

FROZEN LIGHT

The Frozen Light Podcast

Episode 3 – Interview with Emma and Hugh

- Lucy (00:00):** Hello, and welcome to the Frozen Light Podcast!
- Amber (00:04):** A podcast aimed at staying in touch with the PMLD community in the age of corona virus.
- Jingle (00:10):** (Jazzy music plays)
- Amber (00:21):** This is Amber Onat Gregory.
- Lucy (00:24):** And I'm Lucy Garland.
- Amber (00:24):** And we're the Co-Artistic Directors of Frozen Light theatre company.
- Amber (00:29):** So what's exciting since we last recorded, uh, we have now launched the podcast and it's been really, really great hearing people's feedback so far, and that's been really great. We have arranged the next few weeks of interviews, which we're super excited about. So we're so thrilled at the response that we've been receiving so far. We just wanted to highlight as well at the moment, we are still looking for people to join our audience panel.
- Lucy (00:55):** So this panel is to ensure that Frozen Light always has the voices of people with PMLD at its core, and that we're always led by that. And it feels especially relevant at the moment because we're really interested in hearing people's voices and opinions about when they may be ready to return to the theatre, to really support us on that journey. We're really interested in that panel, supporting the company and having an impact on the direction that the company moves to in the future.
- Amber (01:29):** So if you'd like to be on the audience panel, please email us at info@frozenlighttheatre.com. We really can't wait to hear from you.
- Lucy (01:38):** So today on the podcast we are interviewing Emma Murphy and Hugh. We first discovered Emma and Hugh when Emma gave a really amazing talk at the Raising the Bar conference in 2019, which if you don't know about is a really amazing conference, all about raising the bar for people with PMLD.
- Amber (02:04):** And what we thought was amazing about Emma's talk was just about how her and Hugh really live life to the absolute full. It was a talk filled with the joy and positivity that everyday life can bring and all the incredible things that you can do, and we really wanted to hear about how such a positive force really was dealing in such a challenging time.

Lucy (02:26): So we'll give Emma ring now.

Sound effect (02:31): Phone ringing.

Lucy (02:31): Hello. Hi, Emma and Hugh. Thank you for joining us on the podcast today.

Emma (02:36): 'ello, 'ello!

Lucy (02:38): And I've just got a beautiful smile there from Hugh.

Emma (02:43): He's quite enjoying looking towards the computer, actually, while I was getting it all set up, he was really looking at the computer screen, so that was quite nice.

Lucy (02:51): Oh, excellent. Well, that's good. And Hugh's got the most amazing set of ribbons going on.

Emma (02:56): Yeah, it's got lots of rainbow coloured ribbons to match his rainbow colored top, actually. So...

Lucy (03:02): Oh it's all about the rainbows today.

Emma (03:06): It is yeah.

Lucy (03:06): I'm just wearing black. I feel like I'm letting the team down.

Amber (03:10): We are in the middle of a rainy week, so it's a good reminder that, you know, without the rain there'll be no....

Emma (03:15): Yeah (Laughter)

Lucy (03:19): So, um, first off we just wondered Emma, if you'd like to introduce yourself and

Hugh: (Vocalising)

Emma (03:25): Okay, so I'm Emma, um, I'm a special needs teacher. I currently teach, um, children with profound and multiple learning disabilities from the ages of three right up to 19 now. So that's been, that's been really nice. I'm really enjoying that. Um, prior to that, I actually worked in an autistic, specific special school, um, before I had the boys. And then, um, also probably more important, mum to two boys, I've got an old boy, Shaun, who's keeping the dog out of the way in the other room. He's 11. And then I've got Hugh here with me, he's 10 years old. Hugh's got a rare genetic disorder called FoxG1 syndrome, um, which he was only diagnosed with that um a couple of years ago, actually up until that point, he was undiagnosed. And we knew he had a genetic condition of some sort, but we didn't really know what it was. So it was, he had a syndrome without a name really. It's caused, um, profound and multiple learning disabilities, um, epilepsy,

severe epilepsy, um, he's tube fed, he's got a visual impairment. Um, so it's the FoxG1 syndrome has a lot to answer for. But he is the most happy, um, wonderful little boy to have around, he loves, uh, as you can see, he loves playing with his ribbons and twiddly things. Wires! He loves playing with wires! So feeding tubes, uh, the extension set from the, from the feed, from the, the SATs probe, all of those things, things that he shouldn't have. So we try and divert him with the ribbons instead... he loves balloons, he loves bubbles, he loves music. Um, and he's generally like a really, really happy little boy which is great.

Lucy (05:15): And we can see that looks like he's having a great time.

Amber (05:18): And what does your lockdown look like so far? Just to say it's the 19th, Friday the 19th of June. Um, how's things going?

Emma (05:29): Yeah. So it's been, um, it's been different. We uh, normally life would be, I'd be working part time, both the boys would be in school five days a week. We'd have carers coming in to to help with Hugh. So he has um, he has a care package from the NHS because he has issues with his breathing. Um, he has a one-to-one complex carer, so she comes at eight o'clock in the morning, take's him off to school and the school bus, stays with him all day, comes home and is with him until four o'clock. Um, and then we have on the nights before I go to work, have overnight care as well. So he has waking nights, um, and we have a carer, uh, two nights a week to do that. So it's really changed because we've had no carers in the house since the, I think, the 16th of March. Um, so we've been responsible for the, for the care 24/7. Um, my husband was originally working from home, uh, then he was furloughed. Um, now he's actually back at work again. And obviously the two boys haven't been at school, I have been working from home and trying to homeschool in a, in a fashion. In fairness Shaun's been brilliant because he's really done it himself. So thanks to, thanks to the wonders of modern technology and the internet, he's been accessing lessons online, which, which has been brilliant only with, you know, the occasional reminder from me that he really does need to start now or, um, and Hugh's home-schooling has been less successful. (Laughter). He really doesn't want to get out of bed. Actually, Hugh's loving lock down because for him mornings were always an issue anyway. He hates getting out of bed early. So in a morning, I would say rush off to work, I's be leaving at half seven, the night carer would handover to the day carer and Hugh would be fast asleep still. Um, (To Hugh) your're laughing about this aren't you! 'Cause even if he wasn't fast asleep, he would pretend to be asleep. And then you would, you know, you'd give him his medications, dress him, hoist him into a wheelchair, get him onto a school bus, get him to school. This is all while still asleep. They could even get him out into and strapped into a standing frame, while he was asleep. So...

Lucy (07:47): Oh, Hugh this is brilliant.

Emma (07:50): So for Hugh, he's actually really enjoying it because he's been waking up, and he wakes up normally of of half six, seven. He's adamant he doesn't want to get out

of bed at that point. So I'll go in, get, switch off his nightfeed, flush him, and give his medications and I'll be like, 'Oh, are you ready to get up?' And he's, he's got a very definite 'no'. There's 'no, I'm not getting out of bed'. And he'll like have a morning nap. He'll go back to sleep. And then he'll, he'll shout when he's ready to get up. And it's, it can be for anywhere from this morning, he was ready for 10 o'clock and he was happy to get up at 10. Um, but there's been days he's decided he doesn't want to get out of bed till half past 12.

Lucy (08:26):

Oh this is like my ideal life!

Emma (08:31):

He's like a teenager. So he's really, really loving lockdown. So, but it does mean the actual homeschooling, um, side for Hugh is, is, quite a limited timeframe. Cause he's also very adamant about what hours of the day, he's happy to do physio. Um, I know he's not in the afternoon, so we've got a really small window of opportunity in the morning to get his physiotherapy done. So I feel a bit guilty about that actually, because I know I'm not doing anywhere near, as physio, as much physio as he'd be getting at school, which is, which is a shame, but other things is, you know, he's doing, we've got lots of sensory play, and he's quite happy to do that in the afternoon. His music, all of those kind of things. But then the physio's fallen by the wayside a bit and I do feel a bit guilty about that, to be honest.

Amber (09:12):

Obviously it sounds like you had such an incredible support unit before lockdown and that's all been taken away. Was that all due to kind of decrease kind of risk or there being lots of people around? Is that something that you can look at having back in, in the future at this stage or does it still feel too unsure?

Emma (09:32):

Yeah. So, um, I, they did say that carers could continue to come in if we wanted. Um, but because we were shielding Hugh, I just felt that I wanted to minimise the risk as much as possible. So we were literally like, 'nobody comes in or out now' and we, you know, locked the doors and that's it. Um, so yeah, so I, I specifically said, I didn't want carers in, but then the... excuse me, the NHS were really good and sort of said, you know, if you refuse care, it doesn't mean you won't get it back again. You know? So it is there when we're ready to accept people back in. Um, I think now that my husband's gone back to work, it's going to get more difficult. Um, and I might need to start actually having carers because I'll be responsible 24/7. You know, if we've had a really difficult night when Steven was at home, I could just go back to bed. So that was fine. Cause I generally tend to do all the nights anyway. Um, so if we've had a difficult night, then he'll get up with Hugh in the morning and he'll deal with everything and I can go back to bed for a few hours. Once he's back at work, I won't be able to do that. So I might have to start considering having carers back in again then.

Amber (10:40):

And what's happened to your school that you work at, is that currently closed or is that open?

Emma (10:45):

No it's been, it's been, open the whole time. Um, so I think they, they have, they're gradually increasing the numbers now. I think it was about 45 children at

the moment. Um, so it's, um, mixed, special needs. So there's children with profound and multiple learning difficulties, um, uh, severe learning difficulties..

Hugh (11:05): (Vocalising)

Emma (11:05): You know, autistic spectrum conditions as well. So there's a, there's a full range and it's right from, um, nursery right up to secondary. Um, so it's, yeah, it's been open the whole time and they they've been really supportive actually. They've got, um, a volunteer rota. Um, and because I'm at home shielded with Hugh, they've said I don't need to be on it at the moment, which has been great. So I'm not having to go into school, but they've got full PPE and everything, um, when they're in school supporting the children. So I know that when it's time for me to go back it's as safe as it possibly can be, and at the moment I'm just working from home. So we've been sort of preparing lots of, lots of learning packs for the parents to use at home. Um, and look at the curriculum, online training, all of those kinds of things.

Lucy (11:52): We know from Hugh's Facebook page, that he loves music. And, what has music bought through your lockdown experience?

Emma (12:01): Yeah, he does. He really, really loves music. He's really good at it as well. You know, it's something he can do. Obviously he needs lots of support with so many different aspects of his life and music is something that he can access independently himself and he's, he's, he can spend an inordinate amount of time playing the guitar and it's lovely. He gets such joy from that and it's such a pleasure for me, really helps with his, with his moods, with his, he gets anxiety about being in new places or new things happening or, you know, various things caused, cause him to get quite anxious and upset and the, um, having access to his guitar, his ukulele, and being able to play that independently really, really helps him, um, and really helps to calm him down. So it's been, I think probably every single day he's been playing one instrument or another, and his favourite is the guitar. He also likes the ukulele and his keyboard. We've been using the keyboard sort of propped up and then putting him in his, um, and his walker so that we're, we're still trying, so he's weight bearing and standing. So we'll put him in that and then he'll have the keyboard and he'll be playing that. And that will distract him from the fact that he's actually doing physio at the same time. So yeah, every single day I would imagine, he's, if you give him a choice of what he wants, it's pretty much always a musical instrument he'll choose over his other toys.

Hugh (13:22): (Vocalising)

Emma (13:25): Um, and then listening to music, he listens to music every single night before bed.

Hugh (13:29): (Vocalising).

- Emma (13:29):** So it's part of his routine, he, um, he chooses to go to bed around about between half six and half seven, he asks to go down to bed.
- Emma (13:42):** (To Hugh) Yeah, don't you? And then we'll stick on the radio on for him. And he has his disco lights and his bubble tube on, and he absolutely loves that. Now on a Friday night it's 80's disco night. So he has, we set his room up and it's all UV lights and like a fluorescent things. Then he has all 80's music and it's a full on disco in his bedroom. So he absolutely loves it!
- Lucy (14:05):** Gonna say 'cause we all need an 80's lockdown disco night. Sounds great.
- Emma (14:11):** Yeah, no, it is, it's good fun. It's good for, I'll just lie on the bed with him and you've got all these lights going around the ceiling. You've got all these different things. I've got these, uh, fluorescent pens as well. And he's got bumpers on the side of his, on the side of his bed. So we like draw patterns in the fluorescent lights and we just lie there chilling out, listening to music. It's brilliant.
- Amber (14:34):** Amazing! Amazing.
- Emma (14:34):** It's a good job he does like 80's music, I'm guessing he didn't really have much choice in that matter, but it's, but it's good. Cause if he liked something I hated that I probably wouldn't be quite as keen to, to lie in the bed enjoying it with him. He uses music and song to kind make sense of, of the day and the routines that we have, like a good morning song that we do every morning when I go into him. He has a song for brushing his teeth , a song for washing his face. A song for having his hair cut, 'cause been doing lockdown haircuts, and he hates having his hair cut, he really, really does. So we've got a lock down haircut, and I know, we did lock down story massage, as well. And that seems to have a lot less, sorry, a haircut story massage. And that seems to have helped him adapt a little bit better, accept the haircuts.
- Amber (15:22):** Where have you found out, how to do the story haircut massage?
- Emma (15:27):** I mean, the thing with Facebook and the internet and been on lockdown is loads of people have been just giving their resources away for free, which has been absolutely amazing. Um, so I was familiar with story massage, but haven't really used it that much. Um, but then sort of, I've been watching the videos and we've been joining in with some of the sessions. Um, and I just kind of got a bit more confident in the whole process of, of, of what it was really. So we just made one up basically, you know, like a little poem, um 'cause he likes kind of rhyme and repetition. So a little poem to go with, what's going to happen in your haircut and you know, it's all right, you're gonna have a bath and a bit of a splash afterwards. And um, and then just massage strokes to go with it so that he's got, you know, that he knows that there's, there's a start, a middle, and an end. And at the end you get the bath, yay! Do like, um, a story massage live every, uh, I think it's twice a week they do them. They're really, really nice. Really nice.

Amber (16:26): Yeah brilliant, we'll put them on our website show notes for the podcast.

Emma (16:30): Fantastic. Yeah.

Amber (16:32): And also we've seen a very cute video, which I think is a bit old, on your Facebook page. Lucy, nearly lost her mind. Of your little dog, Barnie. And can you tell us a little bit more about what Barnie brings to the household?

Emma (16:47): Yeah. So that, I think I'm guessing the video you're on about is the one that just, um, it all went a bit nuts a couple of years ago. I think it's probably, it's probably, it's about two years coming up to two years old now. Barney was sat, we'd only had him a couple of weeks, um, so he was probably know 14, 15 weeks old Barney was. And we kind of sat him as a little puppy on Hugh's lap. And he was just so like cute and loving towards him. And then they did this like little high five and was just, it was just really, really sweet. But I put it on Facebook and it went, it literally went viral, and it was all a bit scary.

Hugh (17:22): (Vocalises)

Emma (17:22): I had these like news agents just contacting me and it was on Lad Bible. And on like the Daily Mail Snapchat page, it was, it just went everywhere and I was a bit, um, yeah, it was a bit scary. I didn't really know what to do. Um, and I, and I did panic when it went viral. Cause I thought, I don't want, I don't want to be on the receiving end of, of any, any nastiness. I really won't be able to handle it if people are mean and you know what, not a single person was. Everybody was just delighted. We, I mean, I had thousands and thousands of messages, um, with, uh, you know, via twitter and Facebook with people just saying how lovely it was, um, how amazing animals were, how we don't deserve dogs. It was just, it just, it was the, there was this amazing outpouring of love and it was really, really lovely, but I mean, I think, I think it's important to know that Barney is not a gentle dog by nature. So he's a Springer Spaniel. So he is as nuts as you would imagine, a Springer Spaniel to be. He's bouncy, and excitable and he's just full on crazy, um, really energetic. But he's ever so good with Hugh! He's so gentle with him. So, um, this week I've been trying to do resonance boards activities with Hugh, and Hugh has decided, you know, he doesn't like the, resonance board and has been getting quite upset and anxious on it. And Barney, bless him, when he hears him crying, he just kind of climbs onto the board next to him and he's laid down next to him to try and calm him down. Um, when Hugh hasn't been well, there was one night Hugh was really upset and unwell, Barney sat beside him and started crying. He's like, he's so is so lovely with Hugh. Um, and I mean, he's not like that with the rest of us, but he's, he's a lovely dog, don't get me wrong, but he's not that gentle with the rest of us. You know, he runs rings around the park and he's into the river I mean he was swimming in the river yesterday. He's just crazy. He's so he's so lovely with Hugh. He's really, he's really intuitive, really gentle with them. I think, I think for all of us Barney's, um, saved our sanity is, is the truth of it. I think initially when, when lockdown started, I was like so anxious, and so, you know, full on panic attacks about 'the germs!' and you know, what was going to happen to Hugh, and what was going

to happen to me if I got it, and I couldn't look after Hugh, and who was going to look after Hugh if, if we were too sick, cause you know, there is, there is nobody else that that can have that can have him. So I was in this full blown panic mode, didn't want to leave the house, but of course Barney needed walking. So it made me go out of the house. Initially that was so difficult because I mean, there was one day I literally went out with Barney and my oldest son, Shaun, and I was jumping into bushes trying to get away from people. And I was like hyperventilating. I was nearly crying, it was horrid. So I started then taking Barney out at half past six in the morning, so I wouldn't see anybody. But he made me get out every day. And I think I would have really happily locked myself away completely, and then found it really difficult to get back to normality because I wouldn't have, I wouldn't have left the house at all, but because I needed to take Barney out, um, I did, um, you know what, I can walk along the road with other people in, in the vicinity without having panic attacks. So that's good. My husband again, would have really, really struggled if he'd had to stay in the house all day, every day, he's used to being out and being busy. And so again, taking Barney out, I mean, they've gone on some really long walks together. I said, I think, I think it's helps us all, it really has.

- Amber (20:59):** I think when you're in a intensive family lockdown situation as well, just any opportunity to do something that's just a tiny bit different or kind of a moment to yourself as well as just as an absolute lifesaver. Isn't it?
- Emma (21:13):** Absolutely. Absolutely. We're lucky. We live not far from quite a big country park. That's got, you know, like a little river running through it and it's nice big open space and you can, you can walk..
- Hugh (21:23):** (Vocalises).
- Emma (21:23):** You can walk for miles and not see people and it's, it's really lovely. It's been, it's been great being able to do that. I think it helps, getting out into the fresh air.
- Lucy (21:37):** So we heard you speaking at Raising the Bar last year and your talk had a huge focus on living life to the full, how have you been able to take this attitude into a global pandemic?
- Emma (21:48):** So, yeah, living life to the full, but being too scared to leave the house (laughs). I try to be as positive as I can be. We've faced some really difficult challenges with Hugh's health over the years, some really terrifying times. And I've always tried to not let the fear control us, which is easier said than done. When Hugh was, when Hugh was really little, and he was, you know, he was, he was terribly poorly and I would kind of like before I woke up in the morning I'd just like, before I'd open my eyes, I'd literally pray, like, please still be breathing. Please still be alive. We had no care, we had no monitors, nothing. And you know, it was, it was, it was a really, really stressful, difficult time. And I remember thinking, how is it possible to continue living like this? And what if this was all it was ever going to be? You know, like what if tomorrow didn't come and I didn't want to regret not having made the most of today. I worked really hard at trying

to be positive and be happy and do fun things and make the most of, you know, if I couldn't change the circumstances we were living in, I couldn't wave a magic wand and make him better. What I could do is make the most of now and live in the moment as it were. And so after the first initial weeks of the pandemic where I was terrified, I realised 'I can't live like this'. I can't, it reminded me of those early days when I was literally too scared to leave the house with him 'cause he was so ill, it reminded me of that time. And I thought, you know, you have to, this is the way it is now. You have to accept that and make the most of it. And so that's kind of what we did. And once we start, you know, just do fun things, try and find something every single day that that makes us happy. Um, once I kind of got the mindset around that and started to think about things that we could do safely with Hugh. So we went to, um, you know, cause obviously we're still shielding, we went to the stables. So one of his carers mum's has some stables. So we're able to bring him there knowing that there wasn't going to be lots of people around. And he was able to spend time with the animals, which, which he loves we took Barney with us. We just kind of spent a few hours there. That's it really. I think it's always about, accepting that I can't change either Hugh's health or the fact that it's a global pandemic. I can't change any of that. What I can do is change how I approach it and if I can make the most of it and be as positive as possible and enjoy what we can rather than just waiting for it to be over.

Amber (24:27): I mean, it sounds like an amazing attitude and really interesting to, for you to say how, what you've experienced early on in the pandemic was similar to something you've experienced before as well and using the same kind of techniques to adopt that positive attitude. In regards to shielding do you have any idea, have you been given any information at all about how long that might have to go on for?

Emma (24:52): I mean the letter itself didn't come for a good few weeks anyway. By that point we'd already decided to shield him ourselves and pulled him and his brother out of school, even before kind of the government had made it mandatory. Because we just figured that actually the risks to Hugh would be so significant..

Hugh (25:10): (Vocalises).

Emma (25:10): (Laughs) He's in a great mood this morning! And so we'd already made those decisions anyway. And then we had a few texts from, from the government. Um, so I think that the most recent date we've been given is the 30th of June. Um, but to my mind, like it doesn't suddenly finish on the 30th of June. It's not suddenly gonna have disappeared. The world's not going to suddenly go back to normal on the 30th of June. So I've been trying to gradually get my mind around the fact that things are going to have to slowly get back to normal in a safe a way as possible. I'm looking at ways of getting Hugh out of the house, we've been for drives with him. I've gone over to my mum's and sat in her back garden. So that I'm taking those small steps ready for transitioning back into, into a normal life. Um, I've spoken to his consultants as well and, and sort of sought advice from them about what the risk level is to him and come

September, we're going to be hitting flu season again, September, October time when everyone's going to be getting ready to go back to school. The thing is, with Hugh's health, we've been facing, you know, life and death decisions for, for 10 years, um, we risk assess absolutely everything all the time anyway, because of, because of his health. You know, I, I don't go, we don't leave the country to, to go abroad. We, we only ever go to places that are easily accessible to the emergency services. Any place I go on holiday, absolutely always find out about transfer times to the local A&E. So every everything we do in Hugh's life has always been about risk assessing because, um, you know, his health complications are significant. So we will, I guess, transition back to some form of normality. Um, and we'll take each day as it comes and risk assess as we go along and, and decide what's, what's safest and what's best for Hugh. That's all what we can do. And just hope that we have access to the information, um, to be able to do that really. Actually, he's been so healthy since he's been home.

Hugh (27:26): (Vocalises).

Emma (27:26): It's like his communications come on really well. He's like he's thriving being at home, he really is.

Amber (27:33): That's what Joanna Grace said, didn't she, in her podcast episode. That you'd expect that children's communication who've been at home with their families will have come a long way.

Emma (27:44): Yeah and that's not what I'd expected at all. I was really surprised to hear her say that because I kind of thought maybe it would be the opposite because they weren't getting all of that stimulation, um, from school, they didn't have the same routines going on. But I think for Hugh and obviously for the children that Joanna Grace has been talking about as well, and in fact, I spoke to Hugh's, um, the, the disability social worker, and she said that she was finding the same with her families. They've come on in so many other ways. I think the being able to sleep as much as he needs to is really helped Hugh as well, so that when he is awake, he's more ready to learn and, and make, make progress in those areas instead of just being constantly exhausted and catching every bug going at school. So yeah, it's been, it's really, it's, it's made a tremendous difference to him actually being at home.

Amber (28:36): And there been so many changes that we've all been through at this time. And, you know, there's a lot of talk of the 'new normal' and when things can go back to the way they were before. But are there any changes that you hope will support people with profound and multiple learning disabilities in the future influenced by this time in lockdown?

Emma (28:54): One of the key things that I've, I'd like to see is a more flexible approach to schooling. It's been clear to me that making Hugh get out of bed at half past seven in the morning, and shoving him on a bus, fast asleep, isn't really in his best interest. And whilst, that's obvious, I suppose, it's what you do because that's what you have to do. You know, he has to go to school and he has to be

there for nine o'clock and that's just the way it is. And he has to be there for five days a week. And I would love to see, because if I'm not the only person that's noticing these differences in, in the, um, the progress their children have made, once they've not been at school, then maybe there needs to be a more flexible approach to schooling maybe. And it won't be for all children. Some people absolutely need to be there five days a week and will thrive on that routine. But for Hugh, I think the more flexible approach to the hours that he has to do, um, would be, would be great. Another thing I think would be brilliant, um, to continue is the being able to access appointments virtually. So not necessarily having to go to the hospital all the time for different appointments, but they can be done over the phone or by video. So we've had a few of those, and that's been great. I really, really liked that the community nursing team had gotten, thankfully we haven't had to use it, but they've got a system where they would, um, if, you know, it's the called a rapid response team so that if your child starts to get ill it's trying to prevent them going into hospital, they've got like a dedicated team for the children with the more complex needs and they, um, they were going to do virtual video calls. Um, so they would do video calls to try and assess the child like that and then if they felt that they needed to come into the house they would, they would do so, but I think access to, to, to that to continue would be brilliant. I think it would be great to, to be able to have some of your appointments that way, but it's not all about that. Life's actually really, really good and positive and fun. And, um, he brings such a huge amount of joy to all of our lives. You know, my life is better because Hugh is in it. He doesn't take away, all those profound disabilities, all those health needs, doesn't make my life less sad or depressing. You know, I have a wonderful life and it's wonderful because of Hugh, and Shaun of course, and you know, my husband and my dog as well. But you know, Hugh add's so much to my life and I think that people are, uh, frightened of disability. Um, because they don't know enough about it, I suppose, if you've never lived with somebody with profound and multiple learning disabilities, you know, the prospect might be quite frightening. And I hope really with, with his Facebook page, I show that it's, it's not, it's a really joy filled life. It's a life filled with love and laughter and fun. Um, and I really hope that comes across. That's the, that's the point of it now, really.

Lucy (31:59): And that was the reason why we wanted to interview you because we love that spreading that positivity, because that's what we see in our work. We make work for really amazing audiences and have really great times and wanting to, yeah, show the really positive side of it. And I think that's what you do really, really well with um, and you Hugh, with your Facebook page.

Hugh (32:23): Yeah.

Emma (32:24): Yeah. You do. You do, don't you. With your big smile. Yeah, and your music. And your dog. Yeah!

Hugh (32:38): Vocalises

Emma (32:38): You're not bad at this are ya! We'll have to get you some more Zoom meetings. He's quite enjoyed this I think.

Lucy (32:41): You're very good at it.

Emma (32:44): I didn't give him his guitar. Do you want me to pass him his guitar and he can play you a little tune.

Lucy (32:48): Oh yes please! Yes, please High. We'd love to have some guitar.

Emma (32:51): Would you like that Hugh? Of course you would. (Passes Hugh guitar, guitar sounds). Probably needs tuning in fairness.

Hugh (33:06): (Plays guitar).

Emma (33:06): Good boy!

Hugh (33:06): (Plays guitar).

Emma (33:06): Yeah, that sounds like it needs tuning to me.

Lucy (33:11): Sounds great.

Emma (33:11): He loves it, he absolutely loves it.

Hugh (33:11): (Plays guitar)

Lucy (33:13): You can see.

Hugh (33:14): (Plays guitar)

Emma (33:14): You gonna sing for us as well?

Hugh (33:14): (Plays guitar).

Lucy (33:14): Play us out Hugh.

Emma (33:14): Like your theme tune for the end of your show.

Lucy (33:26): Well, thank you so much guys.

Emma (33:29): Oh thanks for having us on. It's been really lovely. I'm really honoured that you asked. Thank you.

Amber (33:33): It was really great to hear from Emma and Hugh and see what they've been up to. It was lovely to hear some of Hugh's guitar. I've heard much more of it on

Hugh's Facebook page and if you haven't seen the dog video that went viral with Hugh and Barney, the dog, you've got to check it out.

Lucy (33:49): Um, but yeah, really lovely. I think it's what I really love about Emma is, is the positivity that she puts into everything that she does, but also how she admits that she's worked really, really hard for that mindset. And I think it would be really easy for her to feel quite stressed and anxious all the time, especially during this pandemic, but actually that she's taken that and flipped it on its head and tried to see the positivity. And really spread that message of positivity around.

Amber (34:24): It's also the first time that we've had someone come on, the podcast who is shielding. And, and it's interesting to see how that has impacted life so differently from those of us who are not shielding. And now as restrictions start to relax what differences that makes to your life and actually how little clarity there is on how to go forward. You know, what support can be given to people who are not sure what to do next.

Lucy (34:54): So thanks again Emma and Hugh! And up next week we have Rachel Wright, who is mum to Sam. She runs Born at the Right time website and blog. She's a trainer, she's a nurse, she's written a book, she runs Camp Jo Jo. We're really excited to talk to Rachel about all the things that she does, to hear about Sam, about what those guys have been up to in lockdown. So do listen, I think it will be a really interesting episode.

Amber (35:07): Now that we are up and running with the podcast, we are aiming to get the episodes out to you every Wednesday.

Lucy (35:20): So please do drop us a line, send us an email, let us know if you enjoy the podcast, let us know if there's anything else you think we should cover and just keep in touch.

Amber (35:30): Um, you can listen to the podcast on all different sorts of podcasts channels, but on our website, www.frozenlighttheatre.com/podcast. You can listen to all of the episodes there as well as have access to all the show notes, which are links that we've been discussing with our guests and links to our guests, and also a transcript of the episode.

Lucy (35:52): And you can find us on Apple podcast, Google Play...

Amber (35:55): Spotify...

Lucy (35:55): All the usual places you get your podcasts! Please rate and review and subscribe. We would really love that.

Amber (36:04): We are /frozenlighttheatre on facebook and @frozentheatre on twitter and /frozenlighttheatre on Instagram. You can get us on email at info@frozenlighttheatre.com.

Lucy (36:20): Thanks for listening. And we will see you next time. Bye!

Amber (36:24): Thanks for listening everyone. Bye bye!

Jingle (36:24): (Jazzy music)