

Ethics discussion questions on AWAKENINGS

1. How do we know that the catatonic patients are 'in there' in a morally relevant sense? Several terms are used frequently throughout the film as though they indicate moral relevance: (a) patients are described as merely 'asleep', (b) they are described as being 'in there' (as though they have 'locked-in syndrome'), (c) they are described as merely lacking 'will'... but that they can still meaningfully participate in the world if they 'borrow the will' of something or someone else (for example, by grabbing a moving object, or being steered to walk by a nurse).

2. Note the following conversation between Dr. Sayer (played by Robin Williams) and the elderly doctor Peter Ingham (played by Max von Sydow) as they watch historical film footage featuring some of the survivors of the Encephalitis epidemic of the 1920s and 1930s

Dr. Ingham: *I began to see them in the early 1930's...I referred them to psychiatrists. Before long they were being referred back to me. They could no longer dress themselves or feed themselves. They could no longer speak in most cases. Families went mad. People who were normal, were now...elsewhere.*

Dr. Sayer: *What must it be like to be them? What are they thinking?*

Dr. Ingham: *They're not. The virus didn't spare the higher faculties.*

Dr. Sayer: *We know that for a fact?*

Dr. Ingham: *Yes.*

Dr. Sayer: *Because....?*

Dr. Ingham: *Because the alternative is unthinkable.*

How should we think about persons in catatonic states? How do we determine whether or not they are able to even register our attempts at communication? What do we owe to persons in such a state in terms of their rights to care? What if people require artificial life supports to continue living? Who decides if and how and under what circumstances to continue or not to continue providing care for them?

3. Note the following conversation between Dr. Sayer and Mrs. Lowe (Leonard's mother):

Dr. Sayer: *Does he ever speak to you?*

Mrs. Lowe: *Of course not. Not in words.*

Dr. Sayer: *He speaks to you in other ways. How do you mean?*

Mrs. Lowe: *You don't have children.*

Sayer: *No,...*

Mrs. Lowe: *If you did you'd know.*

What does Mrs. Lowe understand about Leonard that Dr. Sayer at this point does not? Persons with developmental disabilities sometimes are not able to speak or vocalize their wants, needs, thoughts, etc. in conventional ways. However, they may have just different ways of communicating, and those who know and care for them show themselves able interpreters of their expressed and sometimes unexpressed behaviour. What evidence do we see of this in the film? How might we work to re-see the capacities of persons with mental disabilities in our culture?

4. What are the signs that the various characters use to judge whether the patients are morally relevant people, and are these appropriate? Before he really begins to work with his patients, Dr. Sayer (played by Robin Williams) describes these patients as 'insubstantial ghosts.' His fellow psychiatrists view the catatonic patients on the ward as though they were just live tissue, and their abilities to move or respond to stimuli as 'mere reflex'. Dr. Sayer notices that Leonard (played by Robert DeNiro) has brainwave responses to his own name. Leonard's mother believes her son is aware of his surroundings in some way, although she chalks it up to parental intuition. Should it even matter?

5. How would you (the audience) want to be treated if you were in Leonard's position? Would you want someone to decide on your behalf to conduct experiments on you? If so, under what restrictions: for example, would it be necessary that you yourself might benefit from the experimental treatment? If you knew that the treatment was only temporary, would you want to be 'awakened' at all?

6. It is a common view that researchers are obligated to exercise more precaution with vulnerable populations, like children or persons whose mental capacities are seriously compromised. If Dr. Sayer had taken a similar approach to medical experiments with children as he did with the more mature adult patients seen in this film, would we think any differently about his professional judgment concerning the risks he was willing to expose his patients to? Why or why not?

7. Before Dr. Sayer is allowed to conduct the drug trial of L-dopa with Leonard, Dr. Kaufman (played by John Heard) insists that he obtain the written consent of Leonard's mother. What allows Leonard's mother to consent to the treatment on Leonard's behalf? What makes her capable of this and Leonard incapable of giving the required consent for himself? Did Dr. Sayer give Mrs. Lowe adequate information for her to be able to make a good judgment of whether or not the drug trial was in Leonard's best interests? Was Dr. Sayer forthcoming about the risks involved? Was enough known about this drug to warrant testing it on clinical subjects--that is to say, on patients?

8. Is it even ethical to perform experimental drug tests on these patients before conducting tests on animal models or some other kind of models for testing? At one point, Robin Williams' character sneaks into the lab to secretly triple the dosage given to Leonard of the experimental medicine. This seems morally legitimate because it worked -- it 'awoke' Leonard -- but does this success justify both the risk and the deception?

9. When it is evident that the therapeutic effects of his experimental drug treatment are wearing off and that he is beginning to suffer serious side-effects, Mrs. Lowe in conversation with Dr. Sayer and Dr. Kaufman states:

Mrs. Lowe: *When my son was born healthy, I never asked why. Why was I so lucky, what did I do to deserve this perfect child, this perfect life? But when he got sick, you can bet I asked why. I demanded to know why. Why was this happening? There was nothing I could do about it. There was no one I could go to and say, "Stop this, please stop this, can't you see my son is in pain?"*

Dr. Sayer: *He's fighting, Mrs. ...*

Mrs. Lowe: *He's losing.*

Clinicians and family members or friends are sometimes desperate to see improvement on the part of persons who are ill? Those with illnesses can be desperate to be better. Our need to regain and restore health can blind us to the risks that sometimes accompany experimental therapies. What principles and regulations need to be in place to prevent medical experiments that are too risky with the potential for unacceptable harms to research subjects or patients?

10. The cost of administering the L-dopa to 15 patients was \$12,000 (US) in 1969. Why are new drugs so expensive? What justifies their price if they are not even proven? What do you make of the way the funding was generated for the experiments? Should the kind of research we see in AWAKENINGS be funded by private donors? What drug costs are covered, if any, under Medicare in Canada? What determines who gets coverage and who doesn't? In this regard, what is fair about our social welfare system in Canada in providing for citizens medical needs and what is not? Is this an issue that should concern everyone, those that are relatively healthy as equally as those that are not so well off?

11. What is an orphan disease? The elderly doctor Peter Ingham at the beginning of the film describes the Encephalitis survivors as "medically irrelevant." He adds: "That's the problem with a unique disease. Once it no longer rages, I'm telling you, it becomes very unfashionable." Given that we have limited research dollars and limited funding for health care, how do we protect against the neglect of those who happen to contract orphan diseases or conditions?

12. When Leonard is prevented from going for a walk on his own, is his outrage justified? He argues (reminiscent of ONE FLEW OVER THE CUCKOO'S NEST) that the doctors and society in general are sick for locking him and his fellow patients away from general society out of fear of what they represent. Is there merit to this claim and Leonard's further speech that: *"It isn't us that are defective, it's them. We're not in crisis, they are. We've been through the worst that can happen to a person and survived it. They haven't. They fear it. And they hide from their fear by hiding us, because they know, they know ...Because we remind them that there's a problem that they don't have an answer to. ...We're not the problem, they are the problem."*

13. Whose safety is at risk if Leonard were to have been allowed to go for a walk on his own? At that point in his recovery, was Leonard capable enough to make decisions for himself? What authority do his doctors have over whether or not he should be prohibited from leaving the institution at his own behest? Should Dr. Sayer have fought harder to let Leonard have his walks, or at least should he have been up front with Leonard before meeting with the committee that he would not be supporting Leonard's petition?

14. When Dr. Kaufman asks Leonard what difference it makes if he is able to go for a walk all alone or presumably with an accompanying staff from the clinic, Leonard responds by saying: *"It makes all the difference....You didn't wake a thing, you woke a person. I'm a person."* What does Leonard mean by this? What is it about being a person that includes being autonomous—being one's 'own captain', so to speak? How is this different from just being a thing? What happens when we treat persons as things? Does this ever happen anymore in today's institutions, or in

present medical settings? Have we made any moral progress in this way since the times depicted in the film?

15. Note this conversation at the beginning of the film when Anthony (the hospital orderly) and Dr. Sayer are walking down the corridor together:

Anthony: *Spent much time in a chronic hospital Doc?*

Dr. Sayer: *I....*

Anthony: *You'd remember....*

Dr. Sayer: *What are all these people waiting for?*

Anthony: *Nothing*

Dr. Sayer: *But how are they supposed to get well?*

Anthony: *They're not. They're chronic. ...We call this place the garden.*

Dr. Sayer: *Why?*

Anthony: *'Cause all we do is feed and water.*

Providing the kind of care Leonard and his fellow residents require is both very mentally and physically challenging. It is difficult for the hospital staff portrayed in this film not to slip into neglecting their charges as persons and instead treating them as things. Yet we also witness that many of the staff seem to come up with innovative ideas of how to engage the residents. What allows them to see these possibilities? What are factors that could stand in the way of acting in a hopeful way with residents? How does one nurture hope that is both uplifting and yet realistic (not cynical)?

16. What do you think of the kind of care provided in the chronic hospital where Leonard lives? What do you think of the architectural setting as a 'care facility'?

17. Why is it a compliment when Paula remarks with astonishment to Leonard: "*You're a patient? You don't look like a patient.*" One can feel empathy for Leonard in this situation. Why?

18. What do you make of Leonard's speech when he states to Dr. Sayer: "*Read a newspaper, people have forgotten what life is all about. They've forgotten what it is to be alive. They need to be reminded. They need to be reminded what they have, what they can lose, what I feel, this, the, the, the*"

19. First and foremost, when reflecting on the experiments with L-Dopa conducted by Sayer and colleagues on the patients in their care, there is a pull in two directions: on the one hand, there are serious worries about the moral propriety of what they did; on the other hand, there is a sense that for a brief period of time there was a restoration of what had been hitherto lost (and, in restoring what had been lost, successful treatment). It seems impossible not to be moved by the awakening of Sayer's patients. This seems to speak against blanket judgments about the propriety of intervention, even in cases where the biochemistry of the patient is intentionally, though experimentally, changed. How do we reconcile a compassionate response to the results of such experimentation with worries about using patients as 'guinea pigs'?

20. In what ways is Doctor Sayer a kind person? How integral is being kind to doing his job? Does Dr. Sayer's kindness ever facilitate or get in the way of his professional judgment? What do you make of the following conversation between Dr. Sayer and Nurse Costello as they view a movie of Leonard's deteriorated state together?

Dr. Sayer: *You told him I was a kind man ... It's kind to give life only to take it away?*

Nurse Costello: *It's given and taken away from all of us.*

Dr. Sayer: *Why doesn't that comfort me?*

Nurse Costello: *Because you are kind. And because he's your friend.*

There are many indications that Dr. Sayer relates to Leonard as a friend and not only as a professional. In doing so is Dr. Sayer contravening what is expected of him as a professional? Why?

21. Though it seems an act of compassion to seek such awakenings, even if they only occur for limited periods of time, is such a pursuit compassionate? There was a great deal of anguish, both for the patient and his or her caregivers, associated with the subsequent neurological degeneration post L-Dopa intervention. How is this properly weighed against the brief happiness associated with the period of 'full' awakening?

22. In the movie, Leonard talks of experiencing nothing when he stops engaging with his environment. The ability to catch balls or pass them between individuals, though a remarkable feat of information processing, need not evince an accompanying phenomenal consciousness. The relevant behavior of patients with blind-sight comes to mind here. Though Leonard's executive functions are spared in some sense, they are not in another. For Leonard and his fellow patients, how should we talk of the period between awakenings?

23. When Leonard becomes more assertive, and almost volatile his mother accuses Dr. Sayer saying: *"I don't know who that is up there. I don't think he knows. (to Sayer) You've turned Leonard into something he is not."* Is this true? Has Dr. Sayer done Leonard a disservice? Is Leonard's mother right to expect that her son not be the person he is on L-dopa? How changed is Leonard?

24. In trying to figure out the neurological condition of his patients, Dr. Sayer remarks: *"One would think that after a point enough atypical somethings would amount to a typical something. But a typical 'what?'"* How true is this remark for neuroscience research? Our identities are very linked to stable brain functioning. How might brain changes result in identity changes for persons? How could changes to our brains affect how we think of ourselves and others? How might this affect how we even think about our ethical obligations to one another?

25. After the therapeutic effects of the L-dopa no longer seem to be working for Leonard and his Parkinsonian condition worsens dramatically, he says to Dr. Sayer: *"Sometimes I'm not a person, just a repertoire of tics. ... This isn't me."* What does Leonard mean by this? Is his personhood really under threat from this disease? In what way(s)?