

## **Episode 62 - Dr. Jay Wolfson: Head, Heart, and Hope: The Complex Challenges of Decision-Making at End of Life**

[00:00:08] Welcome to LIVING PROOF the podcast Test series of the University at Buffalo School of Social Work at [www.socialwork.buffalo.edu](http://www.socialwork.buffalo.edu). We're glad you could join us today. The series Living Proof examines social work research and practice that makes a difference in people's lives. The University at Buffalo School of Social Work is making a difference every day through the generation and transmission of knowledge promotion of social justice and service to humanity. We offer MSW and Ph.D. programs continuing education programs and credits online courses licensure exam preparation professional seminars and certificates and much much more. To learn more about the UB School of Social Work please visit [www.socialwork.buffalo.edu](http://www.socialwork.buffalo.edu). Hi from Buffalo. No not the home of two feet of snow on Christmas Day. That's Manhattan. I'm your host Peter Sobota. In 2003 with national attention swirling around the case Dr. Jay Wolfson was appointed by the courts and governor of Florida as guardian ad litem for Terri Schiavo whose husband and parents were in a standoff about her care and end of life decision making. He was charged with preparing a report using his expertise to provide summaries and recommendations. In this episode Dr. Wolfson discusses his experience in the Schiavo's case and the political clinical and legal issues he was forced to contend with. He speaks about the powerful influence of hope in this process and its strength and threat to those making decisions. Common sense compassion dedication are all along for the ride.

[00:01:57] Dr. Wolfson discusses the complex variables involved for all players in this trauma including the loved ones and families and the professionals who interact diagnose treat advocate counsel and interpret and apply the law. He concludes with recommendations for clinicians and other professionals in assisting others with end of life decision making. Jay Wolfson is the Distinguished Service Professor of Public Health and Medicine and the Associate Vice President for Health Law Policy and safety at the University of South Florida in Tampa. He directs the Suncoast Center for Patient Safety at USF and is codirector of the Consortium for one medicine for USF and Stetson College of Law. He holds a doctorate in public health from the University of Texas law degree from Stetson a master's degree in public health from Indiana University a master's degree in History from NYU and a bachelor's degree in History from the University of Illinois. Dr. Wolfson was interviewed by Dr. Deborah Waldrop associate professor of social work here at UB. I'm Jay Wilson and I'm a Professor of Public Health and Medicine at the University of South Florida and professor of law at Stetson University College of Law. Earlier this century I was appointed to serve as the special guardian ad litem for Teresa Marie Schiavo known best as Terri Schiavo who had for many years been in what was diagnosed as a persistent vegetative state and at a point many years after that diagnosis efforts were made by her husband to permit her to die by the removal of the nutrition and hydration tube that had been inserted in her for many years. And this became an issue of national significance when the governor of the state of Florida and the state legislature.

[00:04:00] President Bush and the United States Congress became involved guardian ad litem is a position that I believe every state in this country has as part of its statutory provisions of a law that has the responsibility of representing the interests of persons who may be incapacitated. There are guardian ad litem programs that are run by state agencies as well as some that are run by not for profit community organizations representing special interests children or adults or abused women when there is a party in an action that the state has determined is legally incapacitated and they do not have their own representation and there are other parts such as family members who are disputing issues associated with that person's rights or if the state itself has a concern about the exercise of that person's rights then guardian ad litem may be appointed by the courts. In my case

there was a special law that was passed by the Florida legislature and became known as Terri's Law and the law contained two provisions one it permitted the governor of the state of Florida to in this particular case make a determination as to whether or not the hydration and feeding tube which had already been removed from Schiavo subsequent to a court order should be replaced. And that also required the appointment of a special guardian ad litem by the courts and the governor's office to review and assess the entire medical legal history of the case and report to both the governor and the courts with respect to recommendations on swallowing tests and other clinical and legal questions that are embedded in the law so it's a special guardian appointment.

[00:06:06] And it was based on that law that I received a phone call unexpectedly from the governor's office asking me if I might be interested in serving as guardian I should say that I don't watch much television and I tend not to read local newspapers. When I met with then Governor Bush. But I really didn't know much about the case. And it turned out to be a very complicated difficult case. There was a great deal of contention between Ms. Schiavo's parents. The Schindler's and Ms Schiavo's husband Michael Schiavo could you tell us a little bit about the process that you went through in the beginning to really get the whole picture and I met with the parties first after having read some of the basic legal complaints in the case. Those demands by the parents that she be allowed to remain on nutrition feeding tube. Those documents that were issued by the husband's attorneys requesting that she be permitted to be relieved of that burden and allowed to die naturally. And at the outset I didn't go into any of the court documents. And then I met with the family I met first with Mr. Schiavo and his attorney just to get to know them. The court had ordered my participation and I thought it wise to speak with the parties. They were they had some trepidations at first. But I think we overcame those with relative speed. Mr. Schiavo was attorney was concerned that I was representing the interests of the governor the Schindler's were concerned that I was representing the interests of the ACLU or some other group or that I was some liberal professor who was out there to do with liberal professors tend to do. And I think I disabused all of them of that up front that I was an objective third party.

[00:07:58] And my interests were to the best of my knowledge to represent Ms. Schiavo and to do so by gaining as much of an objective understanding of the facts of the case as possible. And from the beginning all the way through the end I predicated everything I did on good science good medicine and good law. Now it sounds like you had to build trust with the family. That was the most important thing. You're right. And that took a while it took several meetings of sitting down and talking and sharing who I was what I believe in what I know and what I don't know. And convincing them that I didn't have an alternative or alternative motive and only after that was established. Could I have more frank discussions with them about who this woman was and what they could help me learn about her because she couldn't talk to me and she did not have a living will or a surrogacy document. There were only third party expressions of what she had said what her intentions were. Florida law is different from many other states and it does provide for a third party in the guise of a husband as a as a legal guardian or when all else fails the court to step in and act as the interpreter of the intentions based on the totality of knowledge. I think it fair to say that I established a trusting and highly interactive relationship with both sides and their attorneys. And without that it would have been extremely difficult.

[00:09:33] I relied extensively on the discussions we had the facts they shared with me the portraits many portraits painted of this young woman and their relationships with her. They could help me better understand about the way she lived the things she did so that I could fit those into that decision model. I wasn't charged with making a decision. I was simply charged with reviewing the facts and proffering summaries and recommendations concerning some technical legal and clinical things to the judges and to the governor. But the context was important because we're getting more than just technical facts if it's just a matter of saying if the technical facts are a b and c and your options on those are x and y you plug those into a formula and you come up with a

computer can do that and you don't need judges lawyers physicians social workers psychologists guardians ad litem or your family members. Let me simply plug the data into a computer plug it in and get the decisions being made. And that's fortunately not the case. The unfortunate part of this was that early on in the process there had been no mediated effort to bring in social workers end of life discussions that was avoided and it was kind of before in some respects that became more common in hospitals to have committees coming together of ethicists clinicians attorneys administrators lay people on a case by case basis to review particular cases and to be able to communicate more effectively with the family members and say here's where we stand. It also doesn't take into consideration the politics and personalities of what happens when a case goes public that changes everything changes everything because the motivations of some of the parties change. And if you can avoid that it probably keeps things as it should be.

[00:11:30] Fred Thompson who ran for president who I guess was also a character in some television show and is known for his very conservative principles weighed in on this in a very interesting way. His son I believe was a victim of automobile accident and was in a persistent vegetative state. And he had to make a decision and he made the decision to remove the feeding tube. Governor Thompson was asked about this shortly after Senator Frist on the floor of the United States Senate made remarkable comments about a three minute video that he's seen saying that you know I'm a physician and I've seen this video and I will tell you that she is aware and interactive. That was unfortunate because it created all kinds of unnecessary expectations you know appropriate expectations misleading expectations false unscientific not medically grounded expectations in the minds and hearts of the mother and father and family members who were most affected by this. So they were encouraged to continue to believe in addition to the political possibilities and economic possibilities that there was hope and hope is the single most powerful force that can drive a decision of a family member in an end of life issue. And I doubt if there's a scintilla of hope if there is really a scintilla of hope that my daughter can get out of this and come back in a reasonable state. I'm going to do that because I love my daughter. But if you're telling me that this is hopeless or that the best we can expect is that she will remain in a semi-conscious state and not really. Is that.

[00:13:08] Is that what my daughter would want and in your best guess what do you think Terri Schiavo would have wanted. You reviewed tapes you reviewed all the documents you heard all the stories in your mind what do you think she did that took a long time to get to a conclusion on. I did several things. There were 30000 pages of legal and medical documents and I have the dubious background of having clinical and legal knowledge and skills. Plus I had my own health sciences center my own law school and skills and knowledge of experts around the world. I pick up the phone and make phone calls to people I didn't know and told them who I was and what I was doing and I didn't get anybody who wasn't fabulously eager to cooperate. I sent them portions of medical records I ask for interpretation. They were great. And I reviewed every single page all 30000 documents myself to copious notes. I had an extensive conversation with neurologists with psychiatrists with social workers with psychologists I'd met with representatives of every religious faith and such and denomination and had lengthy conversations. And there were divisions at this point within the Catholic Church by the way. And I spoke with both sides on that. And again I spoke with parents and at least one with ethicists and that was a big part of it and professional responsibility. Members of each of the professions. So there were folks in social work for example who write about professional responsibility and ethics at my university. I spoke with them along with physicians who do the same thing lawyers.

[00:14:41] So I tried to together those perceptions those understandings as I could and then I spent at the same time lots of time with Ms Schiavo in her room just the two of us. I spent probably between an hour and four hours every day with her and I did that because I needed to have that personal understanding of what it was. She may or may not have been capable of doing. No I'm not a position that clinically diagnosed her but I'm in a position to be that reasonable person who can sit

and attempt to say is there a response here. And I know the clinical responses are supposed to be and I can read the clinical records and I can attempt to interact with her I can close. I would grab her face and I would shake her. I would play music for I would scream at her. I would ask her things and there was never in more than a month of interfacing hundreds of hours. There was never a scintilla of responsiveness that was consistent and there was a cute story and some of your listeners may be old enough to remember this. There was an old cartoon by a guy who is a construction worker and he's demolishing the building and he comes to the old Cornerstone he takes out a box and he opens the box and a frog jumps out and a frog has a top hat and a cane and sings hello my baby hello my darlin, hello my gal. And it's amazing. And all of a sudden he starts thinking about money and he takes a frog and he runs away and he sets up the thing he's going to make money.

[00:16:18] Displaying frog and crowds come and every time he takes the frog out of the box it just sits down and says ribbet, ribbet. And then as soon as people leave because of his top hat dances the problem is life. His wife leaves him it's shows abandoned and he loses job and becomes impoverished and he said he's disgusted. There's a new building being built on the same site. And he sneaks it in the middle of night and he puts it in the new corner stone and runs away and then it flashes hundreds of years later as this building is being demolished by aliens. They find the box and the same thing happens again. I had Mr. Mrs. Schindler, the Schiavo's parents in the room with me and asked them because they had said that Terri had responses to them for several hours. Mrs. Schindler who really was a remarkable remarkable woman. She desperately tried to recreate in my presence in the corner of the room behind the bed the kind of responsiveness that she said had been displayed over and over again. And that had been touted as I do it didn't happen. At one point Mr. Schindler Bob turned to me and said to me, Jay, have you seen that cartoon and I was thinking at the same time Frog. And that for me went to the role of hope. It speaks to the essence of belief that's something may in the corner of hope that was that for them and if and if you're told by a professional if you're told by a board certified neurologists a physician that we can grow her brain back that we can we can bring her back that she'll be sitting up in bed eating a ham sandwich in two years.

[00:18:05] If you're led to believe that not by some random person on the street but by someone who has clinical knowledge skills and a license to practice and if that's reinforced by others who may have other agendas. Part of that agenda being whatever you do you don't end life. Justice Scalia the Supreme Court in an earlier decision Cruzan talked about ending life and that we can do nothing we can do nothing to participate in the ending that somebody lies down during low tide on the beach with the expectation of committing suicide. We cannot permit them to commit that crime of letting the water come in and drown them. We have a moral legal obligation to take them away because suicide is a crime. And if you really believe that that's one thing there was a great part of this that day Ms Schiavo died. I was in Tallahassee and I was out in the courtyard of the Capitol and there was what was obviously an orthodox Jewish rabbi. The tie, the hat, and the beard, to the black coat and you get a big pile of clothes next to them and you apparently came down from the north and I curiously walked up and I said a rabbi can I can help you with a couple of friends. He said yes yes yes I have to speak with the governor immediately. I have to meet with the speaker of the house and have him to present to the Senate. And I said once I came here to save Terri Schiavo and I said like to help me understand this. He said look the scintilla of life creates hope for all life.

[00:19:46] Now this is a belief that I can accept and it has it has real meaning and I value that. But there were others involved in this process who didn't hope necessarily that belief and who would take either political or clinical or religious values and translate them into something else. And when you do that and you impose that on a party like a parent who is looking for that hope is begging for that hope you're doing a huge disservice. And I think about what what that means for the future. If you've lived with that hope and then what does that do for bereavement in the end what does that do for them create bitterness it creates bitterness in the end as opposed to allowing allowing the

bereavement process to act out natural and there to be some healing in the family. Yeah and because of the politics that were involved in cases like this or in any case where the press is involved and there's that much contention between parties natural healing may never take place where you can have scaring and it's unfortunate. Were you able to see any reconciliation is not the word but any coming together and in the end. No no it became became even more toxic in the end unfortunately and even today there is a great deal of toxicity. If we can encourage more people in advance to say here's what I want to do even if you change your mind that's OK. If this is what your intentions are today memorialize them and make sure that you pick somebody as your surrogate who agrees with your intentions who's not going to say Well I you know I know what they wanted but that's not what I want.

[00:21:38] No Max Max Brod became the guardian of Franz Kafka's memoirs and Franz Kafka told him very specifically I want all of the sperm and I'm entrusting you to do these after I die. And Max brods after he died said I'm not going to burn them, and he didn't. I think it's a particular challenge when there is no articulation. And that's what the law provides for in many states. There is the reasonable standard that those who are closest with you starting from your husband next going to your children your parents are the last unless you're a minor and there's a reason for that. And that's because your parents have hope and expectations that are reasonable but may not be consistent with yours. If you're an adult and when there is a clash of interests as occurred in the Schiavo case between the husband and the parents the law says the husband shall prevail but you may not like what the law says. And if that's the case then you have to change the law. You may not like what the medical evidence presents a persistent vegetative state remains a controversial diagnosis relative to minimal consciousness. And there is actually something new and new stuff that indicates that there have been some misdiagnoses. In the case of MS Schiavo the clinical evidence was overwhelming. Her entire cerebral cortex the entire cerebral cortex was liquid. Her and 80 percent of the rest of her brain was gone, was dead. There was no reasonable medical hope of her ever recovering conscious capacity, it wasn't there.

[00:23:26] So my recommendations were if you really want to make sure of this get the parties get together and agree one last time we will have these tests done by a party not selected by any of the current parties. Why no one has been involved but all the parties have to agree that the results of those clinical tests will be abided. Mr. Schiavo agreed the Schindler's did not and the law eventually played out. Judge Greer who was a very conservative Republican fundamentalist Baptist was the judge in this case. And during the course of these proceedings he was kicked out of his church and ostracized by his Republican colleagues. And in this case the one thing that probably saved the integrity of the process was the process itself the legal process. Now as as Governor Thompson said these are matters that are family matters the government the courts should stay out of lets families decide this. Families and physicians make their decisions which is the way it should be as soon as you start getting the press politicians and even the courts involved. You open yourself up to the toxicity that those naturally create because there are advocates on both sides. And the purpose of those advocates is to stand firm for the positions of their folks they represent. And in cases like this nobody wins and the complexity of it as you say and as you describe in the political context makes it so much more intense and somewhat more difficult. What do you think the takeaway messages are for people who are in the health professions and learning to be in the health professions where does that take us in terms of helping people understand these issues and educating people about. Great question.

[00:25:16] I do love work and patient safety. And what we've learned is that the honest with people is the most important thing we can do. We're not if we make a mistake saying I'm sorry we're not saying gee I'm sorry I screwed up saying I'm sorry this happened to you. Let's fix it. In the case of end of life decisions being as honest and open about the clinical information as possible and doing it early on and in a setting that is comfortable and pragmatic so that there's no misunderstanding and

bringing in those parties. If you're a clinician if you're a physician then you don't really have the people skills bring in the social worker who does. If you're an attorney and you're representing the family in an end of life decision possibility and you don't have those skills bring in the social worker because that's where the skill resides in helping to objectively mediate the facts around that person's life and it's in that person the person who is the subject of the potential of life that this is all about. It's not about the parents. It's not about the husband. It's not about the courts. It's not about the attorney and it's not about social worker either. It's about that person. I think the biggest challenge is when you don't really have any concrete information in advance about what that person said they wanted. Then you have to rely upon either the integrity of those involved the husband or when that is challenged then you have to rely upon the process that is in place legally to resolve the dispute. And if you can avoid contention at that point you're OK.

[00:26:59] But that's where the old adage good fences make good neighbors is early on as you can involve trained individuals who can assist in helping those decision makers understand what the options are and why in an environment that is not contentious that relies on good medicine good science good law and the interest that individual not the people who are being harassed assaulted me. Absolutely. And one final question for you. What was the most perhaps transforming or meaningful aspect of this case for you as a person as a professional. That I what I wrote I wrote in our report. And I remember very clearly when Ms. Schiavo died I got a call from from the facility was that and this is someone I didn't know personally. I was playing an objective almost a bureaucratic role. Something I'm not used to doing and I tried so very hard to connect with this human being through other human beings who knew her. It's kind of like trying to connect with the artist by feeling the painting you know and and getting a sense of what the lifeforce is that created this thing and wondering if I've done everything that I could or should on her behalf because that was my job. And if I had left anything undone but I had a big event during the middle of this. I was I was reading these documents and I was talking with people was very intense I wasn't getting much sleep and didn't have much time. And I woke up, had this horrible dream, was it was a horrific dream. And I assured it with Governor Bush I've shared some of my writings.

[00:28:49] I dreamt that I woke up and that I was inside of essentially a coffin a dark coffin. And that realization was that there was no escape from this and that this was it and that there was abject hopelessness and yet eternal hopelessness. And I woke up screaming screaming at them. And my son my my my wife was used to my talking sleep. My son was always he ran across the house and he said in listen. I said this is horrible dream. You know it was a very subjective experience. But if if there was the slightest scintilla of any awareness that might have been left in Ms. Schiavo, I wonder what it would be like if that's all there was. And from a Catholic perspective she could be allowed to move onto the next stage naturally is that what she would want. And I couldn't do it in terms of what I would want. So I had to project which is all we do anyway and everything we do is a projection on a good day without bad years. It's a profound story and a profound takeaway message I think that gives such an insight into what the experience could potentially be. These are not these are not bureaucratic processes they're very personal. They are literally matters of life and death that affect the essence of what we are as human beings and end of life as as painful as it is as part of a process. And if we have a question about the decision and disputes arise or confusions arise we need to go seriously with the old and had an open heart.

[00:30:43] But we have to do it professional as well not technically there's a difference. Thank you so much for sharing this story with us. It's really powerful really profound. You've been listening to Dr. Jay Wolfson discuss his experiences with the case of Terri Schiavo and the complexities of life ending decision making on Living Proof. Hi I'm Nancy Smith professor and dean at the University of Buffalo School of Social Work. Thanks for listening to our podcast. For more information about who we are our history our programs and what we do. We invite you to visit our website at [www.socialwork.buffalo.edu](http://www.socialwork.buffalo.edu). We are living proof that social work makes a difference in people's

lives.