

# Enabling Technologies : Video 3

## Transcript

I'm a huge fan of assistive technology. I spend a lot of time kind of researching new AT. Because it just makes such a difference to my quality of life and what I can do. There's kind of two big categories of assistive tech that I think have the biggest impact on my life. One is the technology around that lets me use my computer. And that's from quite high-tech things that are built into the operating system and all the way down to sort of very low-tech gadgets that I have that help me use the computer. And once you've got access to the computer, you can just do so many things. Social media, but also, you know, you can take online classes, you can collaborate with people on things, you can do blogging, you can do your online banking, you can manage your NDIS funds.

There's just a whole world of stuff that having access to the computer enables. So, all the AT that gives me good access to the computer is really vital. And the other big category is home automation, the stuff that lets me turn the lights on and off, to open and shut the curtains, turn the air conditioner on and off, without having to get out of bed and go to the switches. That's just really life-changing in a much more physical way. And I'm super glad that that's really accessible and easy to use now. Now, we're in the situation where you can just pop down to the Apple store, or get on the Internet and buy some light globes that you control with your voice, via something like Alexa or Google Home, or your phone that you've already got. I've got some fancy bits and pieces, like curtains that I can control to open and shut. And there's a little fountain in the corner of my room, that I can turn on and off.

All my lights, I can turn on, the CPAP breathing machine, that's in my bedroom when I'm in there, and the humidifiers and there's a fan that I can turn on and off, a couple of other things. And my air-conditioner, which is really big. So, in summer, being able to close the curtains and turn the air conditioner on, that's a really big deal. That just has a huge impact on the amount of time that I can safely be by myself without a support worker around to do those things. So, it's great for independence. And also just reduces the load on the support workers, if I'm not asking them to do silly little things like turn the lights on and off. Then they can do other things that I value more, which is much better use of their time. So, this is one of my favorite pieces of assistive technology, partly because it's super useful, and partly because it's super unexpected. So, as you can probably see, it's a drumstick. It's a drumstick for a bass drum, I got it on eBay for \$10 or something like that. I've added a little hook here, so I can hang it on the headboard of my bed and I use it to push and pull my computer screen, so I could easily turn the computer screen around, to show people what's on it and I can adjust it, if I've moved around in bed a little bit, so it's very handy. It's also very good for hooking things that are on the little trolley behind me. If they get a little bit too far away,

I can just hook them back towards me, within reach. And if my cat's being super annoying, I can get him to get off the trolley by poking him with it. Which I do actually do. Yeah, this is called a hydrant, and it's great that I can have water, it's super easy, within reach. I used to have to bite on the end a little bit to drink it, which is very easy to do and I don't have to have the strength in my arms to pick up a cup and also, because it's reusable, it's a bit more environmentally friendly, than having straws all over the place. So, it was more expensive than having straws all over the place, unfortunately, but that's the way disability works. This is a little call bell. So, when I press this, there's a light that lights up in the kitchen and it plays a little

song. So, it's actually modified from a wireless doorbell, but it means that if the support workers are in the kitchen, doing something noisy, like the dishes, or they're frying something, and they can't hear me calling, then I can just ring a bell and they know that I need them. So, there's also another button in my other bedroom, so that I always have one near my hand. This is a standard Apple track pad. I added Sugru bumpers, on the corners of it, because it gets dropped over the edge of the bed quite a lot. So, this way, when I drop it, it doesn't break.

My experience is, they last about ten times as long, when I put the bumpers on them, which is a very large amount of money saved. And also, I've made a little harness out of string for this track pad, because when it's dropped on the floor, then I can't use my computer. And so, the string is attached to my bed, so that I can, kind of hand over hand, pull it back up when I drop it now. It looks faintly hilarious, but it's actually super functional and it means, again, for the times when there's no support worker available, I can not worry about dropping it on the floor. When I was first bed-ridden, was around 2000, so I had access to the Internet, but most people didn't have access to the Internet, and even for us who did, there wasn't social media. I had a blog and we had emailing lists, and some other things, but there was no social media and mostly no photos. All the things were mostly just text and it was a lot more isolating than it is now.

Having social media has just, it's just life-changing. A lot of my family now are on Facebook and I get this endless stream of photographs of my nieces and nephews and photographs of my friends doing stuff, and my family doing stuff and I'm really cut off a lot from that, by being disabled, so I like a lot the minutiae of things that people whinge about on Facebook. I love when you post photos of your lunch, it's fantastic. I wouldn't get to have lunch with you, so like that let's me into a piece of your life that's otherwise, is just not accessible to me. So, like, yeah, I love that people post really small things about their lives. Pictures of their kids, pictures of their pets, pictures of their lunch, they're all great. I love them all, please keep doing that. Live streaming is really kind of a double-edge sword for me. On one hand, when it works properly and my body cooperates that day and lets me watch it, it lets me kind of watch something that everyone else is participating in, which is great, because otherwise I wouldn't have any access to that thing at all. But also, it really kind of rubs it in, that this is a thing that all my friends are together at, whereas I'm lying here all by myself, not at the thing, which can be even more isolating, than just kind of pretending it doesn't happen. And also, I find it quite difficult to watch video.

It takes a lot of energy for me, so it only works for me on a day, when kind of everything comes together well with my body. So, often I'll plan to watch something on a live stream, but then I just won't be able to. Or I'll just only be able to watch ten minutes, often that's even more frustrating. If something's only just barely out of reach, it hurts more sometimes. It is a double-edged sword. It highlights all the things that I'm not at, reminds me of everyone's birthday parties that I'm not able to go to and all the things I'm missing out on. But, just, on balance, I'm very glad it's there and there's a huge bunch of things that I can do with social media that otherwise I couldn't do. A lot of activism about being bed-ridden and home bound and educating people and connecting with other disabled activists and connecting also with policy makers and journalists, and film makers and other people that can help me get the activism message out there. That's a really great, it enables me to then be more productive.

I really feel like people are becoming more aware of things, of the issues around being bed-ridden and home bound. Because I'm sitting on Twitter and sitting on Facebook and commenting on things and pointing out the relevance of that to people who are bed-ridden and home bound, and also again because of things like Twitter and Facebook, I find about things like government consultations and I can't go to the

consultation meetings, or workshops, but I can ring them up and say, hey, I want to have, I want to have some input here and they'll find, often they'll find a way that I can put some input in, even though I am not able to do it the regular way, which is really great. So, I think like I've done two of those in the last couple of weeks. And it feels like, I feel like the things I'm saying are different to the things that almost anyone else is saying, so, I feel like it can make a real difference.