

Colicky Dementia

By

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Dementia is a term that brings to mind a pleasantly confused, grandmotherly figure -- sweet, gentle and easily re-directable. Adult children believe and trust that mom will only exhibit her most endearing qualities, be socially appropriate, and docilely follow the directions of her caregivers. But what happens when an already misfiring mind responds chaotically to the world around it, veering drastically from the peaceful path?

Dementia presents differently in different people. Existing pre-morbid conditions may adversely affect the face of dementia. Untreated mental illness, undetected substance abuse, and personality disorders all result in frenzied presentation. This presentation appears to be bizarre and disconnected from reality on its face – but is it? Let’s take an out-of-the-box look at human behavior, especially during times when the individual is dependent upon others to meet their needs. And think about it – if the individual could respond directly to the perceived threat or cause of discomfort, they would. Instead they are put in a position of communicating their inner feelings to those who care for them and the message is not always sent in a clear fashion.

There is a very common condition that is well known in the lay and professional populations called colic. The strict medical definition of colic is *a condition of a healthy baby in which it shows periods of intense, unexplained fussing/crying lasting more than 3 hours a day, more than 3 days a week for more than 3 weeks.*^[3] There is much attention given to this condition and much to be learned from the coping strategies that have developed to address the needs of an inconsolable child. So let us return to a person suffering from atypical dementia and define what colic looks like in an adult.

Colicky dementia is unpredictable, inconsolable, and results in disproportionate behavioral reactions to the reality of the individual’s environment, inner health, and caretaking. The individual exhibits a chronic state of anxiety, panic, and circular thinking that last for periods exceeding 3 hours a day more than 3 days a week for more than 3 weeks.

This condition ensnarls the individual in continuous fight-or-flight response with their caretakers and the environment. This is more than a nuisance to the caretaker as it leads to serious caretaker stress especially if they do not find ways to cope with the colicky behavior. These clients become “problems” for programs and facilities and they are frequently evicted, terminated, or fired from traditional community settings. Grandma’s behavior is simply not

good for business. Her public display of distress makes administrators cringe as they bring prospective families in to view their programs with other well adjusted and happy residents. These clients find themselves whisked off to the hospital for evaluation and find an “**un-invitation**” when it comes time for discharge and re-admittance. They become the impossible placements and families are at a loss as to what to do.

Take Ann for example – she is a dynamic, outgoing, intelligent, driven 80 year old, manifesting with colicky dementia. She has an unshakeable need to work, to earn money, to control her environment. Her short term memory leaves her with a sense of unease, unfinished business, a deal undone which leads her into sheer → **PANIC**. Not only does her pre-morbid personality drive her to be in control, it also makes her inconsolable in the face of uncertainty.

The root cause of colicky dementia is a discontent with the environment. The individual reacts with fear and panic when they feel unsafe or uneasy. They simply do not feel in control. Since they cannot communicate normally with their surroundings and those who care for them; they continue to misread the data input from their surroundings and those who care for them and react with escalating and circular panic. The fight-or-flight response has never had a clearer presentation than with colicky dementia. They resort to undesirable behaviors such as shouting, biting, crying and hitting in an ineffectual attempt to reduce the tension in their own mind.

Mary parked herself at the nursing station 24/7 when she became confused. As her panic escalated she blocked others from the nursing staff to preserve them for her own comfort measures. She made sure that it remained “her turn” in an uninterrupted, continuous flow. This worked for her but not for the unit as they were ill equipped to provide one to one attention on a 24-hour basis. It is no surprise that Mary had to go to the hospital for an evaluation and her bed was never available again when it came time for her homecoming.

We say we do not know what to do with this outburst-prone behavior and yet we do. An older person who does not understand their environment is similar to an infant who has yet learned to interpret or control theirs. Their dependence on their caretakers is universal. So why not learn from the strategies that have developed over time to help the caregiver cope and provide comfort for the colic that afflicts both worlds?

Coping with Colicky Dementia

The first thing to do is a complete and thorough assessment of the client to rule out medical conditions that are causing discomfort. One of the most common causes of dementia-related agitation is a urinary tract infection. They have difficulty communicating the symptoms of frequency, burning and pain. Instead, they become agitated, irritable, and confused. When the infection exhibits universal signs that can be read externally, such as temperature and strong smelling urine, the internal signs have been causing great stress for quite some time. Other conditions such as acid indigestion, sore feet, arthritis, and even hemorrhoids can be easily missed by the caretaker when the communication of symptoms is so foggy. When a person cannot clearly communicate we have to look for the tell tale signs to understand their internal turmoil.

One also must do a psychological assessment to rule out contributing mental health conditions such as depression, bi-polar symptoms, and substance withdrawal. A person with dementia is also a person with a possible mental health history that cannot be ignored. Untreated mental illness can be the major contributing factor that results in colicky dementia. Imagine the person with an anxiety disorder such as obsessive compulsive disorder who is plagued with a short term memory deficit that prevents them from completing their self-soothing rituals. The pre-morbid conditions of anxiety, insomnia, bi-polar disorder or compulsive hoarding must all be addressed in a holistic manner to bring peace to the person.

Family dynamics are also important when one sees the picture of colicky dementia. Even if the person with dementia does not understand all of the nuances of the situation, the emotional response to discord can be very clear. When there is a feeling of disharmony the person can react with a need to try to control the situation with emotional outbursts of their own. Care providers must help to calm the environment and have the person feel as safe as possible. If a negative response to something or someone in their environment is consistent then the care provider must alter the situation and protect the emotions of the person. It becomes easy to see how this affects a person if one can imagine someone with a life-long fear of dogs being forced to participate in pet therapy. One must always think of strategies to provide a feeling of peace and safety for individuals who are frightened and unable to control their environment for whatever reason.

What is it all about?

- **Changes in mood** – Do the mood changes seem to coincide with environmental changes, the time of day, or in relation to food or sleeping patterns? For example, if your loved one is cranky in the late morning, watch to see if she or he is sending signals that you are missing—like an isolated yawn or eye rubbing, rocking etc.
- **Reactions to different situations and environments** – People often send signals that we just don't notice. He/she might get over stimulated if too many people are around or become especially upset about schedule changes.

- **Differences in the quality and nature of the outbursts** – At first all will sound the same, but, gradually, you will hear how the “I’m hungry” is very different from the “I’m tired”. Notice noise level, pitch and intensity of the voice as well as body language and facial expressions. An arched back, a scrunched up face, eyes tightly closed to shut out the light, fists curled up, rubbing eyes, hyperactive or frenetic movement—all of these signs communicate something specific about one’s emotional and physical state.

Learning what it takes to soothe and comfort an upset or unresponsive adult may take all of your skills of perception and awareness. Don’t give up if you are having a hard time figuring out what makes your loved one panic—he or she will probably keep trying to let you know.

Soothing and comfort measures are keys to help one cope with their environment

- Assure that basic comfort measures are met
 - A clean/dry environment
 - Warmth
 - Food and water
- Employ soothing techniques
 - Touching
 - Music
 - White noise
 - Aromatherapy
 - Rotating pleasant faces on picture viewer
 - Massage therapy
 - Whole body
 - Partial – hand/foot
- Control overstimulation
 - Bright lights
 - Loud noises
 - Excessive activity
- Provide methods for self soothing
 - Textured cloth – blankets
 - Stuffed animals
 - Religious charms
 - Repetitive tasks – i.e. folding towels
 - Rocking chairs
- Social engagement strategies
 - Reading to them

- Exercise
- Pet therapy
- Directed activities
- Picture albums
- PET – pleasant experience therapy
- Sometimes the problem cannot be fixed in the moment but you can:
 - Keep them safe
 - Frequently check on them
 - Decrease the stimulation
 - Keep trying to soothingly reach out when receptive
 - Let them work it out in a controlled, safe, supportive environment

The family caregiver should:

- **Recognize your limits.** Pay attention to internal warning signs when you are feeling overwhelmed. The sooner you spot your personal limits, the easier it is to plan ahead—for extra help, a break, an excursion outside or a quick pep talk from a friend or loved one. The small things you do to prepare will help you get in the best frame of mind to care for your loved one.
- **Reach out for support.** If you can, enlist help during the worst times of the day. Say yes when people offer to help with housework, meals or respite. Find a caregiver support group to talk to and get out of the house when you can. Knowing you have some help on the way can make a big difference.
- **You don't have to be perfect.** Caretaking is not about perfection. It would be impossible to be fully present and attentive to a person, especially a colicky person, 24 hours a day. Experts estimate that meeting the person's needs at least **one third of the time** is enough to support healthy bonding and secure attachment. Don't worry about getting it exactly right all of the time. Instead, try to relax and enjoy the times when your loved one is at peace.

Am I the reason they are upset?

Are you distracted, overwhelmed, and at a breaking point? If you're stressed out and exhausted, you're going to have trouble relating in a soothing, nurturing way. So it's important to get the support you need. Extra support is essential if you are:

- Depressed
- Suffering from a major illness or chronic health problems
- Overwhelmed or fearful about caretaking

- Exhausted from lack of sleep
- Feeling neglected, isolated, or unsupported

Colicky dementia does happen and it must be addressed head on. It is clear that recognizing the root causes and treating the client in a holistic manner can help. Ignoring pre-morbid conditions prevents appropriate interventions. One must first assess the client for medical and psychological conditions as well as dysfunctional family dynamics. Each identified issue must be addressed in a holistic manner and one must always be on alert to reveal the undiscovered in a person with such dramatic reactions. Utilizing some of the learned interventions from dealing with the colicky infant can help open simple, practical strategies for this population. Providing relief and support for the caregiver with 24/7 responsibility is imperative regardless of the age of the dependent person. Watching for non verbal signs of distress must be employed universally. There is an undeniable benefit in administering soothing techniques for all states of anxiety regardless of its origins.

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