

You First Podcast Episode 70: Not Dead Yet, Assisted Suicide, and Ongoing Disability Fights - Part 2 with Anita Cameron

Maddie Crowley (00:00):

You're listening to You First: The Disability Rights Florida Podcast. In this episode we talk with Anita Cameron about Not Dead Yet, assisted suicide and other ongoing disability rights issues. Welcome back to the You First Podcast. I'm Maddie.

Keith Casebonne (00:32):

And I'm Keith. And we are the host of You First. We are back with part two of our interview with Anita Cameron. If you haven't listened to part one, you can find it wherever you get your podcasts.

Maddie Crowley (00:44):

In part one, Anita talks about the history of ADAPT, the Atlantis Community and the disability disobedience that got our community the rights we have today. But in this episode, we dive into some specific issues facing the disability community today.

Keith Casebonne (00:59):

Yeah, we talked with Anita about their role at Not Dead Yet, how people with disabilities reject assisted suicide and some continued issues related to healthcare. But before we get into this interview, we wanted to let you know some really exciting news, that we are up for a podcast award.

(01:19):

You can vote for us throughout the month of July and help us win a People's Choice Podcast award. So, how you can do that is you visit podcastawards.com/app/signup and we will have that link on our website where this podcast is hosted. Also, wherever you're listening, so you should be able to click that too. You can go to that site, fill in some basic information about yourself to vote, and you'll navigate to the society and culture category

where you will find You First: The Disability Rights Florida Podcast and hopefully select that as your winner.

Maddie Crowley (01:53):

Yeah, and thank you so much. If you take the time to vote, we really appreciate it. I'm really excited to see if we win. So, thank you for taking the time. And without further ado, here's Anita.

(02:06):

Anita, as you just mentioned, this is Maddie. As disabled folks being second class citizens, you mentioned a whole host of aspects of life, but just including living, quite literally like the right to live. And I'm curious if we could pivot a bit and talk about your role and involvement in Not Dead Yet, and explain to the folks listening what medical discrimination is, medical rationing, assisted suicide, and if you can talk a bit about the disability community's resistance to assisted suicide and if possible speak a bit to Made in Canada and how that changes maybe the landscape of what's going on in the United States. That's a big, and it's a heavy question.

Anita Cameron (03:01):

Yeah. Not Dead Yet is my day job, it's a passion of mine. Not Dead Yet was founded 25 years ago in the wake of the Jack Kevorkian mess. And so the big three things that Not Dead Yet fights against, and I'm director of minority outreach for Not Dead Yet. I have been involved with Not Dead Yet since its inception. And then I served on the board of Not Dead Yet from 2013 to 2017. I left the board of directors to take the position of director of minority outreach.

(03:47):

Medical discrimination is when doctors discriminate against you based on things like your disability, your race, your age, your socioeconomic status. And healthcare is either withheld from you or you don't get effective healthcare or you get out-and-out harmful healthcare. Medical rationing is when it is determined that you can only get certain care. This usually pops up when you have crisis standards of care like COVID, few others. And so what ends up happening is that disabled people, I'm trying to figure out a way to put it. It's almost like a triage thing. Disabled people say for instance, like during the height of COVID, a disabled person on a ventilator came into the hospital system. The hospital system could take your ventilator from you, take it out of your body and give it to someone else, deemed more likely to survive, younger, healthier.

(05:17):

Not Dead Yet, we wound up putting in DOJ stuff and getting this process to stop because like people with intellectual disabilities were being denied organ transplants and whatnot. We're not even going to go into the whole racial disparities in healthcare. That's a whole nother chapter. But what ends up happening is that assisted suicide, and that's the thing that Not Dead Yet is really known for, our fight against assisted suicide. Now, I don't use any of that other language that they use. I don't use the other euphemisms that they use because assisted suicide is just that. It is suicide. It is suicide. Some people call it medical assisted suicide. Some people call it physician assisted suicide.

(06:25):

My colleagues at PAMAS, Progressives Against Medical Assisted Suicide in Connecticut, they use that because now... So, let me go back a little bit. Assisted suicide is when you are deemed to be terminally ill with six months or less to live, and a person would request to have a medication given to them so that they can die by suicide. The proponents say that assisted suicide is for those with terminally ill, six months or less live. Oftentimes people make mistakes. My mom. Yeah, my mom was living in Washington state just after literally, oh, I'm going to say nine weeks after the state of Washington enacted its assisted suicide law. I was told that my mom was dying. Her death was imminent. I was literally told, "If you want to see your mother alive, you will get here to Washington State in two days."

(07:47):

So, I did. My mom rallied, but she eventually was placed in hospice and the doctor that she had did everything but outright suggest assisted suicide to her. He had her so convinced that her body was in the process of dying and that she was dying that after six months in hospice, my mom left hospice to go home to Colorado to die. And we literally set up things for her, set her up in an apartment, set her up with nursing care attendant services, and my mom just literally set and chilled out to die, waited to die. But she had a bucket list and one of the things on her bucket list to do was to get arrested with her kid.

(08:45):

And so six weeks after my mom came home to die, she was getting arrested with me [inaudible 00:08:51] in Washington DC. At that point, she decided I'm not, and she lived almost 12 years. She died February 1st, 2021 of natural cause. It's not even what they said she was terminally ill from. And so that happens often. And then when you get a terminal diagnosis, you would figured that the first thing that you would do is to get some type of mental health treatment because depression is normal. You just get told that you dying.

But as it is, it's very hard for disabled people to get mental health treatment, especially if you need inpatient. The places are inaccessible. Often the offices where you go to get therapy are inaccessible either physically or programmatically.

(09:51):

Oftentimes, people don't want to deal with disabled, especially if you have a communication disability. You use a machine or you use ASL or whatnot. And because of the way that doctors feel about disabled people, our depression gets rationalized. So, if a non-disabled person, a young person starts talking about [inaudible 00:10:23], depression and all, often they will get help even when they don't want it. But when you're disabled, ours is rationalized. "Oh, I could see why you want to die. You're disabled. Oh, I'd kill myself too."

(10:40):

Oh, yes. Therapists say these things to us. Chilling, really messed up case in 2019. Colorado had passed their assisted suicide legislation by putting it to the ballot. Unfortunately, I was in Colorado when this happened. Not Dead Yet, did a valiant effort and each time when it was up, legislature would get, but they put it on the ballot measure and it passed. And there was a young woman who had been peripherally involved in the death. She went on an action. She was in hospice deemed to be terminal, but she survived hospice. She had a neuromuscular condition. She was in a nursing home. She had created a life for herself. She was a licensed pilot. She was like 24, 25. Licensed pilot, went to university and all of this stuff.

(11:50):

When she thought she was terminal, her family came from around the country to visit her, to say goodbye to her. A friend of mine witnessed this, but she didn't die and she graduated from hospice, she was no longer terminal. But somehow she comes by the assisted suicide medication and I get a text from my friend, it is a forwarding of her text. She's saying goodbye to her friend. She had gotten the assisted suicide medication and she was going to die by assisted suicide. So, I got involved with Diane and I asked her, in fact, it was the last question. I said, "Do you have a therapist? What does your therapist feel about this?"

(12:46):

And she said, "My therapist thinks it's fine that I'm tired of being disabled." And she then took the medication and she died. It was reported on her Facebook page the following the day that she died. Her therapist gave her permission to kill herself. And that's what

happens a lot with disabled people. I found myself in a situation where I needed inpatient mental health treatment and often we're seen as liabilities. And so it's hard for us to get that and like I said, they rationalize that. And so with assisted suicide, the proponents, they say this has nothing to do with disabled people, but it does because people who are terminally ill are disabled people as well, protected under the Americans with Disabilities Act.

(13:44):

So, assisted suicide is legal now in 10 states in the District of Columbia. Unfortunately, a few days ago, assisted suicide was passed in Delaware. The governor, they're waiting for the governor to sign the bill. If that happens, this will be 11 states in the District of Columbia. Assisted suicide, it turns suicide prevention on its head. The proponents say that the reason that people want assisted suicide is because they're afraid of pain. They witnessed a family member die in excruciating pain and they don't want that for their family members.

(14:41):

Now, assisted suicide laws, they're like immunity bills and they're set up to protect the doctors and they're set up that there really is very little reporting or whatnot. So, when proponents say, "We don't have not one case of people being coerced into it," that's because you set it up so that there's either no reporting or you can't report it. And the states, they don't have the budgets and the infrastructure to get to investigate those things. They'll tell you that it's all about pain. Actually, there's Oregon data that shows that the top five reasons that people want to assist suicide all has to do with disability related stuff.

(15:30):

It's a loss of autonomy, the loss of dignity, the loss of the ability to do things you could do before. The feelings of being a burden on your family, loved ones, caregivers, whether it's a physical, emotional or financial burden. The loss of the ability to deal with bodily changes, continence, vomiting and whatnot. Those are the top five reasons people want assisted suicide. Pain or the fear of it is down on the list. All of those are disability related situations that can be addressed by better access to home and community-based care. Better access to healthcare and a lot of people don't realize is hidden in assisted suicide laws are expansion of the definition of terminal.

(16:27):

So, if you lose access to healthcare, say for instance like what just happened to me, I lost my insurance. And you have a condition that normally is chronic but without medical attention and all, it becomes terminal. For instance, diabetes and in fact, the Oregon Division of Health used diabetes in its examples. A guy named Fabian [inaudible 00:16:56] from Sweden was looking at doing assisted suicide program and he hooked up with the Oregon Division of Health because he had some questions to ask them. And so he was asking about if people lost access to healthcare, if they'd be eligible to receive assisted suicide.

(17:16):

And the Oregon Division of Health told him yes. And not only that, the law was designed to be inclusive, not exclusive, and so you could even decide, "I don't want this treatment anymore." Stop treatment and then be eligible for assisted suicide. A lot of people don't realize that. As someone who lives with level 10 pain every waking minute of my life, we need to fight for better access to palliative care, which you don't have to be terminal to get palliative care. A lot of people don't realize that.

(17:58):

What's also available and legal is something called palliative sedation to where you are sedated to the point of unconsciousness while the dying process takes place naturally. Because assisted suicide is not end of life care. End of life care is not crushing up a hundred pills in water and taking it and dying. End of life care is getting you all the services and supports and things that you need at the end of life while the dying process takes place naturally, you being made as comfortable as possible and all while this takes place.

(18:47):

And Blacks and Latina folks, 65% against assisted suicide. Especially if you're poor. But compassionate choices, they've been going into Black and Latina communities trying to convince us. They are making inroads. They hooked up with NAACP. Assisted suicide, it's not a right. There was a Supreme Court decision that came down. I know, I went, I traveled across country with Not Dead Yet [inaudible 00:19:20] the Supreme Court decision that you don't have a constitutional right to suicide. You don't have that.

(19:28):

Canada, I live in Rochester, New York. We're about 40 minutes as the crow flies, Canada. So, what's going on in Canada is particularly scary. See, in Canada, they have out-and-out euthanasia. They have their assisted suicide where you ingest the medication and they

have out-and-out euthanasia where the doctor gives you a lethal injection of the medication that went through in 2016. Canada's trying to get it to the point... They stopped, put a stop to it. Canada's trying to get to the point where they offer assisted suicide, euthanasia, okay? Because that's what they have in Canada. 60,000 people have died by euthanasia in Canada since 2016 when it was enacted.

(20:32):

People in Canada are dying because they can't find affordable, safe housing. People in Canada are dying because they can't get treatment for their conditions. People in Canada are dying because they are poor and they can't afford to live while poor with a disability. In Canada, it is law, even on a suicide hotline, you have to offer assisted suicide euthanasia. You have to offer that. The doctors have to tell you about it. And so there's been reports of veterans needing wheelchair lifts inside of their homes. The VA telling them, "Sorry, we can't get you that lift, but we can offer you what they term medical aid and dying, euthanasia."

(21:38):

It's off the chain in Canada. Canada has the most permissive assisted suicide laws in the world and they're trying to bring that here to the United States. They're trying to use the ADA to get people to do that. And assisted suicide laws put people in danger because, okay, there was a 2021 Harvard study done by a medical researcher named Lisa [inaudible 00:22:12]. I hope I'm pronouncing her name right. She got MS in her last year medical school, but the medical researcher, and she did this thing on Zoom. She got over 700 doctors and she positioned herself in the Zoom meeting to where you couldn't tell that she was using a wheelchair.

(22:40):

She asked these questions, did these studies and these doctors were very forthcoming to her. Where you have 82.4% of doctors feel that people with significant disability have a lower quality of life than non-disabled. Only 56% of doctors will welcome disabled people into their practice, or feel that they can treat a disabled patient like their non-disabled patients. Only 18% of these doctors feel that disabled people get treated unfairly. There was a 2022 study that showed that well over 70% of doctors felt that disabled people were entitled.

(23:40):

And so when you have these biases and doctors act on those biases, what do you think that's going to happen? Then racial disparities in healthcare, that means that doctors are definitely going to be more likely to write off a Black patient that's terminal, therefore eligible for assisted suicide.

(24:26):

Disabled people have just been designated by the National Institutes of Health as a population that experiences healthcare disparities. I don't understand why it took until late 2023 for them to make that designation, but it is made. And so in the assisted suicide world, a lot of the things that I'm bringing to the forefront, that I'm being a voice in the wilderness for, here in the United States have not come to pass. But when they made the assisted suicide laws, nobody thought that the insurance companies would start denying people cancer treatment and recommending them the assisted suicide drugs.

(25:13):

That happened to Randy Struppen in Oregon. Stephanie Packard, she was out in California. Her treatment for her lung condition was approved, but then when the law went into effect in California, they told her they weren't going to pay for it. And she figured that it was about money and she asked, "If I get the assisted suicide drugs, what's my copay for that?" Her copay was \$1.20. So, it's cheaper to kill you than to care for you. I met Stephanie Packard and she told me the story personally. I met Dr. T. Brian Callister. Dr. Callister, he's from Nevada, had patients in California and other places and his patients were offered assisted suicide rather than treatments for their conditions, without assisted suicide being brought up. These people hadn't asked for that. This is what they were being given.

(26:37):

So, they're saying now, I saw a Oregon statistic that said 76% or thereabouts of people who requested assisted suicide in Oregon are now on public insurance like Medicaid and Medicare. Because assisted suicide proponents are white, wealthy, well off, higher educated, professional class, wealthier well-off folks. But the people who are requesting assisted suicide, now we're seeing are people who are getting government insurance, Medicaid, Medicare, are requesting assisted suicide. People talk about safeguards and whatnot, and I often get told, "Are there enough safeguards that will make these laws safe?" No, there aren't. "Is there a population that this will help?" No, not help.

(27:45):

A couple of people may get their autonomy issues and whatnot met, I don't know, but there's no carve outs. There are no people. Once you decide that there's a certain group or category of people that assisted suicide would benefit, then you cross a line. To me, assisted suicide, it's unjust because it is going to eventually affect, more horribly affect the people who don't even want it. I'm a big fan of science fiction. I love Isaac Asimov. Isaac Asimov wrote a book back in the day called Pebble in the Sky. In Pebble in the Sky, once you turned 60, you had to go and do the 60, and to do the 60 was you went to a center in your city and you were euthanized. You died. And it was a thing that had a whole culture around it and everything like that.

(28:58):

And if we are not careful, that is... And it was mandatory, you had to do it. If you were caught over 60 and you didn't go to do the 60, not only would you be executed, your family members would be executed. That's the way that was. If you became disabled, you were then a useless eater and you had to do the 60. And if you didn't, even if you weren't 60, because one of the characters in this book was a farmer who's the head of household was in his forties, but he had a farming accident, became disabled in the wheelchair and they were hiding him because he was supposed to have gone to die because he could no longer feed his family. And so if we're not careful, that's who we're going to come to.

(29:59):

And people talk about, they don't want you to talk about the slippery slope or intentional, incremental, but there's always that. So, it used to be you needed two doctors to sign off on a request was assisted suicide. Now it's one doctor and another practitioner such as a nurse practitioner or physician's assistant, or in some cases social workers. Used to be 15 day waiting period between the requests and the dispensing of the medication. That 15 days has gone down to 72 hours. In some cases, 48 hours and in some cases none. Get the medication on the same day. Used to be residents requirements. The state of Oregon and Vermont have done away with their residency requirements.

(31:02):

This is all in the bill expansions. So, they pass the bill through. Pass it, okay. HB so-and-so and so has passed, gets passed, gets enacted. Then they go in and these safeguards are now seen as barriers. We don't want to wait 15 days, so we put in the legislation to now make it 48 hours. We don't want two doctors putting in for that. Make it a doctor and a medical assistant or physician's assistant or nurse practitioner. Oregon no longer has residency requirements. Vermont, New Jersey's trying, and there are states that expanded their legislation this year. Because see here, okay, in 2023, 20 states either introduced

legislation or expanded, put in bills to expand their legislation. Colorado just expanded to legislation.

(32:17):

We just defeated New York's bill, but New York has no residency requirements in our bill. They're going to bring that bill back in New York. Massachusetts, they're still in danger. As I said, Delaware just passed their assisted suicide bill. And so this is getting deadlier, it's getting more and more dangerous because it ties in with the healthcare rationing, the medical discrimination and all. And you when look at, so we were here in New York, we were in a situation where New York had changed its eligibility requirements to receive home healthcare services, making it almost impossible to get services. I just got denied services.

(33:22):

On top of that, they were making cuts to attendance services programs and not able to pay attendant a living wage. Now you put all this together. The eligibility requirement situation, the not being able to get attendant services, the not being able to pay your attendant if you could. Don't you think that if assisted suicide went into effect that this would then push someone to request it? Because see the proponents, they think that we are obtuse, that we don't get it when they say, "Oh, no one's been coerced. You don't have to be coerced. You could be steered, convinced." You could have situations happen that pushes you where you feel you have no other choice but to... Here, I've just been determined terminal, I can't get attendance services, I can't get help getting out of my bed.

(34:34):

My doctor is all shady to me and everything. I don't have no choice. I'm going to make the request. So, you're put in a situation. So, this movement for assisted suicide, it is so disingenuous, hypocritical, discriminatory, and then they want to gaslight you by saying this has nothing to do with disabled people when in fact it does. This is dangerous public policy. The National Council on Disability in 2019 came out with a report on the dangers of assisted suicide as deadly public policy. My work and articles were cited in that report. So, you can go and download that from ncd.gov 2019.

Keith Casebonne (35:38):

Yeah, we'll make sure to put a link to that in our show notes.

Anita Cameron (35:41):

And Florida brought forth, just so you know, probably... It hasn't gone anywhere probably because, and this is going to shock you, assisted suicide is a thing that is prized and wanted by Democrats, liberals, progressives, those people who should be friends and consider themselves friends of the disabled, of the disability community, they are the ones wanting assisted suicide. I end up having to work with Republicans and people who normally would not have me in their homes, who would not normally work with me on anything else, but we come together because we're working against assisted suicide and it's the people who are our friends and allies who are pushing for assisted suicide.

(36:40):

There's a piece of legislation in Congress right now, it's one of the congressional resolutions. Can't remember the number right now, but it was introduced by Congressman Louis Correa out of California who's a Democrat and Congressman Brian Wenstrup out of Ohio. He's a Republican. I've actually met Congressman Wenstrup. He's a medical doctor and he is definitely against assisted suicide. And so they put forth this sense of Congress that assisted suicide is dangerous public policy. But it's a matter of, there's lots of Republicans all ready to sign on to that. We need Democrats.

(37:27):

And that's really, like you would think, but they conflate it with the whole abortion thing, not understanding that disabled people have no true autonomy and so not understanding that abortion is healthcare, is reproductive justice, no matter what I feel personally about abortion, but assisted suicide is not healthcare. It is not. And for us at Not Dead Yet, we are secular about this. We bring the disability perspective on this. A lot of folks, because a lot of folks say, "Oh, you're in with the right to lifers and all of that, the church people." No, we're secular. Whatever the church and the right to lifers have come up and they're coming out against, there are specific reasons why we in the disability community are against this, because we're the ones that's going to be affected particularly with multiply marginalized.

Keith Casebonne (38:52):

Yeah, it's very scary. It's a direction that I don't like seeing our country move and we're is so glad that you're in the fight to try to change things. To sort of wrap up, if you were talking to someone, a young disabled individual who wanted to get into this thing, they want to get into advocacy, they want to get involved in the same sort of work that you've done, what kind of advice would you give them?

Anita Cameron (39:19):

Do whatever you can do and don't be afraid. I looked up all kinds of activism, so you can do activism in all kind of ways. If the only way that you can or want to do it is sign a petition, go ahead, do it. I have a friend, a dear friend, they have been stuck in their home now for over 1,600 days. They do activism from their bed. They're stuck in their bed. He's in his bed. I have seen him do campaigns. I have seen him direct music videos. I've seen him do media stuff. And when I got arrested in Ohio, he was on the media team and he was one of the ones trying to find me because they lost me. When I was arrested in Ohio, they took me on what I call the Freddie Gray ride to hell, because what happened to Freddie Gray in Baltimore, how they did him. They tried to do that to me, and before they finally wound me up at the jail. And they did that all from their home.

(40:57):

You don't have to be out in the trenches. You don't have to get arrested. You just have to have that passion, that fire in the belly, that commitment and have courage. I'm not going to say don't be afraid because two things can be true at one time. You can be scared to death and still have courage. Many times on actions, I was scared to death, but you do what you got to do. Don't let people... Look, you tell people, respect my existence or expect my resistance. Don't erase us people out there because you do erase us at your peril, and that's an Anita thing. You erase us at your peril. You do injustice to us at your peril.

(42:04):

So, if someone is out there, and as far as I'm concerned, the younger, the better. I want to see you out there. I just did a book event with a 9-year-old disabled young man who just wrote a book. My very first protest was when I was five years old. We didn't get lunch that day and I joined a protest. Kids make differences. [inaudible 00:42:44] friend Kyle Glosure at 14 spoke to the Democratic National Convention out in California. Children, disabled children are doing things. I watched disabled children be born and to adapt, grow up, have children of their own, continue to do good things in their community.

(43:21):

Fight, fight for freedom, fight. You might get to that point where... Because for me, I think about that Sweet Honey in the Rock song called Ella's Song, and there's a line in that that describes how I feel and it goes, "We who believe in freedom cannot rest." Sorry, my horrible singing. "We who believe in freedom cannot rest until they come. We who believe in freedom cannot rest. We who believe in freedom cannot rest until they come." And cannot rest, not will not rest. Will not rest implies that there is a choice, cannot rest means you have no choice.

(44:36):

I have no choice. I have to keep doing this. I don't care if I lose hope. I don't care how horrible and how scary the climate is as it is currently in this country. We have to get out there and fight for our lives. Fight because as I always said, civil rights aren't given. You got to fight to get them and then you've got to fight to keep them, and right now we have to fight to keep and maintain civil rights, keep and maintain that justice. We have to fight for justice and rights, fight for justice. Be a warrior for justice in whatever way you can do it. Thanks.

Maddie Crowley (45:35):

Anita, that was a moving and incredibly... I don't know, just like I felt that in my soul and as someone who's involved in disability activism spaces and other movement spaces, it's truly been an honor to get to speak with you and meet with you, and I just know that everyone listening will be impacted deeply by your stories that you shared with us today, the impact that you've had on everybody within the disability rights community and that impact is going to be felt for or generations and generations to come. So, I truly appreciate your time that you've shared with us today and that beautiful sendoff message and we will talk real soon.

Anita Cameron (46:35):

Thank you so much for having me because it really is, it's an honor. We have to, especially in this climate of making histories illegal and banning books, and it is even more important that we put it out there, that we tell of the stories of the people being in the trenches, that activists that we're out here telling our story while we'll [inaudible 00:47:19] before we become ancestors. It is definitely, it's my honor, it's something that needs to be done and thank you so much for having me.

Keith Casebonne (47:32):

We're honored to have you as well. Thank you so much to Anita for being our guest in today's podcast.

Maddie Crowley (47:34):

Yeah, seriously. Thank you, Anita, so, so much for sharing your wisdom and experiences with us. And for those who are interested, of course, we have a list of the various things we mentioned in the podcast in our episode show notes for you to peruse and explore to learn more about what we discussed.

Keith Casebonne (47:51):

Yes, indeed. So, be sure to like, comment and subscribe wherever you're listening. We are on all the major podcast platforms and the recording and transcript are also available on our website.

Maddie Crowley (48:02):

Yup. And as a reminder, please take a minute to select us as a podcast winner. It would mean so much to have your help. Again, you can find the information in the show notes or wherever you're listening to nominate us for a People's Choice Podcast award. Lastly, if you have any questions or comments about the show, please email us at podcast@disabilityrightsflorida.org.

Announcer (48:23):

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(48:49):

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