

## MYOTONIA DOCUMENTARY OUTLINE

Proposed title “All the World’s a Stage” (from Shakespeare’s *As You Like It*)

- I. Introduction:
  - A. Caption with lines from Shakespeare’s *As You Like It*:
    1. “All the world’s a stage, and all the men and women merely players.”
  - B. Pictures of “perfect” people -- models, celebrities, sports stars flash up on the screen with fast paced music. Narration about how everyone wants to be a star.
  - C. Pictures of perfect people caught in embarrassing moments—Runway models who trip and fall down in front of magazine editors and photographers? Athletes who trip or fumble during a crucial play?
  - D. Interviewer asks different people with Myotonia who will appear in documentary about embarrassing moments when they have fallen over or couldn’t move. These people include: Nurse, attorney, athletic trainer, person in England, person in Africa, person in India, person in Asia, doctor and body builder.
- II. Fainting Goat scene:
  - A. Talking to goat farmer
  - B. Witnessing goats fall over
- III. Body builder
  - A. In locker room. Narration about bodybuilder’s career
  - B. On stage.
    1. Event announcers mention bodybuilder has Myotonia
    2. General narration about Myotonia
      - a. How many people are affected by it.
      - b. What countries have the highest concentration of people with Myotonia.
  - C. In gym pumping iron – Bodybuilder’s arms lock up on bench press and spotter has to jump in and help him.
    1. Discuss challenge of working out with Myotonia. Bodybuilder says, “Its difficult at times, but it’s what I wanted to do.”
    2. Discuss diet and what foods increase stiffness.
    3. Discuss increased levels of pain associated with disease.
- IV. Scientific explanation of disease
  - A. Doctor with Myotonia explains disease—but doesn’t mention he has it
  - B. Illustrated diagrams explaining how most muscles work
  - C. Illustrated diagrams explaining how Myotonia muscles work—ties in with foods mentioned in previous scene.
  - D. Info regarding the fact that symptoms, manifestations, severity, etc., vary wildly from person to person, making it even harder to really document its effects.
- V. NURSE
  - A. Camera follows nurse through hospital and witnesses her working with patients
  - B. Interview with nurse where she tells about her Myotonia
    1. Go back to shots of her working with same patients—talking, smiling, lifting things, etc.

- a. Narration from her interview as she talks about some of the challenges of the job responding to a code blue or code red, trying to catch a patient who is falling, putting in an IV if your hands aren't 'warmed up'...
  - b. Discusses level of pain and discomfort caused by disease.
  - c. Scene ends with interviewer asking her if she has told anyone at hospital—she answers no or only a few. She doesn't tell any of her patients.
- C. Interviews with other nurses in hospital
- 1. One nurse, "yeah she told me she has it." Shows look of concern for the camera.
  - 2. Other nurse says, "that's what she says—I don't see it, but that's what she says."

## VI. Court Jester—Attorney

- A. Attorney in court presenting his argument to jury
- 1. Attorney gets out of chair and walks stiff legged up to the jury—makes a joke
- B. Interviewer asks him what it's like having Myotonia and having to go up in front of a jury
- 1. Attorney discusses court jester
    - a. Pictures of court jesters in illustrated paintings.
    - b. Problem of appearing inconsistent in front of jury. Sometimes I get up fine, other times I am stiff. Sometimes they look at me like what is wrong with this guy. I wonder if I am hurting my clients case by not hiding it.
    - c. In the original court, literally "court" of the kingdom, the court jester was the only person who was allowed to talk back to the king, but that person would have to dress up in a funny costume, wear a hat and speak in riddles. They were usually very intelligent people and provided advice to the king, but because they were not descended from royalty they had to wear the funny hat and tell jokes. Meanwhile the village idiot got to wear the crown. That's often how I feel. Like I'm the only one that really knows what's going on, but I "wear my costume," so to speak and make jokes to make others feel comfortable with the fact that I walk fine one moment and then walk stiff the next moment.
    - d. Like many major stressors, getting up in front of audience (court, classroom, stage, etc.) causes secretion of adrenalin, which not only causes limbs to get stiff and/or wobbly, but also affects facial muscles, including tongue, so that speaking can be more difficult, and sound garbled or slurred.

## VII. Mom with kids

- A. Interviewer asks her how many kids she has and how many have Myotonia.
- B. Interviewer asks how it was for her growing up
- 1. Talks about having to hide disability
  - 2. Talks about stalling or waiting till no one was around to go up steps
  - 3. Talks about how people thought she was weird or goofy.
  - 4. Talks about being a woman and having large leg muscles.
- C. Interviewer asks does she worry about her kids. She says no, because she has learned to deal with it, and she can teach her kids how to deal with it. It has made her stronger. She feels bad for those who have parents that don't know how to deal with it.

## VIII. Athletic Trainer

- A. Training someone in a work out
- B. Talks about large leg muscles
- C. Talks about unusual muscle development and how looks can be deceiving
- D. Talks about how disease can be hidden by doing isometric exercises in a chair before moving,

which doesn't always work, because sometimes it increases your self-consciousness and anxiety, and it gets even worse.

- E. Talk about pain associated with muscle disease and how the medical community disregards this.

#### IV. Fainting Goats

- A. Shots of cute goats playing with kids
- B. Interviewer asks goat farmer how many times the goats fall over each day
  - 1. Goat farmer responds, "Well, about as many times as they try to run."
  - 2. Interviewer says, "And they just keep on getting up and doing it all over again?"
  - 3. Goat farmer responds, "Yeah, they are just used to it I guess."
- C. Farmer comes out of barn again with some feed. Goats run up to him and don't fall.

#### X. Doctor of Neurology

- A. Same doctor as before talks about why muscles stop stiffening up after they are warmed up.
  - 1. Muscles start out utilizing one chemical process where the chloride channels are blocked.
  - 2. Muscles move into second chemical process where chloride channels work more effectively.
  - 3. Doctor also talks about how intense the stiffening and weakness is AFTER you work out or do heavy lifting.
- B. Interviewer asks doctor how many patients he has that have Myotonia.
  - 1. Doctor reveals how many people he sees.
  - 2. Doctor reveals how many people have Myotonia throughout the world and how rare it is.
  - 3. Doctor speaks about how much misinformation is out there in the medical community about Myotonia. How few doctors really know the true facts about the condition, and how few doctors ever get to see a patient with Myotonia.
- C. Interviewer asks doctor, what brought him to study Myotonia
  - 1. Doctor reveals that he has Myotonia (there is a doctor like this.)
- D. Doctor gives a little history of his life
  - 1. Pictures of him as a kid
    - a. Tells story of parents, family, origins
  - 2. Pictures of him playing sports
    - a. Stories of difficulty, but he did it
  - 3. Pictures of him as a resident
  - 4. Shot of his diploma
- E. Interviewer asks what's the most difficult thing about living with Myotonia
  - 1. Doctor responds the social aspects, because you have the ability to hide your disease and that's what society demands of you.
  - 2. Doctor remarks that just getting a proper diagnosis of Myotonia is difficult.

#### IX. Difficulty getting diagnosis

- A. Nurse, attorney, athletic trainer, person in England, person in Africa, person in India, person in Asia, doctor and body builder all give personal stories about the different diagnosis they have been given.
  - 1. One person talks about getting diagnosis much later in life.
- B. People talk about the fear associated with having something that it seems like the medical community really doesn't know much about or care much about – it's not exciting or glamorous enough)
  - 1. Rarity of the condition

- C. People talk about Myotonia often being confused with behavior oriented issues
  - 1. Laziness
  - 2. Drugs
  - 3. Mental Illness
  - 4. Clumsiness/awkwardness
  - 5. “overweight” – “those aren’t big muscles – you’re just fat – exercise more, and diet.”

X. Mother with kids

- A. Interviewer picks up on conversation they had before
  - 1. So what are you going to tell your kids that you learned growing up with Myotonia?
  - 2. Mom responds, “be yourself, just be yourself. I mean there’s nothing they can do about it. There’s nothing anybody can do about who they are, you just have to accept who you are and make the most out of what God gave you.”
  - 3. What kind of pressure do you think society puts on kids with Myotonia?
  - 4. Mom responds, “Extreme pressure, imagine having to walk stiff legged in front of your classmates one minute, knowing that in another minute you are going to be walking just fine. All those other kids are going to be questioning if you’re faking it trying to get pity, on drugs, just weird, etc.—especially when you have muscles that look like you work out several hours each day.” (Terrible fear of being laughed at, teased, taunted – you know you could fall over at any time – especially if you play in a group and try to run or skip, etc... Tag, Hide & Seek, etc – terrifying games because “Tag, you’re it” means you have to immediately run and chase and tag someone else – but you can’t move)!

XI. Is there anything people can learn from people with Myotonia

- A. People with Myotonia are given two choices
  - 1. Do you hide who you are?
  - 2. Do you accept who you are and allow people to see who you are?
- B. Courage involved in taking the second option
- C. Freedom involved in taking the second option
  - 1. Doctor—because of how few people know about Myotonia, the thing that makes Myotonia stand apart from most diseases is that with lots of effort, effort that often makes living extremely unrewarding—people with Myotonia can hide from others many symptoms of the disease. Hiding it doesn’t mean people don’t notice something weird – they just can’t quite figure out what it is, and therefore just figure you’re kind of quirky, and klutzy. So your reward is you won’t get any nasty looks, but then again no one will take you seriously.
  - 2. While it is human nature to want to hide the qualities that society deems as less desirable, what people with Myotonia have to do to hide their condition is not worth any reward that can come from appearing as “normal.”
    - a. It is extremely exhausting to keep one’s muscles in a “warmed up state.”
    - b. It is very stressful to be constantly trying to anticipate the next moment when one will be called upon to appear as “normal.”
  - 3. Because of how difficult it is to explain to people why one walks stiff one moment and then appears to be fine the next moment, people with Myotonia not only have to deal with the embarrassment of walking stiff, falling over, tripping and losing balance, talking funny, choking on food, having your face “stick” when you yawn or sneeze or blink, or, especially and VERY diagnostic – not being able to let go when you shake someone’s hand – ( THIS is a signature telltale sign!!), but they also have to endure the added criticism that comes with appearing inconsistent.

4. To be able to accept this about oneself, hold one's head up high and not worry about other people's judgments requires an incredible amount of strength, love of oneself (or resignation) and acceptance of others' imperfections.
5. Chekov wrote, "There are a great many opinions in this world, and at least a good half of them are professed by those who have never been in trouble." If we cannot accept others' inadequacies, we will never be able to accept our own.

XII. Individual stories and similarities of people with Myotonia across the world.

- A. Interviewer reveals that each of these people he has been interviewing live in different parts of the world.
  1. Asks each person what they think people in their country think about Myotonia.
  2. Asks individuals on the street if they have ever heard about it.
  3. Interviewer describes the conditions of Myotonia to people on the street and asks what they think about it.

XIII. You can't take yourself too seriously—Laughter is the best medicine

- A. All of the people in the documentary are at the goat farm, and they all run with the goats. Then the people and the goats all fall over.