you and your loved one's doctors to a medication error or adverse reaction. Thus, ruling out delirium as a side effect of a medication is critical. Ordinarily, if a medication is causing delirium, eliminating the medication will resolve the delirium.

The medications most often implicated in causing delirium are:¹¹

- Anticholinergic agents found in many common medications such as over-the-counter cold and allergy medicines and also in many prescription medications
- Benzodiazepines (Some common examples of these antianxiety medications include Valium, Xanax, and Ativan)
- Cardiovascular agents (some medications used to treat heart arrhythmias, for example)
- Xanthine (caffeine)
- Narcotic and nonnarcotic analgesics (some pain killers)
- Over-the-counter medications (e.g., antihistamines and anticholinergics)

Distinguishing Delirium from Dementia

You'll need to know enough about conditions that could be confused with delirium to help your loved one's physician make a proper diagnosis. If I had known then what I know now, I'd have realized that Mom's initial diagnosis of dementia—the one that resulted in her being placed in the psychiatric unit—was completely wrong. Dementia, unlike delirium,

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begins gradually rather than abruptly so it will be difficult at best for the family or nursing home staff to pinpoint its onset. It should be hard for the informed family caregiver to confuse delirium with dementia. Although there is an obvious change in mental status that gradually results in loss of memory and a severe decline in all aspects of mental functioning, dementia, unlike delirium, is not an acute and short-lived disease; it is a chronic illness that progresses and worsens over the years. The patient who has dementia will gradually lose the ability to perform the usual activities of daily living.

Since most dementias are incurable and patients with dementia rarely “get better,” delirium as well as psychiatric disorders such as depression and/or psychosis should be ruled out before dementia is considered as a cause of a patient’s confusion.

Most dementias are a result of such conditions as Alzheimer’s disease, vascular dementia, central nervous system (CNS) trauma, Parkinson’s disease, or far less commonly, Pick’s disease, human immunodeficiency virus (HIV) infection, Creutzfeldt-Jakob disease, and Huntington’s disease. Instead of using drugs, the best treatment for dementia is often a supportive environment and simplification of daily routines.

Reversible Dementia

There are some commonly recognized causes of reversible dementia such as dysfunction of the thyroid gland, vitamin deficiencies, especially B₁₂ and folate, neurosyphilis and other infections, and metabolic abnormalities.

To help you identify it, consider these characteristics of dementia:

- Memory loss. The patient’s confusion generally remains stable from day to day, unless an infection or other cause induces the onset of concurrent delirium.
- Physiological changes. These changes are less prominent in a patient with dementia than in one with delirium. Until the patient reaches a terminal stage in her illness, the level of consciousness is not clouded. There is not usually a marked reduction in the attention span. The patient experiences disturbances in her sleep-wake cycle, but the difficulty is seen in a reversal of night and day, not variability from hour to hour. Likewise, changes in the patient’s psychomotor functions usually occur late in the dementia patient unless there is an occurrence of depression.

Distinguishing Delirium from Depression

Depression must also be distinguished from delirium. In addition to experiencing a change in function such as a depressed mood or a loss of interest in what normally brings pleasure, depressed people typically exhibit five or more of the following types of symptoms over a two-week period:¹²

- Significant changes in appetite or weight (gain or loss)
- Changes in sleep patterns (insomnia or extended sleep periods)
- Changes in psychomotor skills (too active or not active)
- A loss in energy; obvious fatigue
- Expressions of feelings of guilt or lack of worth
- Changes in the ability to think logically, to concentrate, or to make decisions
- Thoughts of death, or a compromised ability to function at prior levels
- Thoughts of suicide, or attempts or plans to commit suicide
- Lack of alternative reasons for a depressed mood such as a natural grief reaction
- Lack of a medical condition or substance abuse to account for the depression
- Prominent distress and a compromised ability to function at prior levels

If depression is a cause of behavior problems, there are approved medications to treat the condition, though antidepressants typically have been under-utilized since depression is often overlooked as a cause of behavioral disturbances in the elderly.¹³

Distinguishing Delirium from Psychosis

There are marked differences between delirium and psychosis, the latter being a psychiatric illness or disorder involving impaired reality testing, delusions, or hallucinations. According to the *Merck Manual*, the differences between the two conditions are as follows:

A delirious patient is commonly confused about the current time, date, location, or even her identity. A psychotic patient, on the other hand, is commonly aware of these facts.

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A delirious patient usually will have difficulty paying attention; the opposite is usually true of the psychotic patient.

Short-term memory loss characterizes delirium. A psychotic patient, on the contrary, may think illogically but usually experiences no short-term memory loss.

A delirious patient usually is unable to think logically or to perform even simple calculations while the psychotic patient retains those abilities.

While the delirious patient usually has a fever and/or other signs of infection, the psychotic patient does not.

The psychotic patient often has a history of previous mental illness; the delirious patient often does not.

The delirious patient may be preoccupied with various concerns or worries but is usually inconsistent in her worrying tendencies. By contrast, a psychotic patient will often be fixated on concerns that are consistently the same.

Both patients will experience hallucinations, but the delirious patient's hallucinations will usually be visual while the psychotic patient's will be auditory.

Tremor is another common sign of delirium and is not a symptom of psychosis.¹⁴ Unfortunately, tremor is also a symptom of Parkinson's disease, and medical personnel are well aware that psychosis is a common condition in last-stage Parkinson's patients. This makes an inappropriate diagnosis of psychosis credible in a patient with Parkinson's disease.

Psychotropic Medications and Delirium

As I mentioned earlier, once Mom was admitted to the psychiatric unit, her bizarre hallucinations and her confusion quickly resulted in the prescription of a dangerous antipsychotic medication. Mom's earlier diagnosis of Parkinson's disease may have been a reason why this medication was prescribed, for psychosis often develops in the later stages of Parkinson's disease. But because the physician directing Mom's care at this stage of the game was not experienced in geriatrics or in treating PD, he made a critical error in choosing this drug, as I will explain in Chapter Three. You will need to know certain facts to help your loved one's physician avoid making a similar error, especially if she lives in a nursing home.

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Dr. Mark Beers and his colleagues have been at the forefront of the campaign to avoid the use of psychotropic medications in the elderly.¹⁵ In spite of their efforts, psychotropic drugs are often used with nursing home residents diagnosed with dementia to “cure” behavior seen as inappropriate, such as “wandering” and agitation. This is true even though (a) there is no evidence that antipsychotics will improve dementia, (b) psychotropic medications do not halt the progression of dementia, and (c) federal law prohibits the use of psychotropic medications in nursing home residents diagnosed with dementia unless psychosis is a diagnosed component of the condition.

Sadly, despite attempts at federal oversight, nursing homes continue to advocate for what are truly chemical restraints. In a newsletter sent to nursing homes by the government agency in charge of oversight, pharmacologist Thomas Snader wrote that antipsychotics are usually useless in controlling problem behaviors and carry significant risk of toxicity, including serious side effects.¹⁶

Antipsychotics Frequently Prescribed in Nursing Homes

Martin T. Miller Associates, a health care data collection and consulting firm, reports that total sales of medications for nursing facility residents for the 12 months ending June 30, 1997, were \$1,387,399,640. The drug at the top of the list was the antipsychotic implicated in my mom’s death.

Given the caution of these physicians and others, it is truly amazing that antipsychotics represent the most prescribed (dollar-wise) of all medications used in nursing homes!¹⁷ In fact, studies have found that most residents of long-term care facilities at some time during their stay receive at least one psychotropic medication.¹⁸ In 50 to 75% of the elderly, antipsychotic-induced side effects and extrapyramidal symptoms (EPSs) will cause serious problems¹⁹ that are examined at length in Chapter Four.

By helping the medical staff analyze troublesome behaviors of your loved one, you may be able to prevent your loved one’s exposure to these drugs. With very limited exceptions, as you will learn below, antipsychotics should almost never be prescribed for a delirious patient; these drugs should likewise rarely be prescribed for the patient with dementia. As I learned while caring for Mom and also later when doing the research for this book, family caregivers need to be aware of the dangers and also of their right to advocate with medical caregivers to avoid use of these drugs.

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PROTECTING YOUR LOVED ONE FROM DANGEROUS PSYCHOTROPIC DRUGS

If your loved one is prescribed a psychotropic drug, I urge you to investigate thoroughly. You will want to look at her records to verify that the federal regulations controlling the use of these dangerous medications have been followed. See Appendix Q. In fact, this may be one of the times when you will insist upon consultation with a geriatrician so that you can avoid the potential for serious consequences.

We were told that our mother could not see her own internist because that doctor was “not approved” to practice in the nursing home where Mom was a resident. We could, however, have made an appointment for our mom with her own doctor and taken her from the nursing home to that appointment. I remain confident that Mom’s doctor would have been very struck by the dramatic change in Mom’s physical and mental condition and that she would have recognized the significance of the sudden onset of confusion that doctors who were strangers to her did not appreciate. We might then have had a medical opinion that confirmed that the dangerous drug Mom was given should be eliminated. That would have reduced her tremor and the difficulty in swallowing that led to her subsequent medical difficulties, and it might have made all the difference.

What You Can Do to Help Your Loved One’s Physician Detect Delirium

Maintain a History. In Chapter Four, you will learn how to put together a three-ring binder that lists each illness and medication your loved one has. You will also learn how to establish a baseline for her medical condition, mental acuity, and physical condition. Using this written record of your loved one’s status together with regular observations of her, you will be able to assess changes in status and should be readily able to determine whether she is suffering from delirium, dementia, or psychosis. You can use the checklist in Appendix D to identify risk factors your loved one has that might lead to delirium.

Use the checklist in Appendix E to identify physiological causes of behavior that should not trigger the prescription of a psychotropic medication for her. For example, one clinician wrote about a female nursing home resident who sat in her wheelchair screaming for most of the day, an unusual behavior for that particular patient. In some facilities, constant

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screaming would trigger the automatic prescription of a medication, often one that could be harmful to the resident such as an inappropriate antipsychotic. In this case, however, a staff member finally noticed that the woman's finger was caught in the mechanism of her wheelchair. Thus, it was possible to rule out delirium, to prevent the prescription of an unnecessary drug, to free the woman's finger from its painful situation, and to attend to her pain and her injury!

Advocate for Your Loved One's Treatment. If you maintain regular contact with your loved one, you will be in a good position to act as an advocate for her. Keep in mind that you are a member of a team and that overwork, tension, and other countless stressors are a part of the larger picture. An adversarial tone may alienate her caregivers or make them defensive. Think in terms of building alliances and make it clear that you are working with her caregivers, not against them. You will want to maintain your composure as a team player, never bullying or harassing other caregivers. It is clear that many horrible results have occurred in some care facilities, but it would be a mistake to assume that the worst will happen. No one wants your loved one to have a bad result. Therefore, by maintaining respectful communications with her caregivers while avoiding becoming part of the problem, you'll be in a position to be a part of the solution.

You can advocate for your loved one's treatment in the following ways:

Rule Out Delirium. Request that delirium be ruled out first and be certain that all possible diagnostics are done. This means you will have to look at all potential causes for the confusion your loved one is experiencing—an underlying illness, medications, or physiological reasons—in light of the facts you have gathered. If you suspect delirium, check her medical chart to determine whether any recent laboratory results exist. Ask her physician about abnormal results.

You can also ask your loved one's physician to order a full physical examination. The physician should observe the resident's neurologic responses. She may order laboratory tests to detect infections, metabolic or electrolyte disorders, and other measurable diseases or conditions that can cause delirium. X-rays may be ordered to confirm or deny the existence of a subdural hematoma. A spinal tap may be ordered to detect infection. A neurological work-up that includes an EEG (electroencephalogram) may help to make a diagnosis. Obviously, if a previous EEG is available for comparison, this will be very helpful. Last, a CT scan or MRI may detect brain trauma or other changes in the brain. Note that these diagnostic tools are

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used in an order intended to detect first the most common conditions that may be the root cause of her change in status. The latter tests are used to find the less common disorders. Often the cause of your loved one's distress will be found earlier and thus not all diagnostics will be used.

Evaluate Medications As a Possible Cause of Delirium. Request that all current medications be evaluated to determine whether a drug reaction caused by too many drugs being taken is the root cause of the confusion. Again, the following types of prescription drugs are most often implicated as causing delirium: anticholinergic agents, benzodiazepines, cardiovascular agents, xanthine (caffeine), and both narcotic and nonnarcotic analgesics.²⁰ Over-the-counter medications such as antihistamines and anticholinergics can also cause delirium.²¹

Advocate for Non-Pharmaceutical Interventions. Request that non-pharmaceutical interventions be considered first in any attempts to modify behavior. These interventions usually include various changes in the resident's environment such as using music to calm a resident who is experiencing auditory hallucinations or using low-wattage lights to calm a resident who is experiencing visual hallucinations.²²

Ensure a Proper Assessment for Delirium. Request that proper assessment and documentation of a perceived need for the prescription of a psychoactive medication be done and made available for your review prior to the administration of any medication. Because of the dangers these medications pose for your loved one, you'll want to verify that she has an appropriate assessment, which could include, at a minimum, the following:

- A chart review to determine whether changes in her drug regimen, occurrences of recent falls, trauma, infections, or delirium due to dehydration, constipation, lack of glycemic control, imbalances of her electrolytes or metabolic system, or neurological problems could be the root cause of the change in behavior.
- A chart review to determine whether recent changes in her medications or physical discomfort could be the cause of the change in behavior.
- A careful assessment of her current medications to determine whether an adverse drug reaction could be the cause of her delirium.

Delirium: The Importance of a Correct Diagnosis

- The laboratory tests described in Appendix C to rule out a newly developed medical condition as the cause or exacerbation of her delirium.
- An assessment to determine whether visual impairment or environmental problems, including stress or grief, could be a cause of the change in behavior.
- A qualitative and quantitative assessment of her need for interventions of any kind, pharmaceutical or not. In other words, how serious is the altered behavior and how often does it occur? Such an assessment could also include a determination of whether the presenting behaviors are transient or permanent.

Refuse Antipsychotics. Your loved one has the right to refuse any treatment, including the use of antipsychotics. If you are her patient advocate and have the legal authority to make her health care decisions, you also have the right to insist that these drugs not be used or, if they have already been prescribed, that they be discontinued.

As you'll read in a later chapter, Mom might have survived if I'd followed through on my request that the antipsychotic be discontinued. Instead, it never occurred to me to check. The drug continued to be used right up until the day before I transferred her, despite the fact that by then she was bed-ridden and unable to raise herself, let alone a cane.

It may be foreign to your nature to be assertive, but as your loved one's advocate, you should strive to prevent the use of these powerful, potentially harmful, and usually useless drugs.

Remain Actively Involved in Assessment and Treatment Options. How your loved one's physician treats delirium will depend upon the underlying cause. Infections, for example, will be treated with antibiotics; abnormal salt and mineral levels in the blood will be treated by regulating levels of fluids and salts. Your loved one's medications may be modified if the cause of the delirium is a reaction to one or more drugs in her current drug regimen. That very issue, medication errors, is addressed in the following chapter.