14. Chronically Overlooked

**Bridget**

On New Year's Eve 2019 award winning journalist and disability advocate Zoe Simmons watched her hometown of Batemans Bay on the New South Wales south coast burn. She is now writing a book about her and her community's experiences of the black summer bushfires. I'm Bridget McArthur. This is Chronically Chilled.

And today we are so lucky to be joined by Zoe for a special Disability Day episode to discuss climate change and the many ways it disproportionately affects the disabled and chronically ill community. Thanks so much for joining me, Zoe. Where are you chatting to us from today?

**Zoe**

Thank you so much for having me. I am currently in Wurundjeri country in the Kulin nation in Melbourne.

**Bridget**

And to kick off with, I'd really love to hear a bit about your own experiences of the black summer bushfires of 2019. Especially coming up to three year anniversary.

**Zoe**

Sure. It’s wild that it was three years ago because it doesn't feel like that. It doesn't really feel like time has passed at all, but it does at the same time. So it's a really, really interesting experience I guess, of trauma. So, in 2019, I went back to Batemans Bay, which is where I grew up, and it's where my mum lives. I was going back for New Year's Eve. It had been a long time since I've seen her.

I really, really really needed to see her. And unfortunately, we got caught by bushfires, I woke up the morning of New Year's Eve to fire trucks in my street and birds flying and screeching away and red skies and living smoke.

And it was just such a terrifying experience. And the embers were not even supposed to reach us, not even the embers, let alone the actual fire front. So it was just a shock waking up that morning, checking the app and seeing how far the fire had spread overnight without anyone really being aware necessarily.

**Zoe**

And it was a very scary experience. And we didn't have power. We mostly didn't have reception. There were some random pockets. There was still reception, but everything was on fire. And it is not a fun thing to see everything you've ever known, go up in flames, basically.

We ended up evacuating, that was just a really horrible experience, of preparing the house and thinking “oh, if I don't do this, my stepdad who's staying to defend it is gonna die”. It's just not something I'm ever sure you can fully understand. Unless you have experienced it or you've read lived experience accounts.

**Zoe**

What you see in the media just does not convey what it's actually like to go back and to know people who died and to know that many of your friends are homeless because the fire caught them unawares. It wasn't a normal fire. It's what all the firefighters I've interviewed tell me and yeah, we just get forgotten. As soon as COVID here showed, we were absolutely forgotten. And I think every natural disaster gets the same thing.

**Zoe**

That people forget, as soon as there's another hot story. People move on. But the people impacted by it are still suffering, we still have people that are living in tents, living in caravans, that are still fighting with insurance, that are still coping with the trauma of losing everything. And even people that have been able to get houses. They just they tell me that nothing feels comfortable because their whole lives were taken.

**Bridget**

Yeah, we all have seen those images of some of the events on the day, but we're not really seeing many images of the longer term effects or how the community is building back. And your book, I'm guessing is kind of your own attempt or contribution to trying to make sure those stories live on. How has it been collecting some of those stories from the local community?

**Zoe**

It's been really hard. Especially as more time passes, being disabled myself living with chronic pain and chronic fatigue, it is really hard to exist. Unfortunately, my work currently doesn't provide me income, so I have to do other work as well so I can live and I feel a lot of guilt that I haven't gotten these stories out sooner.

**Zoe**

But it is a really traumatic topic and it's traumatic for me in my own stories. It's traumatic for me, right and basically living other people's experiences. But I think it's really important, I noticed that there was no real information in the fires. Even the Fires Near Me app in New South Wales wasn't working. So there was no information on what the fire was doing or where it was going or where we're safe.

And the roads were blocked off by flames so news outlets couldn't come in. So I started sharing what I was experiencing, sharing what I was seeing, sharing what people were safe. Because a lot of people had loved ones in the area, and they couldn't get in touch with them, because no reception, no internet.

**Zoe**

So when I did have those pockets of reception, I shared as much as I could. It helped a lot of people to know okay, this place is safe to go to. And if your loved one is here, they are okay. It is okay if they are here. Because a lot of people didn't hear from their loved ones for days. And it was just such an extraordinary experience.

And I just kept thinking that thousand word articles just couldn't capture it. And that's what I was initially doing, writing my own experiences, one of which I actually wrote by hand and then used my laptop's last few minutes of charge, to quickly type up the fastest article I've ever written in my life.

**Zoe**

Plus driving somewhere with reception, hotspotting my phone, and then sending it off to an editor. But after the fires, I just kept writing stories to raise awareness. To help people feel like they weren't alone, as well as to raise money. I put a lot of fundraisers in the articles I wrote to try and help people. And I think it did. I ended up raising $30,000 or something. I mean, it's hard to know if that was directly my impact, but I at least was able to share those stories and those fundraisers was big audiences.

**Zoe**

But I just kept thinking that it just wasn't enough. And there was so much of our experiences we just weren't seeing, I just kept thinking, it can't all be for nothing. So I decided to write a book, I've always wanted to write a book. But when I had this idea, I just felt this blast of creativity. And I just knew I had to do it, I just knew I had to capture these stories.

**Zoe**

Because people in cities who have never experienced these things, they don't get it. They don't know what it's like to see everything burn. And they're not impacted by it. It's easy to turn a blind eye when it's not affecting you. But it does affect a lot of people. And it's not a matter of if this will happen again, it's a matter of when.

**Zoe**

So my book is sharing the experiences of people who feel forgotten. Sharing the fact that we have been forgotten over the last couple of years, as well as my own experience as a disabled journalist, grappling with these feelings and traumas. And finding out that someone you went to school with passed away was pretty rough.

**Bridget**

And probably pretty resonant for a lot of people going through the floods at the moment. Obviously, it's a different kind of natural disaster. But a similar thing in terms of it being quite hard for people who aren't there to fathom what that's like.

**Zoe**

Absolutely. I've never lived through a flood of that scale. I have through a bushfire and it just changes you and you're just in this constant state of fight or flight and nowhere feels safe. After I came back from the fires and came back to Melbourne, I couldn't leave my house because I was convinced that it was going to catch on fire.

**Zoe**

I couldn't function if I heard sirens, even the colors, red and blue. Or hearing helicopters overhead. All of those just brought me straight back into the evacuation center and the memory of looking up at the cliffs before me with the black smoke and that if the fire came, we run into the water behind us. Those are things that most people don't have to even ever think of. So when you've been through a fire or a flood, there's things that just don't feel real, but they are and it does stay with you.

**Bridget**

You're listening to a special Disability Day episode of Chronically Chilled, I'm speaking with a journalist and disability advocate Zoe Simmons who experienced the Black Summer bushfires firsthand in her town at Batemans Bay.

So you live with fibromyalgia and undiagnosed adenomyosis, if I'm pronouncing that okay, and bipolar and anxiety. How did you find that? I guess your disabilities and chronic illnesses affected the evacuation process, but then also how has the kind of experience of that trauma also interplayed with your disabilities in the longer term?

**Zoe**

So at that time, I did really diminish my disabilities and the impact they had on me. I didn't have a diagnosis of fibromyalgia back then. So I didn't really know what was happening to my body. I just knew that I was in a lot of pain, that I experienced a lot of fatigue, that my hands and legs would go numb quite regularly.

And it just wasn't a fun time to exist. So that morning, the night before, I remember feeling so anxious about everything and anxiously checking checking the app and it was early hours in the morning and I didn't end up getting much sleep that day because my mum knocked on the door and said "hey, there's a fire we have to we have to get out".

**Zoe**

So running on low sleep is not good for anyone, especially when you have chronic pain and chronic fatigue. But that morning, the adrenaline just kind of eradicated everything. For me. I didn't think about the pain. I didn't think about the fatigue until a lot later. And in that moment, it was just, go go go go.

Okay, pack the car. Okay. Are the dogs in the car? Do we have our documents? Do I have the stuff that my dad and pop gave me before they passed away? Have we closed all the doors and windows? Are their wet towels on the window seals? Are there containers of water around? It was just go with me the whole morning. Although there one was one moment where I had a pretty major freakout.

**Zoe**

My mum has quite a large garage underneath her house, and she was storing timber furniture for some people. And the back door is an old wooden back door with cracks in it. And as part of me going through the house and trying to prepare, I kind of broke the door. And I just was like "Oh god, the house is gonna burn. And it's my fault because I didn't close the goddamn door".

The struggles of thinking if I didn't prepare the house correctly, it would mean that someone died. Or thinking that if our house went, then other houses would go, so it'd be my fault again and other people in my neighbourhood lose their homes. And obviously, they're not logical thoughts, but they were the trauma thoughts I was having in that moment.

**Bridget**

And I've heard that there is a thing called "bushfire brain" which is actually like the literal sapping of oxygen from the air, from the bushfires, that literally was causing people to not be able to think straight on top of the stress.

**Zoe**

I mean, yeah. I remember having such bad headaches, just from not having clean air to breathe. So that was also another thing to tack on to everything and just feeling so sick. But most of that morning was preparing and getting to the evacuation centre. My disabilities thankfully behaved, because they were just kind of destroyed by adrenaline. But later on I did notice how sore my body was. But even at 3am the next day, I was still pumping full of adrenaline.

**Zoe**

I just didn't think. I didn't pack my medication, for one. I didn't think of packing food and drinks. I didn't think of packing somewhere to sleep. So by the time that things started calming down a little bit and we weren't in imminent danger.

I didn't have any of the things to help me manage my body which was not great at all. That was probably the most uncomfortable night I've ever had. I just had, my partner and I had his car. Which is a two seater tradie ute. And we first tried sleeping inside the cab because less smoke. But it was so uncomfortable. Like you can't recline. And I remember we tried to fall asleep on the tray in the back.

**Zoe**

Even in the evacuation centre. I'm really grateful that I had the capacity I did back then because I struggle a lot more with mobility now. And unfortunately, the places they put the information and all the food was upstairs. So you couldn't get upstairs, you couldn't get that information or you couldn't get food, someone would have to bring it to you. And while the stairs did hurt me to go up, I was able to go up there and sit there.

**Zoe**

And I remember feeling the cold metal and not having pillows, I think we're laying on shoes or something with a drop sheet over us and I still couldn't sleep, I was still so tired. But I was awake, but stressed and you'd see the updates coming through.

And I saw that a person I went to school with had passed away. Seeing all these houses lost, and all this information. And then also at the same time, seeing so many people in the cities with fireworks or celebrating and just felt worlds and worlds and worlds apart.

I just didn't really think of anything. I kept thinking of the firefighters that were risking their lives and diminishing my own self. That did have the impact of then, when my body calmed down eventually, feeling just very, very, very sore. The impacts still affects me now. I don't ever think I've necessarily gotten out of that adrenaline rush.

It kind of always feels like it's there. It always feels like you're in fight or flight mode or looking for danger of the next natural disaster. And that did significantly flare my pain when I got back. I had to take time off work. I just really was not well, and I think that's part of why I started writing the book. Because I just needed an outlet to express that. And a place for people who felt like I did. So I wrote it.

**Bridget**

And in writing your book, have you come across any experiences or documented any experiences of others, who were living with disabilities at the time?

**Zoe**

So a lot of people have had mental illnesses and conditions like that. So that is a discussion I've had with some people or even if they didn't, beforehand, they have trauma. Now a lot of people are coping with PTSD, for example.

I did interview, another wheelchair user, electric wheelchair user, and they're actually radio hosts down there. So they had a really good insight into what was happening in that part of the world. And what it was like using an electric wheelchair.

They drove their electric wheelchair to work instead of driving, because the roads were so blocked, and there was no fuel anyway. And where there was fuel, there wasn't electricity. So if you didn't have cash, you couldn't pay for it. And the lines are so, so long.

So this person ended up saying that it was much easier just drive the wheelchair in. But also electric wheelchairs do you need battery power, and you need electricity eventually, for that. They do last quite some time, at least the ones I've used. But there's so many things that people don't necessarily think of. That person wouldn't have been able to go up and get the information upstairs. I just don't think it was really considered for the most part.

**Bridget**

Yeah, absolutely. And I mean, you're seeing that on the wider world stage as well. I mean, this year was the COP27. And it's been over a decade since I think the Cancun Agreements, which landmarkedly identified people with disability as disproportionately affected by the climate crisis.

**Bridget**

But since then, the Paris Agreement, and the Glasgow Declaration, barely referenced it. And it never really seems to be high up on the agenda in terms of, for example, the recent Victorian elections or federal elections. I mean, have since become more engaged in the global discussion around that intersection? How are you seeing that develop?

**Zoe**

I think disability is definitely forgotten, for the most part from pretty much everything. So it really doesn't surprise me that disability is being left out of the conversation, particularly when it comes to natural disasters and climate change. I feel like we often don't exist for the non-disabled community, because we aren't represented and our views aren't represented for the most part. That is changing.

But it's still a huge, huge, huge divide. And honestly, in all these years, I've heard so many people talking about the bushfires, and the number of people talking about disability, as well. I've only heard one person talk about that once. So compared to the hundreds, probably thousands of people talking about it in general, it's never looked at through a disability lens, because nothing ever really is unless we, the disability community do, or our allies happen to help us.

**Bridget**

Drawing the parallels to the floods again, I mean, I hadn't even thought about it till now. But I haven't heard anyone talking about disabled people's and accessibility during the floods.

**Zoe**

Yeah, like what are you supposed to do if you don't have mobility and car? I don't know, jump on a boat? I mean, I'm not really sure about floods. But I'm assuming if you know that the floodwaters really high, you have to be able to get onto a boat or get somewhere and even having things like not having power, not having internet, not being able to access your community.

**Zoe**

Having your medical appointments disrupted, not being able to get your medication. I know that was a problem in the bushfires, because I couldn't get the medication, people forgot it, it got burnt. All these little things that no one really thinks of, because they feel like disability doesn't affect them.

But the fact is, it does affect most people. Even if you're not disabled, the things that benefit the disability community benefit the non-disabled community to access to medication, access to food, access to electricity. It's just these things, obviously impact disabled people more, because it's not as easy to just function without them, obviously, depending on what disability you have as well.

**Bridget**

I'm speaking with a journalist and disability advocate Zoe Simmons who experienced the Black Summer bushfires firsthand in her town at Batemans Bay. Zoe, how has the rebuilding process been, particularly from a kind of disability perspective?

Do you feel like that has seen the accessibility of the town decrease because of destruction of previous accessible building features? Or do you think in some ways, it has been an opportunity to have discussions around that and create more accessible planning?

**Zoe**

I'm honestly not too sure in terms of accessibility being changed. One of the places that burnt down, were residential homes. I think there were some factories, so they weren't the main thoroughfare of the town, for example, which is somewhat accessible, at least by the fact that it has pathways that are flat and elevators. It's not terrible for accessibility, but it's not great. Again, I don't necessarily even think these conversations like disabilities have been considered. Again, it's just not something people think about.

**Bridget**

And it's interesting as well, because potentially, I mean, disabled people could be, as you say, contributing a benefit for all. Because they're experts at the forefront of getting creative with, flexible, adaptive solutions.

I know that some people have talked about disabled people long before the pandemic, we're talking about adapting to working from home and making that more accessible. And if we listened to them back then, then we might have been more prepared for those kinds of accessibility requirements when we all needed them.

**Zoe**

Yeah. And they benefit a lot of people, disabled or not. Yeah, exactly. It's everybody.

**Bridget**

As a journalist yourself, and advocating for the disabled community, what do you think the power of words is for creating change and healing post crisis?

**Zoe**

I think words have so much power. And they really can show you what it's like to be in a situation. It shows you how that person felt, it shows what that person thought, it shows how it impacted them. And it humanises it. And I think that is so important, because it's so easy to ignore these stories when they don't necessarily have a human face. And when you give that personalised story, it makes people stop. It makes people think, it makes people feel. And I think that is key in creating change.

**Zoe**

Because I do think most people want to do good. Most people want to make things better for the disabled community. I do believe that most people want to do better. But it's not always the easiest to do that, especially if you don't know what exactly to do.

So I think by providing these stories, where you share these experiences, specifically from a disabled lens, it can be so powerful, because often these are perspectives that people haven't considered at all, even the non-disabled stories I have in my book, for example.

**Zoe**

Even though stories are so incredibly powerful, because without those words, they wouldn't have been told. And I think words are so powerful, especially in terms of trauma, because you can take that dark experience, you can take the fear, the trauma, the guilt - everything that comes along with those experiences, and you can create it into something beautiful and into something powerful.

**Zoe**

And that is why I write anything, in terms of my disability advocacy, in terms of my copywriting in terms of my book. I think it can really, really make change. And I really want to be a part of that in various forms. I've done that as a journalist, I do a lot of speaking and media gigs now and hopefully one day, we'll be able to get my book out.

I'm hoping that an agent or publisher will see the value like I do in these stories, because I keep getting told that "oh, it's been too long. And no one cares about these things anymore”. But I don't agree with that. And the feedback I've been getting from my communities are that this means so much to them, that someone is still fighting to have us be heard.

And it can feel really isolating when no one understands, and adding disability to that as well as, an extra level of I think grief, that you just don't understand, unless you've seen those experiences or felt them. So I hope I can help bridge the gap between that and make whatever kind of difference I can.

Whether it's just raising awareness that these things happen and they will happen unless we do something. Whether it's showing that yes, people with disability are impacted by this at different levels to non-disabled people. And showing that it's okay to feel traumatised by these things because they are traumatising.

**Zoe**

You're allowed to not be okay, you're allowed to need help, you're allowed to still not be healed. I mean the landscape may be starting to heal, but I don't personally feel healed. And I just want people to know that that's okay. No matter what stage you're at, in this. It's all right. And just having people bear witness to our pain, and to our trauma means the absolute world. So I do hope my words can help, and at least help people feel like they're not alone.

**Bridget**

Absolutely. And apart from any publishers listening too, to reach out to you, if you could give one action for the audience to take away today? What would that be?

**Zoe**

Honestly, I just like people to think about disability, and that it exists and that it's often not visible. So you can't tell what someone's access needs, or what how they're feeling or how their body functions just by looking at them.

We need to really change this perspective of visibility and increase representation. And in terms of climate change, we need to look after the planet, we need to make sure it's okay for future generations. So it's not their burden to bear.

And I think also as part of helping manage the potential impact of bushfires, for example, we need to do bush management, we need to let First Nations people do their thing with their cultural burns, because they survived many, many, many, many, many years before white people came.

And we just need to listen to other people and consider other people and know that this does impact a lot of people. And it will keep impacting a lot of people. There are so many stories that you do hear. But there are even more stories that you don't.

And I think it's everyone's duty to bear witness and to learn and to do better in all areas of life, whether it comes to natural disasters, whether it comes to climate change, and disability and accessibility in general. We are just not thought of.

**Bridget**

Yeah, absolutely agree. Listen, I think is a perfect, perfect message to end on. And that's what we're trying to do here at Chronically Chilled as well. And I hope that the audience really enjoyed listening to you today. So we thank you so much for joining us. It's been a pleasure.

**Zoe**

Thank you so much for having me and thank you to anyone listening and bearing witness.

**Bridget**

If you're interested in finding out more about Zoe's work you can head to zoesimmons.com.au. If you are interested in finding more Chronically Chilled episodes or if you missed some of today's episode, you can head on over to 3cr.org.au/chronicallychilled or wherever you get your podcasts. You can also find us on Instagram at chronically.chilled and on Twitter at chilled\_3cr. Playing us out today, we have our new Chronically Chilled theme song which was put together for us by a local musician Connor Black Harry, thanks for listening.

**Voiceover**

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