

FROZEN LIGHT

The Frozen Light Podcast

Episode One- Interview with Sharon Slade, family carer and Frozen Light trustee

- Lucy (00:01):** Hello, and welcome to Episode One of the Frozen Light podcast!
- Amber (00:08):** A podcast aimed at staying in touch with the PMLD community in the age of Corona virus.
- Amber (00:27):** Hi everyone. It's Amber here.
- Lucy (00:30):** And Lucy
- Amber (00:31):** It is Wednesday, the 3rd of June, and we're very excited today to be interviewing Sharon Slade, who is on our board of trustees.
- Lucy (00:41):** Sharon is the mum to a wonderful young woman named Lauren. Who's one of Frozen Light's, regular audiences. Sharon and Lauren have been coming to our shows since The Forest, and when we were looking for trustees, Sharon approached us and said, she'd really like to come on board for the role of audience advocate, which is a role that we created to ensure that our audience with PMLD had some representation and somebody to advocate for them on our board.
- Amber (01:10):** Sharon and Lauren have both always been super enthusiastic audience members, and actually one of my first memories of meeting Sharon was after The Forest and we asked her and Lauren to do an audience response video, which you can find on our YouTube channel.
- Lucy (01:25):** Okay. So we'll just call Sharon now.
- Sound Effect (01:27):** Sound effect of phoning someone
- Lucy (01:30):** So hi, Sharon, thank you for joining us today. Um, I suppose first off, would you like to introduce yourself and Lauren?
- Sharon (01:39):** Yep, absolutely. Hi Lucy. Thank you for inviting me to join you today. My daughter, Lauren is 19 and she has a condition called Rett Syndrome. And part of that condition is to have profound, multiple learning disabilities. That that's part of the package that Rett Syndrome sorta gave Lauren. Um, she's just about to graduate from her special needs school. She's

been in a special needs school since reception, since she was four. Um, she moved to a different special needs school when she was eight because the implications of Rett Syndrome and the ability of them, and the capability of that school, um, on how to sort of, they didn't, to be honest they didn't have a set up to work with, um, children with PMLD specifically, you know, they were much more of a, a medium sort of special needs school. So we moved her to a more specialist school, which was best thing we ever did, and she's been there since she was eight. And she graduates in a couple of months time. We're on, sort of, the spectrum of Rett Syndrome, and we're quite lucky, Lauren's quite high functioning, as far as she's mobile, she's likes to be engaged as she would engage with things. Some of the, sort of the things that Rett Syndrome can do sort of affect in sort of the physical side, disability side of things, we were quite lucky. We got to, you know, we got off quite lightly. But unfortunately the, the PMLD side of it is pretty profound. So, um, hence why, you know, we've come across, we've come across you guys a few years ago, um, because you know, I'm constantly on the hunt for, people and organisations that understand and get it. So, yeah. So that's our background.

Lucy (03:18): Thank you. And where's, and is Lauren having a nap?

Sharon (03:20): Yes, this is her nap afternoon. She was up quite early. So we've done our walk. We've done a morning walk. She's had a zoom activity with a sort of local day provider and lunch and that's it, game over now. She's snoozing, tea and then bed. That's kind of it. So.. (Laughs).

Amber (03:38): I mean, I think you've just answered my next question. (Laughter) What does your lock down look like? What's your day to day and how's it different from what it was before?

Sharon (03:47): Um, oh massively. Cause Lauren's got a younger brother. Um, Joseph who's nine, so he's obviously not at school either. Um, so my day has to be split between the two of them because my other half has now returned to, work. When he was off work, it was great. We had two adults in the house, so, um, our day was a lot less restricted, but nowadays back at work, we've had to really make sure that the routine is there. It's definitely got harder, I think as the lockdown has changed slightly. Um, where we are now, um, so I'm on my, sort of, own with them all day. Um, so I tend to, because Lauren is a morning bird, so I tend to concentrate on her. Joe is very much not a morning boy, he's happy to laze about, um, so what I tend to do when Lauren wakes up and I kind of let her wake up on her own, so it can be anything between seven and half nine in the morning. Um, so I get her up feed her, look after her personal

care side of things, get her dressed wash, dress, teeth, change, all that kind of thing. And then pretty much after breakfast, we go out on her walk because as I say morning is her best time. She's got more energy, she's more focused, she's more engaged.

So we go out and cause she's mobile the one thing that I was terrified of, I think when lock down kicked in was that she wasn't going to move around as much because when it's not lock down, just getting into the school taxi, and out again, you know, all those things that you do in the day, moving that you don't realize are moving. I was very aware that if she didn't keep moving, then it would affect her whole, not just her mental health, but her physical side of things, because, you know, with, with Rett Syndrome part, you know, a lot of their issues are internal. So, you know, if you're not moving about digestion can be affected, everything can be affected.

So my main aim from day one was that Lauren has to move about. She would spend all her day in her bedroom. You know, she's very happy to sit on the bed and watch DVDs all day. She can get up and downstairs. So she'll bring herself downstairs if she's a bit bored or she wants a DVD changed and throw me the DVD down the stairs or something or whatever she wants to do to get my attention. But other than that, she would happily stay, just lazing about so, um, making sure that she gets out, um, and we kind of found out, you know, it was a bit of a hit n miss because she, when she's at school all the time, I kind of know what her stamina level, what she can do physically, but it's, it's never really been tested. So we kind of said, right, let's just see how long she can walk before she gets tired and grumpy and we've worked out, she can, you know, sort of pretty much for a certain amount of time, we've got woods behind us. So I can give her a certain amount of freedom. You know, that's another thing as well, is that I don't want her to feel like she sort of has to be stuck beside me or hold onto her or push her in her chair so we can go wherever out the back, we can go for a walk. Um, we try and go out for an hour. We find the hour is her length, the maximum length of time that after that she'd had enough and she wants to come back and it does mean that if she's grumpy that day and she wants to scream and shout and make a noise or make a fuss, it's easy because there's not many people about, she can be as loud as she wants, you know, without thinking oh, you know, wondering whether she's disturbing anybody, that, that kind of thing that you always got in back of your mind. So she loves being in the woods. She loves the trees. It's Lauren's ideal sort of scenario. Um, as far as getting out and about, she loves being outdoors. So yes, the morning walk every day, out, it's key, it's key, for me, for

getting Lauren out. Um, and we make sure we do that every day. And then it's lunch coming back, changing, you know, personal care again, feeding her. And then in the afternoon, up until recently, I tend to let her not do a lot, honestly, a chill, but as this has gone on longer, and now we can get out and about a bit more, a couple of days already this week we've been out. So in the afternoon we've been down the coast for a couple of hours or we've been to see our friends. So I'm trying to do a little bit more in the afternoons now that we are allowed to, which helps me as well. It helps all of us just, just to get out too, then it's coming back. It's tea, you know, looking after her personal care again, getting her into bed, getting settled for bed, then it all starts again, really. So it's pretty, pretty much then where, where, where Joe bless him has to, you know, I make sure that we do, I do have an hour with him in the morning doing PE. And then in the afternoon we do something together, the three of us, or if we don't get around to it, because Lauren is just not up for it. Then when dad gets home, he takes her out, takes Joe out on his bike. So he gets some time.

Um, so it's just a juggling act, really trying to, um, make sure Lauren's personal care is looked after so that she doesn't get bored and that she's still happy. But also that Joe is also doesn't feel that he's second best all the time, because you know, sometimes you might do, but then he goes out and sees his friends. And when he was out of lock down, there was school and football and swimming. But now I'm very conscious that he's around us all of the time and he's around Lauren all of the time. So it's, it's a balancing act every day. So yes. So yeah, it's, it's pretty much full on from the minute you wake up to the minute you go to bed because there's always something to do. (Laughter)

Lucy (09:04): But it sounds so nice, like, getting out in nature and having the woods cause who doesn't need a space in the woods. I know that's been our saving grace getting out and about.

Sharon (09:18): It has. I mean to have the country park literally on our doorstep, you know, it would have been harder. I think if not, she's in an environment that I know she loves. So, and also she loves meeting people out and walking their dogs. She loves looking at dogs and stuff. We got loads of dog walkers over the back of the woods. So we always bump into somebody. 10 weeks on how I judge, I think that it's working is that one she's not put on any, any weight, which is good, cause I have to be careful about that because she don't, you know, I'm totally in control of that as well. 100% of what goes in her mouth and what exercise she does. Um, she is happy, and she's sleeping well and everything's working, you know, health wise. So she's sleeping well and sleeping properly every night at

the moment. So I kind of think, oh, it must be working.

Lucy (10:02): One thing that you keep mentioning, which I think is really important is that it gives her that independence away from you because obviously outside of lock down, she's, she's a 19 year old woman. She goes to school. She has friends and does stuff away from her mum. And actually in lock down, that's stopped her from being able to do that. So that's really great that you have a place to go, to be able, that she can have that little, little bit more independence from you.

Sharon (10:27): Yeah, no, absolutely. Yeah, yeah, absolutely. Even if it is just, you know, walking a couple of steps behind or in front of her or to the side of her and also she, you know, she can sort of tell me when, you know, she doesn't want to hold my hand or she doesn't want to do that. She will pull away, which is good. So I want her to carry on. It's easy to baby people like Lauren. Um, it's easy to just assume what they're going to be because they can't talk or they can't express how they're feeling that, you know, you just do everything for them and just, just get to baby them for want of a better word. And I'm very anti that when it comes to Lauren, because I don't think that's how she should be treated. Um, so yes, it's something that, you know, the, the babying, my mum and dad or grandparents doing that kind of stuff, I let them still do that. I let them indulge in that. But my side of things, I feel that it's especially cause at school, they don't do that at school. They treat her as a 19 year old adult. So I have to remember that I've had to take over that, and it is quite hard. You do forget some time because either just to do it for her just because it's easier, but I've had to stop and say, no, I'm gonna make this a little bit more difficult for you and you're going to have to try a bit harder. And... (Laughter)

Amber (11:40): And you've spoken a lot about the importance of going outside. Have there been any other highlights?

Sharon (11:45): For us it's sort of how I think I suppose, how the family dynamic has kind of shown that it is working, because as I say we are such busy family. You know, I work, we both, you know, both parents work. Joe is at football or swimming and we've never actually spent a lot of time together as a family. So although we knew that it worked, we never kind of, you know, we just, we just did. Whereas now we can, I can actually see that, you know, despite the massive differences between like Joe and Lauren, it is working because usually I'm rushing about, so I have no idea, you know, we don't have conversations about how he feels about Lauren and that kind of stuff, but that's, that's come through now about how, you know, I was very conscious that he doesn't feel left out and, you know, we have

these conversations. That side of things has been a real positive is to see that actually. We always knew we were alright, but you just never know, but it's nice to have...we're okay.

Lucy (12:43): Sounds like you're doing really well.

Sharon (12:46): Another highlight I suppose, is, you know, we've seen Lauren's personality sides of it, you know, when she's not happy about something or, you know, that, that side of things and how she sort of has a sort of sense of humour. Seeing, like, because I'm spending more time with her. She, I'm seeing all aspects of her, I mean, it's not always good, but on the positive side, I've been able to enjoy that more because I'm not rushing off to work or sort something else out. So I think rather than just being a carer and charging around like a lunatic all the time, it's nice to kind of get to know her a bit better. That we can actually get on, you know, most of the time. (Laughter)

Lucy (13:31): (Laughter) That's like any parent.

Sharon (13:34): Yeah, I think she, I think she does like me some of the time so, I feel I'm winning.

Lucy (13:41): What support have you had from Lauren's school? And I know you said Coco Care, which is, am I right in thinking that's the, the day support she's going to after she leaves school? They've been sending things?

Sharon (13:52): I think unfortunately, because Lauren was literally in the last six months of school and when lock down happened, what she should have been doing was transitioning, getting ready to leave. So what she would have been doing is spending loads of time out of the classroom. She wouldn't have spent much classroom time. She would have been going to different day centres to try and see if she liked any better than Coco Care. And they would have been getting her out and about a lot more, in preparation for doing that once she leaves school. So it's 16 to 19 in that class. So the stuff that they sent home from school or sent home, but, you know, sent out online, wasn't really appropriate for Lauren. She's passed that, She didn't, you know, there was no point in doing that stuff. You know, they've got an app that they upload stuff and you have to upload evidence for learning. Well, there's no point because she's not going to be there. So I kind of felt that was a unfortunate, you know. I would never say the school didn't support us, but we kind of, I think she kind of got forgotten about, a little bit, because you know, we're in transition. So yeah, I kind of think from a school point of view, she's almost gone, you know, so I think we were forgotten on that bit. But

luckily Coco Care was the opposite and they agreed, although she's not officially with them, they know her, she knows them and they have included her, and they're using some funding that they've got to enable them to do that. So, yeah, so they, um, they don't do the full package cause obviously she's not being funded to go there at the moment. So they just sort of do a watered down package for Lauren, um, which has been brilliant. So almost like a transition package, they're getting her ready, I suppose, doing what school would have been doing. Um, so every day she gets invited to attend their like lunch, um, Zoom meetings. So we just go on for an hour at lunchtime and they're about, there can be four people, 14 people, and everyone's just sitting there either saying nothing like Lauren and just eating her lunch cause I'm feeding her or there's a couple of them chattering away. So it's just a menagerie of faces and sounds on the screen. She does bingo once a week with them, Joe does the bingo, but sits next to his sister to do it.

And then twice a week they do, um, activity with Lauren. So they send home, every Friday, a bag, or they deliver a bag of stuff. And on a Wednesday, and a Friday, we'll have half hour Zoom call with one of the support workers and I sit there and do this activity and she's there on the screen just watching and just interacting with Lauren, and chatting to Lauren really. So yeah, it's great. It's that, that side of thing I haven't personally enjoyed doing the activities. I think Lauren has lost patience with me a few times because I'm kind of like, Oh, she'll like what I'm doing? But yes, it's, it's all, it's all part of the fun, and it gives us a structure to the week, you know, it's that, another half an hour, she's got something that's just dedicated to her. So, um, I'm happy with it. So yeah, that's been good. That's been best, been really getting fingers crossed, standing in good stead the funding moving forward.

Amber (16:53): Yeah. And hopefully it has actually given the opportunity for hopefully a smooth transition as well.

Sharon (16:57): Oh yeah. I mean, without, without them, it would have been a lot, lot harder. I think we just felt that we were part of a community part of that community that know Lauren that care for her, but know, her, um, and it's her group, her group, it's her peer group, her group of buddies, you know, if she was at college or uni- it's her little group. And it's just nice to know that we're part of that. So...

Lucy (17:20): And has that felt really important during this time that there is still some connection and that people are thinking about Lauren?

Sharon (17:25): And yeah, Massive. Yeah. Massive. I mean, it's all about, you know, it's all about Lauren. They actually, you know, they talk to her, you know, rather than, you know, they'll chat to me, but they're, they're sort of aiming their conversation at her and her friends, a couple of friends who can talk, that do talk at Coco Care, you know, they'll talk to her and chat away and stuff. So yes, it's that really, that's really important that um, it's, it's geared to her and that she feels, feels part of it really, so..

Amber (17:56): And is there any other support that you feel would have been useful to you and learn at this time?

Sharon (18:03): I think for Lauren, I think if I hadn't had Coco Care I probably would have given you a long list (Laughter., Cos school really, you know, haven't... got nothing from school at all. And so I would have been yeah, probably saying, yeah, there's nothing of that we've not had anything we wouldn't have without Coco Care we wouldn't have had any support or no contact from anybody. Luckily it worked out, but it could have easily not.

Lucy (18:29): Are there any changes you hope will support people with PMLD in the future, influenced by this time in lockdown?

Sharon (18:34): I was thinking about that and I've kind of turned that on its head, cos I thought well we all could go on for hours, about what people outside in the community could do, more for people, you know, people with PMLD because I think it's just a constant battle because a lot of them, especially like Lauren who are nonverbal, just get forgotten, they get, they get talked at, they get talked over. They just think that, you know, they're stuck in a chair. They're not saying anything. They're just making weird noises, they get looked at strangely, you know, or they are ignored, you know, and it's a very small insular world that we live in. And, and, you know, part of what we're trying to do is make that world what, you know, bigger, but it's a constant battle because people don't understand, you know, it scares them. It scares them, anything that disability, anything different though. We know it's because she doesn't talk, and you know she does make odd noises and sounds and stuff. People are scared of it. So it's trying to, you know, change that perception. But I think one thing that I've learned in this lock down is how hard caring is. And I think a lot of the time people don't realise that the job carers do is massive. It's it's, you know, I think it's seen, I think it's still seen as a job, but you know, it's not to be paid for- not just paid carers, but just carers, generally, just how hard it is. And I think you do get, you do get forgotten. So for example, with, um, you know, with whether or not Lauren has got good support

from school and the Coco Care is all about, you know, making sure that Lauren is included, but Lauren can't do anything without me or her carer. And, you know, as much as we want to give her as much independence as we can, it is tiny. You know, all of the time she's going to have one of me or they're going to have one of me next to them, not necessarily mum, but carer, they can't do this stuff without someone, working really closely with them. I think that side of things is sometimes forgotten about, how that person is dealing with it. And it's not easy just because a person isn't talking doesn't mean it's easy, it's harder. You're trying to work out what they want.

When people are looking at who can support young people and adults with PMLD, it's looking at the carer is important as well. How the person with PMLD and how, how they're interacting, it's looking at the skills that, you know, what that carer is like. Because unfortunately, as we all know, especially if you've got someone like Lauren, who will just happily sit in a chair. If you haven't got someone that is actively trying to engage with her, it's quite easy not to do anything. And because it's hard work, we don't get anything back. You know, it's a thank.., it's kind of like a thankless job. It's a one way street, you know, you have to do a lot to get a small thing back. So I think it's, yeah, just, I think raising awareness of how caring for somebody- and that's personal care, mental health, not physical, mental health and personal care, all of those things, it's really tough on the person that's doing it.

Lucy (21:47): Absolutely and I think we see with you, that it's like a constant fight for Lauren's rights. And, as you said, she would happily sit in her bed, but you know, that Lauren, to keep that mobility needs to keep going and stimulated and being stimulated for, um, her age and everything that she enjoys doing. And we're always really aware of how there's a big proportion of people with PMLD that don't have that person to fight for them, because for, for a number of reasons and the massive difference it makes when they do. But not to forget that parents and carers it's exhausting and you're not, um, yeah, well, paid carers aren't paid enough and parent carers aren't supported enough.

Sharon (22:32): Well no, and I think that, that, I think that, well, this lock down is going to really, it's shown up massively. I was speaking to another, um, you know, one of Lauren's friends who, you know, she's exactly the same situation as Lauren and it's, you know, because I think because also you're mum as well, they just think, well, it's part of the job and it's what you have to do. And it's what you, you know... Okay, it's tough, but you know, you, you'd care for them anyway. It's a totally different way of caring. It's totally

different. It's not a parent thing, it's a carer thing. And it's, and I think, yes, that side of things, whether you do it, you know, unpaid like we do, because she's my daughter or whether I'm a paid carer, it's I just never realised how hard it was. I've never had to do it. Cause there was always, you know, there was always other people around to help and other places to go. So yeah, I think that's, that's a big thing for me. That's come out of it.

Lucy (23:26): You've also got, you know, another little boy that needs looking after, and a job, and a partner. You're exhausted, I think, is that something that's come out of lock down that, you know, all the services have gone and you're kind of...

Sharon (23:41): Yeah, exactly. And you don't, you know, unless that, till it's all taken away, you don't realise how hard it is to do it all day, every day. I mean, you know, we, you know, we tend to, it's really just weekends where we've had to do it, all of the time. And to do it Monday to Friday, as well as the weekends is, is massive. Um, and you can't, you don't, you don't, you can't just say, I don't want to do it today, or can't be bothered, you just do it yourself. You can't do that. It makes me really appreciate the providers and the people that I can let Lauren go to without me being there. And I think that'll be one thing that when I come out, when we come out of this, is that I will try and increase that circle a bit more. I was always a bit nervous and a bit sort of wary about, sort of, people coming into the house to help, you know, because it's easier for me to do it myself- rather than PAs and that kind of thing. Because of the horror stories you hear about when it goes wrong. But I think if you spend the, you know, I think that side of things, I'm going to look a bit more as well. It's just to see what else I could be doing to, to make her that bit more independent if I can, but also to give me the break. Cause you do, you do you need that distance.

Amber (24:54): And is there anything else that you think you'll be, you'll take going forwards once things resume to a world that we recognise slightly more? Is there anything else that you'll take forward from this time?

Sharon (25:05): I think you're just amazed that we're all sort of still standing and smiling and being able to string a sentence together- it's quite good. (Laughter). Yeah. I mean, I think it's just a renewed appreciation of what, how you need other things, other people, other motivations and things to make, make the world go round and make things work really, and that you can't do everything. You're not, no one person can do everything. To accept, help a bit more readily, you know, because I think you do quite, you

know, we're all independent women that have been brought up to be independent and we all work and delalalala. And actually it's quite hard when someone offers to help you. Like, no, it's fine. I can do it. So I will. I will, one thing I've thought is actually, yes, I'm going to accept that help when someone offers because when it's not there, it's like, wow.
(Laughter)

Lucy (26:00): And it sort of chimes with like our Frozen Light approach, we're always about like collaborating and working with big teams of people and bringing extra people on to support in areas that we can't do. And we've really missed even having that during this time.

So yeah, we should also mention that Sharon is a marathon runner.

Amber (26:18): A regular marathon runner!

Lucy (26:21): Have you been able to keep training?

Sharon (26:23): Oh yes, yes, yes. I've had to do it. I had to switch it around. I usually go out running in the evenings. I now have to get up at silly o'clock before everyone's awake. Really early, ridiculously early. So I set my alarm and get up and go out. So yes, I'm still making sure I do that because I just, I couldn't survive without that, without that, that's my one or hour and a half. I sort of go out, hour and a half, sort of three times a week and that's my time. But, so, I am literally out the door ridiculously early.
(Laughter)

Lucy (26:58): Sounds kind of hideous.. (Laughter)

Sharon (27:01): I like it, by the end of the day I'm too tired, you know, it's just, you're just knackered by the end of the day. You're just worn out. From the caring side of it! Cause I'm not, you know, normally, I'm tired cause I've been at work, but you can still just get back, put the trainers on. But it's the exhaustion you feel at the end of the day when it comes to five o'clock you feel as though you've done a marathon already and that's just from being too, everything, all your senses everything. Everything has been switched on a hundred percent so that you can meet everybody's needs. So yes, the morning is best for me. And I'm like, yep!

Lucy (27:32): I'm pleased you're still getting like a little bit of time for you, even if it's at like god know what o'clock in the morning.

Amber (27:38): ...and even if it is running the whole time! (Laughter).

Lucy (27:46): Amazing! All right. Well thank you Sharon. I think, unless there's anything else you wanted to add...

Sharon (27:53): I just think this sort of thing is, is really important because in this lockdown period, you are kind of off the radar of social services and all that kind of things. You haven't got anyone official sort of checking in with you. So I think, I think this sort of thing will help because there's lots of people like me because we're very low down on the organisation's priority lists as far as Lauren's concerned, because they know she's in a loving, caring, healthy, safe environment. So we're all right. That's that box ticked. Um, and I think that's sometimes is, you know, so it'd be nice. I think people can hear this and go actually, yeah, I'm not on my own, you know, if everyone's well and healthy, but it's still, you know, really hard work and has it's really hard work. And I think, you know, they don't realise that you're in need, but you're not going to, but you know, social services are stretched at the moment. So to have someone official come and say, you know, how things doing, how you're feeling? You're like, they just haven't got the capacity at the moment. So there's probably a lot of people like me, you think, yeah, it's really hard. And are you on your own? And you're not. We're all going slowly mad together. But you know, our young person is fine at the end of it. (Laughter).

Amber (29:05): And I think that's where the idea of this podcast came from, just that strong need to feel connected with a community- that strong need to feel connected at a time that we have all been pulled apart, you know, to stay, to stay together and strong and keep talking to each other, in any way that we can.

Sharon (29:23): Yeah, I think, and again, that goes back to the carers again, because the other one thing I did learn about Lauren is that she's not, she's not a screen time person. So she's, although they, you know, like Coco Care include her in the zoom calls and that, she prefers to be in the physical presence of people. That's, that's her thing. She's a people person, she's not a face on a screen type person. So she gets, she just looks at it and then she's done, you know, checks in with them and that's it, she's happy just to disappear. Um, so I think, you know, again, it's looking at the carers like, okay, well, you know, your, young person might have not wanted to engage with that, but do you just want to still be part of this group to have a chat? And I think, again, that, it's just checking in because every person on the screen, when we do our Zoom calls for lunchtime at

Coco Care, everyone's got an adult sitting next to them, either off screen or camera, that's doing stuff, supporting them. Um, and it's, you know, when Lauren disappears I just still hang around for a bit or, you know, just have a chat because, you know, even though you're not chatting about that person, who's off screen supporting that other person on the screen knows what you're feeling. It's like, you're not alone.

Lucy (30:36): Yeah. Yeah. Which is really, really important. And I think even more important, for that community, yeah. I've really enjoyed our first episode! (Laughter) So thanks Sharon for the interview, it was so lovely to hear what you and Lauren have been up to during this time.

Amber (30:56): And I think as me and Lucy ourselves are both two mothers in lock down and it's really interesting to see different families experiences of this time- the similarities, the differences, really fascinating.

Lucy (31:09): And I think a really key thing that came out of that interview with, with Sharon was that the message about carers and often how forgotten and undervalued carer's are, whether that's family carers, paid carers, support workers, people are forgotten. And it's, it's exhausting looking after someone constantly. And you could love that person to the moon and back, but it doesn't mean you're not absolutely physically exhausted and the effect that that may have on that carers mental health. I think it's a really important thing that came out of that conversation. Bearing in mind Sharon's a carer all the time, and not actually having realised the difference that the support of, of school and any care support respite that she gets and how important that is to be able to maintain a happy and, and safe and stable environment for Lauren.

Amber (32:01): And I'll link on the show notes on our website, that YouTube video that Sharon and Lauren did for us after they came and saw The Forest in 2015. We're really excited that in our next episode we'll be interviewing Joanna Grace, who is the founder of the Sensory Projects. And we're super excited about what she's got to say. We've done Joanna Grace's course, which everyone talks about how amazing it is. And then you go and do the course and you realise also how amazing it is, and now we're those people who talk about how amazing Joanna Grace's sensory course is!

Lucy (32:37): So do join us next time. Just before we go, if you want to keep in touch with us, you can do that through our website, and our social media channels, which are....

Amber (32:48): Our website is www.frozenlighttheatre.com. You can reach us on info@frozenlighttheatre.com. If you want to come on the podcast or you've got any comments that you want to write to us about it, we're really keen to use this opportunity to reach out, to connect with new people in the PMLD community, who we don't already know. So please do get in touch. We are [/frozenlighttheatre.com](https://www.facebook.com/frozenlighttheatre.com) on Facebook and [@frozentheatre](https://twitter.com/frozentheatre) on twitter and [@frozenlighttheatre](https://www.instagram.com/frozenlighttheatre) on Instagram. I also mentioned our YouTube channel in this episode and we're just FrozenLight on YouTube.

Lucy (33:28): So thanks for listening. We will see you next time.

Amber (33:31): See you next time. Bye!