

Director's Statement

From the start, this project has been one of the most moving and revelatory I've ever had the privilege of being involved with. We were called in to film Oliver Sacks only two weeks after he received the fatal diagnosis that would end his life seven months later, on August 30th 2015. From the moment my colleagues and I walked into his apartment on Horatio Street in New York in February 2015 - to begin what became eighty hours of filming with a remarkable 81-year-old man facing the end of life with courage and wonder and honesty - it was clear that virtually every issue of importance about what it means to live a life and to be a human being, was concentrated in his unusual life story: survival, beauty, art, science, storytelling, love, individuality, difference, dignity, autonomy, agency, wonder, language, meaning, consciousness, community, friendship, yearning, loss, connection with something larger.

The two dozen people we have talked to on-camera in the course of the production - writers, editors, scientists, neurologists, patients, journalists, family members, friends - have spoken with a depth of insight and feeling that has been humbling, illuminating, riveting. Brilliant, sometimes maddening, empathetic, driven, stubborn and filled with a kind of childlike wonder and gratitude, Oliver Sacks was a person obsessed throughout his whole life - as he put it in a deeply moving piece in The New York Times announcing his fatal illness - with what it means "to be a sentient being on this beautiful planet." His hard-won capacity for connection with an amazing array of patients, readers, colleagues, friends, collaborators, philosophers, and scientists - forged in the course of a lifetime filled with challenges, often self-inflicted but always overcome and transcended - is itself a moving testament to the power of growth and survival.

Some projects call to you because they are meta projects; and this is certainly one of them. Meaning they're not just about what they're about, so to speak - in this case, a brilliant, idiosyncratic doctor and writer hellbent on conveying the essential mysteriousness of what it is to be a human being. Meta projects tell you why it is you do what you do. They speak as much to the essence of the process you the filmmaker- and by extension everyone else looking on - struggles with and goes through as we search for meaning, order, beauty, truth, purpose and resonance in our lives. I knew in a heartbeat that working on this film would be that kind of meta project. Oliver liked to surround himself with people who belong to the freemasonry of the vulnerable, the open, the seeking - the uncynical. That's a pretty large group, obviously, but we sensed from the start he felt safe with us, safe in our hands; and all of us were deeply touched, and honored, to be so trusted. He was a dying man with a lot on his mind, and not a lot of time left; he brought everything he had to the table, and it was the least we could do to respond in kind.

At Oliver's memorial service in New York in the fall of 2015, David Remnick, the editor of The New Yorker, said something incredibly powerful and true about Oliver's work, and the uncanny impact it has on people, and certainly has had on me. "In nearly all of Oliver's pieces," Remnick said, "there comes that moment, that epiphany, that shock, when the reader realizes that Oliver was just as strange, and just as wonderful, and just as elusive as the person he was writing about. And there came the moment, too, when we his readers realized: so are we - so are we." My colleagues and I have had the privilege of an extraordinary adventure working on this film, and we are deeply grateful to have been included on the journey.

–Ric Burns

Q&A with Ric Burns

Q: How did you find out about this opportunity and were you familiar to Oliver's work prior to filming?

A: I was familiar with Oliver's work in the way most people know him: from "Awakenings" and his essays in the New Yorker and the New York Times. In January 2015, I got a call from Kate Edgar who was Oliver's chief of staff and described by Oliver as his editor, friend, ghost writer, and companion. Kate played a huge part of Oliver's life for the last 30 years. She called to say, "I'm sorry to say Oliver is dying, would you come in and film him?" and without any thought or any preparation we just immediately dove in. Within a few weeks my colleagues and I were crowded into his apartment on Horatio Street in Greenwich Village in New York and for 5 days in a row, 10-12 hours a day accomplished some 60 hours of filming him in his apartment. It was an extraordinary way to begin a project, but we wouldn't have had time to stop and think and we wouldn't have had time to fundraise because Oliver would have been dead before we could have accomplished that.

Q: What was it like to meet Oliver and to film with him?

A: We met a man who was 81, who had just finished an extremely self revealing memoir talking about things which had been the hardest things, things he had assumed he would never talk about. He had just received a death sentence and nothing quite focuses the mind like knowing your own mortality. To be staring death in the face, it was almost like the value of his life was on steroids. We found a man at the end of his life talking directly with humor, passion, and profound perspective and who had a unique accommodation of bashfulness, a tremendous kind of curiosity and wonder about himself, about other people, about the process of being alive.

Q: What surprised you most about Oliver as you were getting to know him?

A: I don't think I ever met a more boundlessly curious person. Someone whose sense of wonder and curiosity about the world as he found it was inexhaustible. Although I met him when he was 81, it was almost like meeting a child - and I don't mean that in any patronizing way. The same quality of wonder, the same glee and excitement, and the same sense of wanting to share. He was a person who lived a life of awareness to the fullest.

Q: What do you think was Oliver's biggest impact in the medical field?

A: Oliver found a late career validation from the top tier of neuroscientists. Having been largely either ignored or in fact critiqued by his own discipline for being a popularizer, in the 80's and 90's Oliver was discovered by people studying consciousness: Francis Crick, Gerald Edelman, and Christof Koch. Oliver had this unique data on human beings. Data that you don't get from putting somebody's head in an MRI. Data you can only get by interacting with empathy focused on patients over a long period of time. Oliver called it the intersection of biology and biography: he tried to find out what it's like to be someone else. His friend Lawrence Weschler said his question was always, "How are you? How do you be? What is it like to be you?" Not just, "What disease do you have or what challenges do you face?" Sure, those were important and he never ignored that, but what is the interior subjective reality of having Tourette Syndrome or being autistic or having no ability to recognize faces, or to be deaf, or to be colorblind, or a whole range of neurologically atypical circumstances?

Q: Was there ever a sense of fear that Oliver had about dying?

A: His friends said after he died that he gave a master class on how to die. That master class was not morbid - it was inspiring, hopeful, and in line with every theme, intuition, and every aspect of what has made him a

vital person. Christof Koch saw him shortly before he died, and he said, "I left a dying man in a wonderful mood." He was filled with hope and inspiration - he had to overcome 35 years of celibacy, drug addiction, and often, despair. Oliver was embracing everything and lived right up until the end to the fullest.

Q: What was your process in identifying the documentary's main focus out of all the countless hours of footage you shot?

A: In your gut you know going in it is just not an accident to be invited into a dying man's living room and then talk with him for 60 hours. He was a fascinating, sometimes grumpy, shy, charming, funny, irreverent, often volatile, old man. We knew those 6 months as he faced mortality was one narrative strand in the film, but there's a second strand woven in as well: this retrospective of his amazing life going all the way back to his childhood. That was a challenge. Because of Oliver's own storytelling gifts, and because of his incredibly fascinating life and the enormous challenges he faced, it was possible for us to create our own double helix. The story of a man confronting the last months of his life and at the same time to look back at his entire life, which is the subtitle of our film. His life was really a series of set-backs and the story of Oliver's life is surprisingly like a roller coaster. You are sitting there saying "hang on, man," and just when you think he's out of the woods, he's back into the woods.

Q: The film has such a wonderful collection of interviewees sharing their stories about Oliver. What were some of your favorite interviewees you had throughout filming?

A: The people that surrounded Oliver over the course of his lifetime were just extraordinary. The 25 people we interviewed was the most remarkable group of people I've ever had the fortune to talk to. Lawrence Weschler (from the New Yorker), Isabelle Rapin (fellow neurologist), Christof Koch (the head of the Allen Institute for Brain Science), Robert Calasso (his Italian publisher), and Shane Fistell (a Touretteur from Toronto). All of them share something in their differences that is really remarkable. You really got a great sense out of all these people that he knew how different and unique they were and how they shared Oliver's truth-telling instinct and his empathetic genius. That was his family.

Q: You're a writer of documentaries and you've won three Writers Guild Awards for your work. What's the difference between making a narrative vs. a non-narrative film and why did you choose to go without narration this time?

R: The quality of a film shouldn't be determined by whether there's narration or not. A film's a film. A silent film, a written film, a cinematic film, a fictional film, a documentary film, we take it all in. It's all about the experience the viewer is having. We chose not to write any third person narrative because we had 25 or more of the greatest talkers we ever met. Oliver was an extraordinary talker and it became clear that the chief resource of the film is an individual first person reflection. However the process of making it is really, really different. The problem is you don't have any ability to create new logical connections when you need them. You just have to take the material as you find it and craft something from that.

Q: How would you best describe the legacy of Oliver Sacks?

A: I think it's important to remember this is a person who literally changed medicine, and the way we think about people with uncommon neurological circumstances. I think he was responsible for a massive shift in how we think of mental illness, arguably more than anybody of the late 20th and early 21st century. Lawrence Weschler pointed out that the Head of Columbia's Neurology Department said that 70% of the doctors in training who choose neurology said they were deeply influenced by Oliver Sacks. He influenced generations of doctors and nurses and how we think about people with all types of atypical neurological situations. He helped us unlock the door to other people.

Q: Did Oliver have an overarching message that you wanted to get across with the documentary?

A: *In a sense his message was: we are all alike in our uniqueness and we are a tribe of irreducibly individual people linked by our connection to each other. That's an incredible message to be carrying abroad in a life's work. It is the definition of humanitarian and humane.*

Q: What do you want the audience to take away with this film and what do you think Oliver would want the audience to take away from these interviews?

A: *People who are religious, agnostic, or atheist all share the mystery of life. Oliver's message is how the mystery of life is profoundly affirming. Yes, there are challenges. Yes, some people suffer enormously, and that is sad and terrible. He wants to change, he wants to heal, but he also wants people to engage with reality. I think that that's really what he knew his own message was. It was the message that his life inculcated in him, and what he wanted to share. You can call it religious or you can call it atheistic. It is an understanding that we are, all of us, individuals engaged in something larger than ourselves. The universe is a mystery, a joy, and it's beautiful.*

Q: What were your favorite scenes from the documentary?

A: *There is a moment where Oliver goes on to talk about orange jello in scandalous ways and the unusual use he makes of refrigerated orange jello. You watch Oliver through the camera lens as he thinks. For me the beauty is not the scandalousness of the scene, but the beauty of watching a human being thinking and feeling. It's often just a nod of a head or a looking down or a look on a face that makes me really feel so grateful to be a documentary filmmaker. Because the most precious thing is seeing the inside invisible part of your subject. That is what every filmmaker is trying to do.*

Another one of them is at the very end when he stops reading what is in a sense is his own obituary that he has written for the New York Times before he dies. He looks up and he sees the surrounding group of people are in tears and he says very simply, "Well, that's it." It's such a stunning moment because it has so many different resonances. Like every story, in some way, a wonderful life could end with a moment of, "That's it."