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Miracle Pill

by Clarke Pollard, Executive Director of the Alzheimer's Support Network and PAC Mentor

What if there was a pill that would control aggressive and dangerous behaviors of Alzheimers patients? What if this magic pill would take an "agitated, demented patient" and turn them into a little lamb? Wouldn't that be a miracle?

Would it?

Jim was an ironworker in Pittsburgh for 45 years. His hands are cracked and covered in calluses. Since retirement, he has stayed busy working on his home's plumbing and irrigation systems, digging up and moving fruit trees so that they are positioned in their optimal locations in his yard, and working on the transmission of his '67 Stingray.

Jim's wife, Doris, couldn't take it anymore. "He took a fully-grown lemon tree and dug it out of the ground. Then, he dug a hole about six feet away and tried to replant the tree. It didn't survive." She shook her head. "I still can't flush the guest room toilet. I don't know what he did, but the plumber said it would be \$2,000 because they need to rerun all the lines."

Doris was visibly upset. "Just look at this!" She pointed to a small, blue shed just off their driveway. Tools lay scattered around, a socket wrench here, a spool of electrical cable there. The hood of Jim's classic Corvette was propped up with a large concrete brick. "I just couldn't anymore. I just couldn't."

When Jim arrived at the memory care facility, the staff greeted him warmly. Doris had his room already set up, furnished with his pillow from home, some pictures of their kids, and his leather recliner. The first few days, Jim just walked. He had no interest in bingo or ball toss. He was never a social person and didn't feel like socializing now with people he didn't know. He just walked.

After about three days of nearly continual walking, Jim sat down in his recliner. And for the most part, that's where he's been ever since.

This has been a rough road for Jim. There have been several major "incidents."

The first incident happened when an aide came to get Jim to come to dinner. He was sleeping in his chair. When Tilly tried to wake him, he punched her in the gut. She couldn't catch her breath and fell to the floor.

The next incident happened when Louie was called in to get Jim to take a shower. Lou is 31 years old and stands a solid 6'6". He played left tackle in college. Lou's formidable presence usually results in compliance, and that's why he is picked for these "tough cases."

Lou left Jim's room bleeding and with a broken nose. He quit and sued. Jim stayed in his chair.

Ultimately, Jim was Baker Acted (involuntarily held against his will) and sent to a psychiatric facility where he was medicated to the point of not being able to walk and couldn't produce more than a couple of words at a time. Gradually, the psychiatrists lifted the medications to a point where Jim could function while still being passive and less combative. He returned to the memory care facility three weeks later and has been there ever since.

A consulting physician specializing in research visited Jim at the family's request. "Wow" was the first comment that slipped out of Dr. Gould's mouth as he looked at the med list. "Those are some substantial doses." With the director of nursing, Dr. Gould went over each med one by one. He would call out a medication and simply ask, "Why?" Going down the list, he called out the name and asked, "Why?" again and again. The answers were the same; it was prescribed by the psychiatrist for agitation and aggression.

"And what caused this?" Dr. Gould inquired. The director of nursing rattled off the incident reports, eight major occurrences in all. The last one was when Jim grabbed Susie's arm and caused her to fall. Susie is another resident in the community. She was trying to give Jim a flower when he pushed her away. Her fall resulted in a broken pelvis, a hospital stay, and eventually her permanent placement in a skilled nursing facility at the age of 92.

"We just can't have that here," explained the nurse.

Doris's eyes teared up as Denise, the director of nursing, recounted the events. "That's not my Jim," she said quietly to herself.

"I see." This was not a new story for Dr. Gould. "And now? How is Jim now?"

"He is compliant," Denise declared flatly.

"He's a zombie!" There was anger, fear, and sorrow in Doris's voice.

"It's the only way we can have him here." Denise was doing her best not to be rude or dismissive. She cared for both Doris and Jim. But in her mind, the facts were the facts.

"I see," repeated Dr. Gould. "Well, I think he would fit with our study." The doctor went on to explain to Denise and Doris about the new experimental pill that was designed to treat agitation. "We could probably replace all six of these," he said pointing to the med list. "And the side effects of lack of appetite, fatigue, and decreased motor control would be significantly lessened."

"I see," parroted back nurse Denise.

"Oh Doctor, that would be a miracle!" Doris wanted to spring up and give him a hug. "I would do anything to have my Jim back."

"It's not going to fix the disease," the doctor cautioned. "It's just going to get rid of the agitation and aggressiveness and not make him so...zoned out."

"Yes, yes, wonderful!" exclaimed Doris.

Over the course of the next three weeks, Jim was given the new medication and weaned off the host of anti-anxiety and antipsychotic medications he was on.

Success

"This is a remarkable success!" Mr. McAllister said to his team. Mac—as they all called him—was the administrator of the facility. "Three weeks ago, Jim wasn't able to get out of his chair without assistance. He wasn't eating and barely speaking." Mac looked over his collected crew of nurses, aides, activity personnel, and dining staff. "Now, he's at bingo, right Abby?"

"He is!" Abby was always positive, always upbeat. As director of life enrichment, Abby knew everyone's name. She worked to include each person, making them feel welcomed and part of the group. "He sits in the game room for the whole time." She spoke with a sense of pride. "Before, I couldn't get him through the door."

"And he's going to the dining room and eating?" Mac motioned to his dining staff.

"Yes, sir," replied Mildred, who had worked at the facility since it opened 15 years ago.

"And there have been no other incidents with any other residents or staff since he's started the new medication." Mac looked around the room to find Denise. "Isn't that right?"

"Not a one," Denise promptly answered.

"Well, let's keep on top of this, and let's keep our eyes peeled for others who might benefit." Mac was talking to the whole group. He wanted each one to be on alert and aware. "I'm thinking, Mrs. Jasmon."

Denise met the knowing gaze of her administrator and nodded.

Dr. Gould and his magic pill: It's a miracle! Or is it?

Jim is compliant. He sits in the game room obediently during bingo. He sits in a circle for ball toss and catches the ball and tosses it away. He goes to the dining room and eats with others now. His wife reports that he seems more comfortable where he is, and she even gets a smile every so often from him. The facility is happy, Jim's family is happy, and Jim seems content. Why wouldn't this be considered a miracle pill?

Let's take another look.

Jim goes into the game room during bingo. Does he play? Does he interact with others?

Does being in the game room during bingo bring him any sense of joy or purpose? Or is success measured by the fact that he stays the whole time?

Jim sits in the circle for ball toss. He will catch the ball and toss it away. Due to the changes to his brain caused by Alzheimers disease, his response time is slowed, and his startle reaction is heightened. When the ball comes towards Jim, he reacts with a startle response and catches the ball as an act of self-defense. He grimaces as he tosses the ball away. Those looking on record this as a smile and active participation.

Jim refused to play ball with his kids as they were growing up. Jim never played sports. He was a *get down and get dirty* kind of guy. He never liked games.

Does the fact that Jim is now going to the game room and sitting through bingo and “playing” ball toss mean he is turning over a new leaf and making up for lost time? Given what you learned about Jim, what’s your assessment?

Jim is taking his new medication. Jim is compliant. He is doing what others want him to do. He is not resisting. He is not complaining.

He is going to the dining room and eating with others. This is remarkable because he never enjoyed eating with his own family. He preferred to eat in the garage. When he first came to the facility he wouldn’t go into the dining area.

This is a great success in the eyes of the facility who want him to eat in the dining room. And it is a success for his wife, Doris, who always resented that he never ate with her and the kids. She even said to Dr. Gould, “I wish I had this pill 30 years ago; our marriage would have been so much better.”

Thirty years ago, when Jim was just being Jim and wished to spend evenings working in the garage—rather than eating with his family—would it be proper to force Jim to take a pill that would make him more obedient, more compliant?

If it’s not right to do so 30 years ago, why is it proper to do so now? What’s changed?

The quick answer back is *Alzheimers!* He has a disease that is impairing his thinking, judgment, reasoning, and logic. He has a disease that is causing changes to his brain and affecting his ability to modulate his emotions and control his reactions. He was never physically aggressive before, but he is now. He’s lashed out and hurt people. That cannot be tolerated. Something had to be done. And while he might not be choosing to take this pill, it’s better than the alternatives: no pills at all and repeated episodes of violence or a host of medications that turn him into a zombie.

Is the choice above a fair one: either he is violent and hurting people or he is drugged up to the point of being a zombie?

These appear to be the only options, especially when those providing care can see no other alternatives.

Alternatives

What other alternatives are there? To answer this, let's go back and look at what is the root cause of the problem.

We have been operating on the assumption that the root cause of the problem is Jim. Jim was digging up perfectly good fruit trees and killing them. He was tearing the plumbing apart. When at the facility, he was the problem because he wouldn't go into the game room and wouldn't eat in the dining room. Jim was the problem because he refused to take a shower, and he was hitting people who came into his space.

What if Jim wasn't the problem? What if Jim was just being Jim like he has been his whole life? What if Jim's "behaviors" were not seen as problems to correct but rather as forms of expressive communication?

"You're just going to let Jim hit people!" This is a typical outraged defense.

This is hard. And everyone is doing the best they can. *Everyone* includes the staff at the facility, Dr. Gould, Doris his wife, and Jim himself. The point here is not to attack or lay blame or criticize. The point here is to take a moment to reexamine.

Are we just going to let Jim hit people? No, of course not. But let's take a moment to look at why Jim did what he did and try to look at his actions, not as behaviors to be controlled, but as forms of expression. With his actions, what was Jim saying, and why was he saying it?

The first incident happened when Jim was sleeping in his chair. Tilly woke him up, and he punched her. When it was written up as an incident report, Jim was labeled as demonstrating aggressive behavior. The first response of the facility was to review his medications.

If you were sleeping in your chair and someone startled you, and you woke to find yourself in a strange place with a stranger standing over you, what might you do?

Jim has Alzheimers disease. He has profound damage to his hippocampus. Since the hippocampus helps us form new memories, Jim has great trouble remembering new information, such as remembering who Tilly is and why she is there. The hippocampus is also our internal compass or GPS system and our internal clock. Alzheimers has broken this clock and set this GPS system pointing him in different directions. Jim is having trouble assimilating to his environment because of this. "His room" doesn't feel like his room yet. Structure and routine will help in time, but he's new to the facility, and when he woke, all he knew was he was in a strange place with a stranger standing over him. He reacted.

Could it be that he saw Tilly as a threat? Could Tilly have done anything differently?

These are the questions that often do not get asked. Instead, this situation was viewed as Jim punched Tilly. He was violent. Let's review his medications.

If we are interested in why this happened and how we might prevent it from occurring again, it would help to start asking some probing questions.

When was Tilly going into his room? What time of day was it? How did she approach him? Were the lights on or off? Did she knock? Did she introduce herself? Did she wait for Jim to wake up or did she enter his personal space before he was fully awake? Did she enter his personal space before he gave her permission to do so? Does Tilly know how someone living with Alzheimers disease might be able to indicate permission for someone to come closer? What was Tilly's tone of voice? Why was Tilly going into the room in the first place? What task was she attempting to achieve? Did Tilly value creating a relationship with Jim before trying to achieve a task?

Were any of these questions asked? This is not to blame Tilly or the other staff for what happened, but it's also aimed at not blaming Jim for reacting as he did.

Is anyone at the facility curious to know why the incident occurred?

To help answer why it occurred, we need to ask more questions.

What training does the staff have in Alzheimers disease and other forms of neurodegeneration? Do they understand how someone living with Alzheimers disease processes sensory information? Do they know how to adjust their approach to accommodate and effectively respond to people living with brain changes? Do they know who Jim is, more than his name? Do they honor Jim and allow opportunities for Jim to do what he likes to do, taking into account what he is able to do?

How about the incident in the dining room with Susie, the 92-year-old woman living with Alzheimers? Why did that happen? How could it have been prevented?

To help answer those questions, it helps to ask another: What do we know about Jim?

Jim always ate alone in the garage. Where was he when the incident with Susie happened? He was in the dining room eating with everyone else. Why was he there? Is this Jim's wish to be in the dining room or someone else's?

The incident report said that Jim lashed out at Susie without provocation. Does that tell the whole story or even key parts of the story? Does that help explain why the incident happened or give any insight into how to prevent such incidents from happening again?

The stated answer was that Jim acted violently and needs to be taken immediately to a psychiatric facility.

Jim likes to eat alone. Would it be acceptable for Jim not to eat in the dining room? How have Susie and Jim interacted in the past? When this happened, who else was around? What time of day was it? Did anyone see the events leading up to this or just the aftermath? If no one saw, why not?

These are just some of the questions that could be asked. Were these questions asked? In this case, no. It was decided; the problem was Jim. The solution was extremely high

doses of antipsychotics and anti-anxiety medications. And then, the ultimate solution was a magic pill that turned Jim into a little lamb.

We return to the question: What's wrong with having a magic pill that makes people living with Alzheimers become compliant and obedient? Wouldn't that be a miracle?

My response would be to ask the following: Would you want to take it yourself, right now? I am sure there are people who wish for you to be more compliant and obedient—a spouse, a boss, a government. Why not just take the pill and stop causing so much trouble?

If you are unwilling to take the pill now, if it is not right for you, what makes it right to give such a pill to people who have a disease like Alzheimers?

What makes it *appealing* is the fact that proper care takes time, effort, and energy. Proper care for someone living with Alzheimers requires understanding how the person's brain is changing, how they are processing information, and being able to adjust one's approach to fit their needs. It takes time set aside for learning. It takes patience, dedication, and devotion. It takes trial and error. It takes a desire to connect, respect, and love. It's not easy. It's not foolproof. But it is possible.

It's possible to allow someone living with Alzheimers to be who they are. It is possible to learn approaches that promote autonomy while ensuring security. It is possible to adjust, adapt, and set the conditions for the person to be free to express their emotions, be valued and respected, and feel productive and useful. Moments of joy happen every day for people living with Alzheimers disease. It is possible to learn how to promote, encourage, and bring those moments into existence.

All this is possible. But a pill would be easier.

The Bigger Question

If any such miracle pill were devised that could make people living with brain change docile, obedient, and compliant, would it be a miracle? Would it be the answer? The solution? Or would it be just another way to take something more away from people who are losing so much?

In the quest to develop such a pill, as a society, it would be wise to ask ourselves, would I take a pill that would make me docile, obedient, and compliant? How would I feel if someone forced me to take such a pill against my will?

And more to the point, if I develop a disease that causes neurodegeneration, do I give up my right to express my wants and needs? Do I give up my will?

If you couldn't say what you wanted to say with words, how else might you make your will known?

What would happen if every memory care facility in the country stopped labeling reactions as “behaviors” and started to recognize that “behaviors” are forms of expressive communication?

Calling reactions “behaviors” places the blame on the person “acting out” and provides a ready solution of controlling the person’s actions, usually by limiting his or her freedom and autonomy.

Calling reactions “communications” highlights that people with changes to their brains are doing the best they can to communicate. And they are communicating, not through words but through actions. Could the real problem be that we don’t like what they have to say?

This is the danger inherent in a pill of compliance. It is a pill of obedience. When reactions are seen as forms of communication rather than “behaviors,” then we might see that the purpose of this pill is to promote silence.

We wouldn’t tolerate such a pill being forced on protestors to keep them quiet and in line, to keep them from causing trouble. Imagine how such a pill would have been used in the Vietnam War era and during the civil rights protests of the 1960s. Imagine how such a pill would have been used in the days of slavery.

If it is wrong *then*, what makes it right to be used on someone because they have a disease?

Clarke Pollard currently lives in Naples, Florida. He joined PAC in 2017 and currently serves as the Executive Director of the [Alzheimer's Support Network](#), a 501(c)3 Nonprofit that offers private consultations, support groups, respite programs, [Wanderer's Identification program](#) (Collier County Florida), a 24-hour helpline, and more.

Pollard states, “the names of the persons presented in the article have been changed. Their stories are used with permission. Dr. Gould is an amalgamation. Quotations in this article are not attributable to a single person. Quotes are presented for presentation purposes. Thank you to all who assisted. We are honored that Teepa serves as a Member of the Board of Directors for the [Alzheimer's Support Network](#).”

Feel free to contact [**Clarke Pollard**](#) with comments, suggestions, or corrections.