

RCPCH and Kizmed podcast | Pill swallowing in children

Episode 4: Daniel's story

Full transcript of podcast 2022

RCPCH: This podcast is brought to you by KidzMed, a programme set up at the Great North Children's Hospital in Newcastle. And by the Royal College of Paediatrics and Child Health.

Emma Lim: OK, so today I'm very excited that we are going to talk to Daniel. My name is Emma Lim. I'm a general paediatrician at the Great North Children's Hospital, and we're here to listen to Daniel's story about learning to swallow pills.

Daniel: I'm Daniel. I'm 14 years old, soon turning 15. I have been diagnosed with a spinal cord injury. So, it's been 7 months since I've been in hospital. About eight months ago, I was diagnosed with transverse myelitis, an auto immune disease, which changed my life in a sense. And so, it's been a bit hard. It's been a long time in hospital. But I also quite like music. I like, um, sport. You know, that's kind of what I'm into as well.

EL: That is really a lot of stuff to go through in seven months, and actually I think you're being really modest because you were a really good runner, weren't you. So, you did a lot of running, you won medals and you've actually recorded your own raps already, haven't you?

D: Yeah, so I am, I was, I think it was hard, especially as a runner, like right now before I was watching the Olympics. The 5K and the long distance and it is one of my favourite things, but it is quite hard. You've got to just move on and you've just got to see and open yourself up a different kind of sports. Like I have just found different sports and music helped me a lot during my time in hospital. I have just been to a studio where I recorded songs and I'm very grateful for the opportunity. And it's just lets me express myself. But I think it showed that it's not the end of the world, if you have, like an injury of your own wheelchair and stud like that. You just can open yourself up to so many different things. It is different now and I've got to just look to the future and just forget about the past. And there's nothing more. As long as I'm happy, as long as I can enjoy myself, that's the main thing. I mean, just got to do it differently really.

EL: The thing that comes across so strongly to me is you've got this incredible mental attitude, you're really resilient, you're really able to see opportunity and see how you can change or adapt. And one of the things that we were going to talk about today was how you found it learning to swallow pills, because I think that was something that when you went to hospital, you did not had to do much? .

D: My parents had said quite a few times to me, that out of all people it would be me that would get ill! Because, you know, I was the least one in the family who never got ill. I didn't even need to regularly get like a paracetamol pill or anything. I'd never even had in my mind that I need to swallow a pill in my life. I probably swallowed one pill in my life. And then it was that transaction, when you're in hospital, and I'm still on to this day quite a ridiculous amount of medications. I've had a relapse, so it's been quite hard.

Especially when I first arrived in hospital and they were like, 'oh do you swallow tablets?' And I said, 'I'll have to have liquid medications as I've never swallowed a tablet in my life'. And I was

on liquid medications for about a month and it was traumatising literally, and it's all I can think of. So, when I was the back in my hospital stay, they ask me what is most important, what's made the biggest change to me? What's made the biggest change is definitely swallowing tablets because I used to get huge side effects from the liquid medications and now with tablets, I can just swallow them every morning and, you know, I don't worry about the medications, despite the fact I'm on a ridiculous amount medications.

Looking at how much I had to take, liquid-wise, it would be horrible now. I think if people know the taste of the liquid medications, it isn't good and it's less effective as well. And now it's much easier, even if I have to swallow sometimes 20 pills in the morning, it's just, I always feel grateful that I'm not on them liquid medications. It was really important. Despite how much physio and all these brilliant changes and improvements I had in my condition, I still look back and think that taking pills, because I'm going to be, I'm on medication for life now. So, I'm going to be taking pills the rest of my life and if I didn't learn to do it, what would it have been? Where would I be?

EL: So, you said to me about having to take really large volumes, it tasted disgusting, you had a lot of side effects. What kind of side effects were they?

D: So, I was on really strong medication because I have an autoimmune disease. In spinal cord injury its different effects. So early on, I was in quite a lot of pain. So, they gave me a lot of strong, strong, strong pain like Oramorph and Gabapentin type of medications that were really strong. So, they would have quite a bad taste inside the liquid medication. But then it was also bladder medications because I had issues with my bladder. You know sometimes take bowel medication, different stuff like in a spinal cord injury, spasms. So many different things, it's like so complicated. It's not just the pain itself. And then taking so many for pain as well is ridiculous. And then of course, the steroids, you know how would I be able to take them? I can't take them liquidly. And steroids I've had to take two sets of them because.

EL: And we met somebody in one of our previous podcasts who was really important to you. It was one of the pharmacy technicians, do you remember?

D: Is that, Lisa?

EL: Lisa said you've been really nervous and worried about learning to swallow tablets. And then she came to see you. Do you want to tell us what happened?

DA : When I first, when they tried to try me on taking tablets early on, I don't know if it was a swallowing issue because I had had problems of swallowing. I couldn't really speak a lot early on, but, um, I choked a few down. It was not very, it's not very comfortable and um, and that stays on your mind. And then when they came and said, you know, they're going to make you learn to swallow tablets in just like less than an hour, I was like, no way. There's no way this is possible. So, when she came in and by 30 minutes, I was swallowing the biggest tablet possible, and I never, I couldn't believe it. I was like it was, it was unbelievable. And then the next day I was on medication. I started to see a big impact in my recovery, actually, because that switch when I was in liquid medication makes me so drowsy in the morning and I wouldn't be able to interact with physio, interact with school. I had I start to notice less pain. It was just so much; it was such a big change. And it meant a lot to me.

EL: That's amazing. So, 30 minutes of work swallowing a tablet and the next day, the very next day, you already noticed the differences that you weren't drowsy. That you don't have to take these nasty medications. That actually because you can concentrate, everything else improved.

D: It was so important for the physio as well, because every morning I had physio but if I was asleep I just couldn't interact with them (And of course, I've got a lot of credit to physio because that's how I managed to do so well in the movement side of things). If I was still on liquid medications I would be drowsy and I wouldn't be able to interact with physio and once I was taking tablets and I was interacting more with physio and I was able to get my movements on the recovery back and I was able to start working with them. It was so important.

EL: I don't think people realise what a difference it makes. So, when Lisa came and she said that you were brilliant, if somebody else was listening to this podcast, what would you tell them? Explain how you learnt to swallow pills and what it felt like.

D: First thing I think is if someone, even for a week, has been on liquid medications (for me, I was on medications for a month) even a little bit of liquid medications, they'd be immediately determined to take tablets because they know, oh, my God, this tastes disgusting. In terms of the actual process, it's just you just need to put the tablet in. But I think inside it's the main determination and knowing that you can actually do it. You just got to give it a go and put the tablet down, in your mouth and just try drinking it down and it'll come, and it'll make a massive difference.

But I think if someone was on liquid medication and they did not know how to take a tablet before and they would on liquid for a period of time, they'd get sick of it, they'd notice and they'd be very frustrated. And I think it would bring a lot of determination inside you. And if you had a determination inside, you can get anything. You can get the job done. And that's what I managed to do. But all credit definitely to Lisa, because she gave me the confidence because I had not taken tablets ever! It was really, really, really good to be able to do that and to be able to try and get to the hardest tablet in just thirty minutes. It's incredible.

EL: I think that you've put your finger on something really important. The process is actually really easy. You literally put the tablet in the middle of your tongue, pick up a sports cat bottle, take three sucks and the tablet goes down. That's not the hard part. It's what you said. It's the belief. It's the worry. Can I swallow it? Is it going to be difficult? What's going to happen if I don't? And it's your determination and the people who support you to learn around you to get over that hump. That's the actual hard thing. It's just like you say, it's the belief that it can be done. I think a lot of people are very anxious or worried about taking tablets.

D: Yeah, you could be worried because I was worried, and I can understand that. But if you keep imagining the fact that, oh, I'm not going to do this, I'm not going to do this, you're not going to do it, simply, it's not it's not going to work for you. If you start to just realise it's possible and you're getting closer, you're going to see improvement. You need to stay positive. It's going to come. Keep trying. It will go down because the actual process isn't that hard. It's about what's inside you. And then for me, what determined me was getting off the liquid medications. And even when Lisa came and taught me, it wasn't that hard, really, the process itself. It is just about what is inside you and what you can do to do it.

EL: Such a life lesson for everything, and that for me is why you are so brilliant, because you have in a determination and that belief, so you will do things just like you said. So, we've talked about how you realised from being completely well to having seven months in hospital. From being a person who'd never taken paracetamol to a person who has to take medication every day of their life, you suddenly realised how important the skill of pills swallowing was. You've told us about how it's actually easy to learn. And what holds people back is something about believing you can do it and being confident.

D: And then you know what as well, even when I was on lots of tablets, I used to get me quite low even because the amount of tablets I swallowed. One time, I literally counted in the morning twenty-six tablets and I was quite like, you know, it brings you down. But I always look back and just say, you know, the worst is liquid. And gradually you get lower, lower medications and then you start to realise, oh, you know, you start to forget about your illness in a sense because you're on less medications. It shows that you're getting better when you are on less medication. I think that's really important as well.

EL: I think that's really, really interesting, because my background is that I have worked with children with HIV and the liquids are so disgusting, you literally can't take them. So, we had to teach children about, from the age of four, to be able to take tablets. And I think that they had a very similar story to you. Taking medicine every day reminds you, you are all. It's always there. It's just a reminder things are not right or you're different. And so, the quicker and easier

you can do that allows you to forget that bit. And lots of people take vitamins and pills just regularly, so swallowing a tablet quickly in the morning, like mom saying 'here, have a vitamin' that's more normal and at least it's over quickly and you can carry these pills around without people sort of staring at you, wondering why are you carrying so many medicines and things?

D: Yeah, definitely. And I'm still on quite a bit in the morning, but I just take them quickly and get on my day literally. I mean, I have some during the day as well, but different times. But they are gradually going and you know, if just every morning you just take them and get on with your day and it does look like you are ill but you have just got to forget about it, just get on and live, live the best you can. Definitely medications don't stop it, because I take ten minutes in the morning and I'm over and get on with my day. Instead of when I used to worry about liquid medications, I used to have a platter of food to get the taste away in your mouth.

EL: That's why you have to buy so much fruit.

D: It was horrible, but yeah, definitely now there's no taste in your mouth. Because when you have that taste, you carry it around and you just think about it all the time. Now, you just take on tablets, you go.

EL: So if you have three tips, three top tips for any kid or young person learning to swallow pills, what would they be?

D: So number one, I think, need to be definitely determined and ready. That is so important because you can't just say, I'm not going to do this, I'm not taking a tablet in my life, I've struggled to take it in the past.

You've got to start small as well. That's also another really important thing. And find the best tablet that works for you, you can start with the smallest of the smallest and gradually see improvement. Some people don't get as quick as I did. Of course, some people might take time. But you're actually swallowing a tablet now. And for me there is a big variant in my tablets. Some are really, really small. Some are really, really big. So that means if you struggle with the big ones, you've got a small one. Lots of pharmacies can give you a smaller tablet. You know and that means that you're actually getting progress, even if you are not on the biggest of tablets. It's hard but once you gradually get used to it, you're taking tablets, you're actually taking tablets, you're doing it. Even if it's really small. That's pretty important as well.

And the third thing I think it's just about really. When I had my injury, it was like a shock. And when you're in a lot of pain, if it's someone who, doesn't take tablets and you've taken liquid medications before and there is problems with liquid medications, you'll have issues with them. And I think that drives you on to take tablets. I don't think it's the way that people say like treat it as how you swallow food, because I didn't find that helpful. I think it's just, seeing it in terms of how important it would be for your medical health as well. And lots of people have been so, so brave to tough operations and certain things, so do the same with the tablets because it will change your life literally.

EL: That's so true, I think I've heard a lot of people say, oh, you swallow a big lump of food, why can't you swallow a tablet? It's a different skill set, but it isn't difficult.

I love your three top tips. So, first of all, is about your positive mental attitude. Secondly, start small and be good to yourself, look at your successes. Swallowing anything is a success. And thirdly, like you say, just be determined.

D: Yeah, I was on an NG tube and literally I couldn't swallow. So, anything, just swallowing anything, let alone is hard. I was on an NG twice. So, it is such a frustrating thing not to be able to swallow even food let alone tablets. So, if you actually swallowing a tablet, to get to that moment, it is a huge success. And anyone else who does that, especially after all the trauma and have never taken it before, should be really proud of themselves. So, this is really important.

EL: Yeah, I think that's a lesson for everybody that you, who had a nasogastric tube so you couldn't swallow anything at all, had a really sudden illness and had to take 27 medications in one morning, can go from not swallowing anything at all to be able to take all your pills in 10 minutes. Well, I mean, if you can do that, then everybody else should be following your example!