

~ Motivation For A Cure ~



## WHAT IS YOUR CAKE?

*Barby Ingle, President*

*Power of Pain Foundation*

*Author \* Advocate \* Motivational Speaker*

480-882-1342 [barbyingle@powerofpain.org](mailto:barbyingle@powerofpain.org)

What is *CAKE*? *CAKE* is something that you can't do because you are in pain but wanted to accomplish. When I started to watch this movie, I came in with biases of people in the pain community saying how it was all about addiction and not much on chronic pain. Those people had not yet seen the film. So, I got out my paper and pen and decided to take notes. I thought this movie was a great representation of what I see and hear from millions of pain patients across the United States. This movie is one of the best, in-depth depictions of what we deal with on a daily basis as patients. Here is what I saw in the movie.

I saw the reality of what I have been living with since September 26, 2002 after an auto accident that led me to have no choice but to live with chronic pain. The main character, Claire shows the challenges of living with pain. Her symptoms matched many of the symptoms that I have dealt with on a daily basis. With not only showing the pain that sometimes makes you scream out. They also did a great job showing the loss of energy, balance -coordination issues, body temp regulation problems, depression & anger, dystonia, loss of appetite and vomiting, memory issues (reminders about reminders), and sleeping problems.

The movie also gives a great perspective on some of the treatment options that are available. Claire went through so much to get out of pain, but to no avail. She had to find ways to cope. They showed a wide variety from invasive surgery, medications (not just opioids) but other medication, and aqua therapy. They showed less invasive tools that can help with the coping of life with chronic pain; quiet/dark room or house, music therapy, and even turning to other substances like alcohol.

This movie shows a woman who is processing her own chronic pain from physical injuries, but takes it even further. The script writer was clever enough to have the character Claire use of her friend who committed suicide to help process the situation and tell her story (it was easier for us as viewers to follow verses a woman talking to herself, it put a face to the story of the person who committed suicides story). I can say for myself losing over 50 friends in the past 12 years who were living in pain I know how much of a struggle this is and how delicate it is to navigate with those of us still living and fighting this daily battle. We are in a way relieved that our friend is out of pain, but at the same time sad that we are here on earth – left behind. We see how great it would be to be out of pain for eternity, but know that we have a purpose here and it is not our time to go.



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*CAKE* reminded me of a few important lessons. First, you can't get better by working harder, you have to work smarter. We need to figure out how, where and on what we want to spend our energy pennies<sup>1</sup>. Second, people who don't live in pain want to know how we do it. We typically say moment by moment, or I don't know how I do it. We find a way. We negotiate with ourselves to do what must be done, what needs to be done. Does that mean we get to do all we want to be done? No. Does that make us less of a person? No. Thirdly, people in pain take less life for granted. The closet scene where she takes out only a little bit only to make a messy pile outside the closet. That was a step. That was an accomplishment in the daily life of a chronic pain patient. We are not asking for people to save us, we are working to save our energy pennies for what is important in life while still maintaining a life of whatever sort we can muster up.

For those reading this who don't have chronic pain. Maybe you are a caregiver, or a friend of mine who just wanted to see what I had to say. It won't hurt if some of my pain friends cover some of these lessons for ourselves either. Here is some life nuggets for you. Yelling at someone you are made at won't fix anything and really it doesn't even matter. Why stress yourself? The people who question are the ones on the outside of our inner circle. Everyone grieves differently. People tell you what to do/try so that they feel better about not being able to help you. Other people's views of someone in pain, even when they have pain themselves is skewed.

A keynote to watching this movie is viewers should remember that medication has to be taken every 4-6 hours to stay in the bloodstream (unless extended release and then 1-2 times a day). Patients are going to need to take them 1-6 times a day depending on the medication, dose and formulation of the medication. Pain like that isn't just physically limiting – it is morally debilitating. When we don't get our pain under control it becomes a cycle that at its worst is unbearable and best is survivable. Add to that the injury of being told you may not be able to access the pain medication you need because a physician worries that you may be abusing the medication. Although not directly addressed in this film, it is a problem faced by many who have legitimate need for pain medication. Instead of being treated with compassion, pain patients are too often treated with suspicion. Prescription pain medications are an important component of modern pain management. Abuse and misuse of these products, however, have created a serious and growing public health problem. Opioids remain an important option in the treatment of chronic pain.

Just as the main character Claire does, patients are going to Mexico to get medication or turning to street drugs here in the United State – Its Reality. The question should be, how we can make pain medication available to those who need it and address the legitimate concerns of physicians and law enforcement about misuse? Fortunately, there is good news. One important step towards the goal of creating safer pain medication has been the development of opioids formulated to deter abuse. For patients with pain, help comes in the form of three letters: ADF. Pain medications with abuse deterrent formulation (ADF) make it difficult to tamper with the pills, reducing the risk they will be used improperly. The good news is that several formulations of ADF now exist, giving physicians a range of options for their patients with pain.

As a leader in the pain community and someone who personally advocates for pain patients on a daily basis, I strongly believe that we can combat the issues of abuse while still giving patients who need pain relief a safe, effective and accountable access to these medications. With many new medications, private and government insurers put limits that make it difficult to access the medicines. With the societal cost of limiting pain management so high, such an approach is penny wise and pound foolish. There are many things we can do to increase access to these treatments, but we need to start with the recognition of their value and the promise they hold for many pain patients who have been denied care due to suspicion.

The responsible patients should not be punished by the crackdown on prescription drugs and opioid abuse. There is a need to stem the tide of drug abuse, but not at the detriment to those who need proper and



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timely care and access to tools for better daily living so they may function in a more productive way in our communities and provide greater benefit to society as a whole. In the movie, there is a scene where Claire has visitors over and chose to skip her medication. This doesn't show she was addicted it shows a willingness to try to be social and check her physical pain strength, or show courage, or just a desire to be 'normal' and not have to rely on medication to get her through. The movie shows her as a responsible patient who shows up to every appointment. Yet, her providers expect you to improve. When you live with chronic pain, improve is relative. More likely, we maintain if we are lucky and work smart at life. There was a scene at the hospital where Claire says, "no more medication". I've been there, I know how hard it is to be poked, prodded, and researched on like a rat. She was also dealing with the stress of loss of a friend, loss of her son and marriage while finding her life boundaries of living with pain.

There are other obstacles in receiving proper and timely care. The movie demonstrates some of these challenges through spotlighting the immense amount of paperwork and complicated medical system (ex: needing referrals). Just facing the invisible disability of living with chronic pain even if you have scars, a cast, or wheelchair can be difficult, especially when learning to navigate the health system. Another life challenge for pain patients addressed in the film *CAKE* is keeping a 'normal' human connection with a partner. All humans need physical contact. Imagine is feeling like someone is cutting you with knives every time they touch your legs. We need to find ways to have positive, personal, and sexual human connection for our own welfare and health benefits

Suspicion is rampant in society when it comes to pain patients. I reacted with a cringe when I watched as Claire's adrenaline kick in when she saw the man who was responsible for her son's death. Then, in the next scene you see Claire in bed, not much is expressed as to why she is in bed when she just displayed that much energy and physical strength when most times she doesn't have it in her to even take a shower. It goes back to how you want to spend your energy pennies, emotional ties to a situation, and knowing that you will pay for your actions later if you overspend or outspend your abilities. Many of the patients I come across in pain are similar to Claire. I see myself the same way most of the time. Mostly due to finding out that my body and mind has limits. I have reached my limits and tried to push beyond only to pay for it in the end, much longer than any of my 'healthy' friends. After having a chronic illness for a while, many of us learn to choose where we will spend our energy pennies and what is important enough to warrant a penny, two or more. Also keeping in mind that each patient is different, brings different life experiences to their future, and will react differently to every medication and treatment option than the person standing next to them. Yet, we look and strive for commonalities with our fellow human connections.

Watching the movie brought me back a few years. Before I had a proper treatment plan to address my pain, I too was laying in the car on trips. Having to pack blankets and pillows for comfort and vomit bags for chronic vomiting from the high pain levels. Crying as we drove over bumps and potholes in the road, and knowing that after seeing that doctor, I would have to return to a painful car ride home. Or as in the scene where Claire tries to get the tape off of the box and she just doesn't have the strength, I am still facing that daily even with a good treatment plan.

What would your dream be if you didn't have chronic pain? My *CAKE* would be to continue to raise awareness, take action, and make a difference that brings us together as a society in a unified force for those still living with invisible disabilities. May our lives be easier, less stigmatized, and blessed with good health.

## What is YOUR CAKE?

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<sup>1</sup> Caregiver Toolbox: Saving Energy - <http://www.painpathways.org/caregiver-toolbox-saving-energy/>