

# FROZEN LIGHT

## Frozen Light Podcast

### Episode 6 – Interview with Lucy and Thomas Williams, Riding on a Star

- Lucy:** Hello, and welcome to the Frozen Light podcast.
- Amber:** A podcast aimed at staying in touch with the PMLD community in the age of coronavirus.
- Jingle:** Jazzy Music
- Amber:** I'm Amber Onat Gregory.
- Lucy:** And I'm Lucy Garland, and we're the Co-Artistic Directors of Frozen Light.
- Amber:** We're usually seen around the country touring multisensory theatre shows, but now that the theatre industry is currently in lockdown, we are making a podcast to stay in touch with our audiences.
- Lucy:** So, on today's podcast, we've got Lucy and Thomas Williams joining us from Wales, and we've come across Lucy on Facebook where she runs a great page called Riding on a Star.
- Amber:** She's also got a blog which we will link on our show notes.
- Lucy:** And we're really excited to hear what they've been up to in lockdown
- Amber:** So we will give Lucy and Thomas a quick ring now.
- Thomas W:** (Vocalising)
- Lucy:** So, hi Thomas, and hi Lucy, thank you for coming on the Frozen Light podcast today.
- Amber:** Lucy, would you like to introduce yourself and Thomas?
- Lucy W:** Good morning, I'm Lucy, this is Thomas. Thomas is nine. I blog about life with Thomas at Riding on a Star on Facebook and Twitter. I write about our experiences because I've just learnt so much from life with Thomas, and Thomas brings us so much joy. So much joy and happiness, and I like to share happy photos, happy videos, and just try and brighten people's day, but also educate people on living with someone with PMLD.
- Lucy:** So, Lucy, what does lockdown look like and how has life changed for you and for Thomas?
- Lucy W:** Well our lockdown started like mid-March, so before it was officially announced, I was getting quite nervous. My husband works in Liverpool

so we're in a busy urban area which is a couple of hours away from us, and I was starting to feel anxious about him being there and saying, "please can you start working from home?" because he was doing once a week. But he did do on Friday 13<sup>th</sup> March. He would have been home anyway, and he said "right, I've asked, from now on I'm going to be at home." And the children were still going to school, but by the Tuesday we kept them both home. Partly my daughter had a sore throat which wasn't listed as a symptom of coronavirus, but we felt like this has made us just too sort of anxious about it now and kept them both home from then. But it was sort of two days later I think the schools closed anyway.

**Amber:** And you guys are in Wales, aren't you?

**Lucy W:** Yes. We're in North Wales so the rules are a bit different.

**Amber:** And that's really interesting actually being in North Wales but your husband working Liverpool, because obviously there's been so much about not being able to cross that border.

**Lucy W:** Yeah. So, he's not had to go into work since then anyway, so it's not been an issue since then, but we have – I think early on, maybe, we did visit local shops, just dashed into the local Co-op or something. But since the first couple of weeks, we've not been anywhere apart from outside for a walk with our dog, or me and my husband run. But other than that, we've just remained –

**Thomas W:** (Vocalising)

**Lucy W:** Other than that, we've remained completely isolated.

**Lucy:** Thomas isn't going to school, and I've read your daughter's not going to school, is that correct?

**Lucy W:** No, sorry, so they're both at home since mid-March. And so, we have like our kind of routine really. Like I do Thomas' physio generally in the morning. I got his standing frame home from school like the day after we kept him home so that I can put him in that. He has his own Eye Gaze equipment at home, so he goes on that, and then it's trying to juggle everything really. We're trying to persuade my daughter to do some schoolwork, getting, you know, jobs around the house done, because whilst my husband's at home he is working full-time. We stopped care that week as well, so we did have respite care two afternoons a week, and we stopped that then as well. We were still entitled to it, and we still would be, but we felt anxious that, you know, the carers coming in would be going to other vulnerable children, and obviously having more contact with people in the community, so we just felt like it wasn't really worth the risk.

And my mum would also look after Thomas sometimes. She comes, you know, some afternoons and helps out, so we've not – well we haven't had her in until this week actually, things have changed because we've got PPE, but for that period, you know, till this week we just haven't had anyone in to look after Thomas or any respite.

**Amber:** And just to say, this week we are currently recording on Tuesday the 30<sup>th</sup> June and this podcast will be going out in a couple of weeks, and things are changing quite rapidly. So, was it easy enough for you guys to get PPE this week to have your mum come round and things, because I know that's been a really difficult thing for everyone?

**Lucy W:** Well we hadn't looked into it initially, I saw it advertised by Well Child charity that they said that they had some PPE that had been donated and that families could apply for it, so we thought that's one option because we know with my mum that she's been very limited with who she has contacted with. You know, she is visiting some shops, but really minimally, so we knew that, you know, she was less of a risk than the carers that would be coming in from the health service. So, I contacted Well Child and put through the application, and spoke to them and said this is why we'd like some. And so, the box arrived Friday or Saturday.

Obviously checked with my mum as well, "would you be comfortable doing this," so she said "yes," and she came on Sunday all sort of – well, we sort of left the things on the doorstep, she got changed on the doorstep, and she had her mask and her apron and the gloves, so it was a bit – you know, it's a bit of a shame that she's obviously in that situation and not got the proper contact with Thomas, but we had a bit of a sit down and read our books for an hour or so while she was here, and we could hear loads of laughing so obviously Thomas wasn't too stressed by it.

**Lucy:** And she must've been so pleased to see you guys and to see Thomas.

**Lucy W:** Yeah, she was really pleased to like have close contact with him, because since we've been allowed where you can have someone come to the house, and it be in the garden and the two-metre distance, we have done that. We haven't been really clear about Thomas' position regarding shielding because he didn't get a letter from the Welsh government which people who were told to shield should do. I spoke to a GP and said, "well what do you think?" and they said "well, yes, I think he should be." So, we had a letter from the GP, but that didn't trigger a lot of the other support.

We were fine with that because we struggled for shopping deliveries, and I did get on the priority list with Tesco through showing this letter and speaking to them, so that's not been too bad, and we haven't – I think we were told there's things like food boxes, but we weren't worried about that, it was just being able to get shopping delivered. So, it's not really been clear with like how much of a risk, you know, Thomas is, but we felt

well he must be at risk and we'd rather keep him safe, but we did sort of have – I'd say that's as far as we've gone is have my parents in the back garden sat on chairs sort of a good couple of metres away, so it was nice for the – you know, they've enjoyed seeing the children.

**Thomas W:** (vocalising)

**Lucy W:** Thomas has liked hearing my mum's voice and he does react to that, but I think because he's visually impaired then perhaps not seeing her kind of was a bit strange because he keeps seeing her close up, but he still seemed quite happy, and they were happy to see him, and it's obviously better than nothing.

**Lucy:** And nice for you to have an hour to read your book.

**Lucy W:** Yes.

**Lucy:** Yeah.

**Lucy W:** And she's coming again later this week, so ...

**Lucy:** Yes, good old grandmas.

**Amber:** And I'm really finding that like the first time you see people as lockdown is easing, like it's really lovely but it also feels quite odd. You know, it feels quite strange and –

**Lucy W:** Yes.

**Amber:** – different, and nothing is the same anymore, but I find the more you slowly, slowly see those same people the kind of more you develop what that kind of new normal looks like for your relationship which is really lovely.

**Lucy W:** Yeah, it is just very strange isn't it, but sort of the normal for now.

**Amber:** And you've mentioned the Eye Gaze technology. We've seen some great photos of Thomas using Eye Gaze technology at home. Can you tell us a bit about what this technology enables?

**Lucy W:** Well at Thomas' stage at the moment his communication with it is really quite minimal, but it does give him the opportunity that he's got some control and some agency, you know, over some things. So, he's got like the main grid and he can chose something off there. And there's some activities that involve kind of interaction with me. Like Thomas Says sort of based on the Simon Says game, so he will look at Thomas Says and then there's six different things he could choose from like tickle me, rub my head, clap your hands, so he can then obviously choose something and

then I'm responding to it. Or there's things to do like shooting bubbles, and then I've got a bubble gun and that sort of thing.

And some of the things are just like videos, there's a selection of YouTube videos for him to look at, and he can just spend hours looking at them, a bit like his sister really. And then we've got then the stop/more on different screens, where if he seems to have like stopped engaging, I'll give him that option and he can choose different, and then I'll go back to the menu and he can select something else. And more, we go back to what he was on. Or stop, then we stop being on the Eye Gaze altogether, so that hopefully he can build up one day and – yeah, or build up over the years.

**Amber:** And did that technology – was that something initiated by school, or how did that come about?

**Lucy W:** It came about six years ago now, then I came across the company Smart Box at the Kids Up North exhibit, so they talked to me about Eye Gaze, and then he had a trial then which happened in school, but that triggered then other things with Speech and Language referring him to an Assisted Technology Department and they got involved.

He had the E-Tran frame for eye pointing, a further trial with the Eye Gaze, but then when the NHS assessed it all, decided that he couldn't use it to a sufficient degree to be able to fund one, and he can have the E-Tran and sort of build up with the E-Tran because he would then learn eye pointing from that, and if he could demonstrate he could use that enough they may fund an Eye Gaze in the future.

So, I was then told about the Sequel Trust which funds communication devices, and I went to them and applied to them, and we did some fundraising to contribute to it as well, and my friends did, and he received that a year last November. And in the meantime, sorry, the school did purchase one that Thomas could use, but it was obviously a shared device and it was in one room that he could then go to in his slot. So, he's had his own since a year last November which goes back and forth to school so that he can use it there as well.

**Amber:** What's so tricky with that is obviously to not get funding for something that you're not able to use at that point in time, but, you know, the whole point is, is that it's developing communication over a period of time, isn't it, so how can you show that it's something that you can communicate with in the future.

**Lucy W:** Yes, exactly, so we were just sort of stuck then with that, you know, from their point of view.

**Lucy:** It seems such a shame that there was like a price tag put on Thomas being able to have something that could assist him in communicating and having

his own agency to make choices and decisions. It just seems really wrong in that aspect.

**Lucy W:** Yes, it was really disappointing. Because, like you say, how is he then supposed to show he can use it if he's not given the opportunity to use it.

**Thomas:** (Vocalising)

**Lucy W:** Because the problem with the E-Tran frame is it's dependent on you judging whether he's really looking at something or not, and I've never really felt that confident with it, whereas the Eye Gaze does seem to register him better. He's got to look at the same thing for a – well it is sort of – you can adjust the length, so because Thomas doesn't necessarily look at it for a long period it is just, I think, 1.5 seconds. Whereas I felt, when I'm holding this E-Tran frame in front of me, it's like "well is he really looking at it," because he's got a squint as well, so ...

**Lucy:** The E-Tran frame, is that less of a digital thing, is that more something that you would hold?

**Lucy W:** Yeah, so it's like a perspex frame which then has like a whole in the middle for you face so you can see him, and then handles at the side so you can hold it. And then you can stick things to it, so that like we've got the Velcro pieces to the top corners, and then cards with Velcro, you know, the opposite Velcro on the back to stick on there so that he could make choices between toys maybe and books and so on, which I've tried by photographing different toys and different books, but actually I'm probably not pursued it enough because I don't really feel confident that I'm judging it properly. And then I feel like if I get it wrong, he's going to be frustrated maybe, or he's not going to learn how to use it if I've interpreted, you know, his intentions wrongly.

**Amber:** Whereas what the Eye Gaze technology does is that that interprets his intentions, is that right?

**Lucy W:** Yes, so the camera picks up his eye movements, and therefore you can see, like the cursor going round the screen, and then to sort of select something he has to look at this one image for this 1.5 seconds. I mean it's not completely failsafe because you can calibrate it each time just to make sure it is set up for his eyes and the position he's in that day. So, you do see a difference, if I calibrated it for Thomas and then I try and test it I find that it's activating something slightly to one side to where I'm actually looking. So, obviously if it wasn't set up and calibrated properly when Thomas was using it, then it could be interpreting his eye movements wrongly, and so I have to set it up each time. Well I do, do so just to make sure, but certainly like the one in school being used by different children, you know, it would have to be checked for Thomas each time you used it.

**Amber:** I mean it's really just having that opportunity to communicate, isn't it? It's like how when we create a theatre show it's not about everyone necessarily coming and having the same experience at that theatre show, but it's the opportunity to access theatre, and this, again, it's like the opportunity to access a form of communication.

**Lucy W:** Yes. I think giving him those opportunities sometimes that he's got some control rather than just having things done to him. He's got at least that period where he can have some choice, and sometimes that choice is immediately to go to "what next?" "stop" as soon as I've put him on it, where I'm like "oh, OK, not in the mood today."

**Lucy G:** Well I think that's come through in a lot of our interviews, that importance of somebody being able to make a choice and have space and time to be able to do that.

**Amber:** And in Episode Two of this podcast, Joanna Grace talks about the importance of visibility of people with PMRD in our online world. We know that Thomas has recently been involved in an advertising campaign for a children's play product, how did that opportunity come about?

**Lucy W:** Oh, well local to us there's a company called Doctor Zigs that makes giant bubbles and bubble kits, sensory bubbles and all sorts, and we met them, we think, about six years ago when they visited the hospice that Thomas has respite at, and they brought their product in then and demonstrated them and gave some to the hospice. And then I came across the owner of the business in other occasions, and we can't actually remember how now, called Paola, and so we've just kept in contact since then.

They shared some photos yesterday from their new campaign which has come about as a result of the Black Lives Matter movement and they felt, you know, what can we be doing more to be more diverse as a company, so they've had a new photoshoot for their product to put photos on their products, so including children of different backgrounds, ethnicities and so on, and they got in touch and asked if Thomas would be willing to go along and be photographed and be one of the children that features on their products and in their advertising in the future.

**Amber:** Amazing, and I've seen the photos on your Facebook and they're amazing, and I've also had a look at the website and I've seen a previous photo of Thomas on there, and there's an entire bubble that surrounds him which just looks so cool and it must have been a lot of fun to shoot that, Thomas.

**Lucy W:** Yes, it was when we – again, when we visited, they have a – where they sell the products they also – they have like a barn, a Bubble Barn they called it, and birthday parties could be hosted there and things. I've just realised Thomas has pulled his glasses down.

**Lucy:** You've lost your glasses, Thomas.

**Lucy W:** So, we visited there for another child's birthday party, and then the week after they had like a Halloween event.

**Thomas W:** (Vocalising)

**Lucy W:** As Thomas may be telling us. And so, they had a fancy-dress competition, and Thomas went dressed up as like a Halloween spider.

**Thomas W:** (vocalising)

**Lucy:** Yes. Nice.

**Lucy W:** He won a fancy-dress competition that day, and as you saw, he was enclosed in a giant bubble while he was there which was very nice.

**Lucy:** Look, I mean who doesn't want to be enclosed in a giant bubble, it looked amazing.

**Amber:** I do. I want to be enclosed in a giant bubble, that's now what I want.

**Lucy W:** I did one to

**Lucy:** Is it good?

**Lucy W:** We did that, like I say, the first time we met them in the hospital they brought kit to be able to. I think at that time they couldn't put Thomas in one, but they then developed stuff they could do something big enough to go over a wheelchair.

**Amber:** But that's really cool, so previously that product wasn't accessible for a wheelchair user and then they adapted their products to make it accessible?

**Lucy W:** Yes, I think so, from recollection, because, like I say, at that time it was just myself, my husband, and my daughter and staff at the hospice that went in the bubble, the way they did that, the way it sort of lifted up. But then we visited them in their place which was about three years ago, they then had like with the bubble wand, in the same way that they do their giant bubbles, so then they'd have two people stood either side and then it's a sort of square with string. I don't know how much you could pick that up from the photograph, but then they could get the mixture on the string and then pull it down over him so that the top of the bubble would stay above him and the bubble would then come down around him until it popped on him.

**Lucy:** This sounds like a Frozen Light priority, Amber.

**Amber:** It does, it does, we need this in our next show, this is amazing.



**Lucy:** So, in your latest blog post in regards to shielding for 11 weeks, you end up by saying “we’re therefore left wondering so what now?” And this was on the 4<sup>th</sup> June. So, have things changed for your family since then, and what support and advice do you feel would be useful for you?

**Lucy W:** I think it’s just been all really unclear about the risk to Thomas. You know, like I explained, we didn’t get a shielding letter from the government, and the GP thought Thomas was at risk, or could be classed as extremely vulnerable, but we don’t know for sure, and I appreciate obviously with the nature of the virus, nobody is really going to be sure, but it just has been difficult not knowing. And we then therefore have seen people that are just really relaxed about it. When lockdown was in place, people who were then breaking those rules and meeting up and putting others at risk, and then since it’s all been loosened, which it has been less here in Wales –

**Thomas W:** (Vocalising)

**Lucy W:** – but we are getting to the – you know, we are loosening up now, shops are now opening, the schools were going back this week but they’ve closed in this – or they’ve now not reopened in this area due to a big spike in a local factory, so then they were due to open. In my daughter’s case, she’s in Secondary School, and it was one year per day, so they were going to go in on Mondays for four weeks, but then they’re now not opening this week anyway, but I don’t really follow exactly what the rules are now because we’ve just said “right, we’re still sticking to the same things.” But when you see that like cases are still climbing in this area, and yet things are being loosening up, then it makes us sort of more anxious really. We’re still concerned, but other people are getting more relaxed and going out and about more.

Things have changed for us in respect of now being able to see some family members, and we’re considering whether to get the carers back in, because we were struggling, and we’ve kind of come to a realisation of we’re not going to escape this, we’re not going to get to the stage where it’s gone away and we can relax and everything be perfectly fine. When it comes to September then my daughter will certainly have to go back to school. I think she’s struggling now, and then we’re going to then have that risk that she could bring it back into the home. My son – sorry, my husband should still be able to work from home. Thomas as well, is what do I do about him, because do I keep him off all the time.

I’ve got a job I’m supposed to start, so, again, that’s like looking at September time, so we felt like well do we at this stage sort of give in and say “OK, well we’ll have the carers in,” because they will have PPE, it won’t be, you know, really risky, but we still feel like even with that there is that slight risk, so we haven’t been taking it before, but we’ve got to the point of saying well, for our own sort of welfare and mental health, we say “OK,

we'll have to accept something," and, you know, the risk being minimal, but do we do that. But, again, we sort of delayed that decision because of the local outbreak, so we're still trying to weigh that up for the next few weeks.

**Amber:** Yeah, when did you find out about the local outbreak? When did that become apparent?

**Lucy W:** About a couple of weeks ago they started saying there's an outbreak in the chicken factory, and there was, I think at the time, sort of 13 cases, and that was when we were discussing with the manager from the community childrens nursing team could we have the carers back, because they check with us, you know, every month "do you want them in at the moment," and we said "yeah, we are thinking about it, but, you know, can we talk to you and weigh everything up," and then we seen this in the news, and then sort of contacting them back going "yeah, well we're a bit worried about this now," that there could be a spike in the area, and then it's built up to 200 positive cases.

And I think prior to that, the only confirmed cases in the area, or the number of the confirmed cases in the area was around 250 altogether, but I think there is some – I think it's probably a bit skewed, because they have tested everyone there, or pretty much all the staff there, whereas obviously prior to that there would have been a lot of people in the area having the virus but not been tested, wouldn't there, so I guess it's not a complete picture.

**Amber:** No, I think in all of this so much is guesswork, and it's so tricky when that guesswork is left up to us as individuals, isn't it?

**Lucy W:** Yes. And like so that's the thing with weighing up what to do now, because you think well we stopped having carers in in March, and we stopped seeing everyone in March, and yet there was probably like next to no cases in our area, and now we're reaching like this kind of number –

**Thomas W:** (Vocalising)

**Lucy W:** – and, you know, perhaps the risk is at its highest now, so it would be perhaps stupid to then have, you know, people come back in who are in contact with other people in the community and other vulnerable children.

**Amber:** Completely. And you've obviously gone through a huge period of change throughout this period. Are there any changes that have happened that you hope will support people with profound and multiple learning difficulties in the future influenced by this time in lockdown?

**Lucy W:** To be honest, not really, and I was thinking this before when I listened to your previous interviews and caught up with Joanna Grace's, and what she

said, and, again, she – you know, I’m probably more negative than she can be, she’s always very positive, but even she said similar to what I was thinking of “I feel like we’ve been forgotten.” And it’s only amongst the PMLD community itself that I feel like we’ve supported each other, but other than that, I feel like we’ve been forgotten. I feel like when you’re talking of, you know, extremely vulnerable people, the governments seem to think it’s like elderly people and yet pretty much anybody, you know, like that’s vulnerable because of disability or, you know, long-term illness, certainly children, so I don’t feel that much has really changed to make people more aware of children like Thomas and, you know, other people with PMLD. So, therefore, I think that maybe in the future people will remember them, and remember the issues that they can have and therefore make further adaptations in future.

**Lucy:** One of our reasons for wanting to start the podcast just to try and document people’s stories and try and get them out there a little bit, and obviously there’s a big community on Facebook in particular of people like yourself, and that’s how we found you, who have Facebook pages and do blogging all about, kind of, being a family, and living with someone with profound learning difficulties. And I think you guys do amazing jobs at, you know, keeping that in the public eye, but it’s just about how do we get it out, because that reaches our communities and it needs to go further than that, doesn’t it?

**Lucy W:** Yeah. I mean there have been some things. I mean we appeared on like the Welsh news about the issue to do with getting shopping, priority shopping slots at the time and the struggle we were having then, so, you know, we did have that feature where Thomas was, you know, visible. So, there have been things, but I don’t know how much, you know, people really have taken that on board, or certainly those with, you know, the power.

**Amber:** What do you think would be the best support that you could be given at a time when it’s so hard to receive support. I think that’s the great challenge isn’t it? It’s so hard to receive the support that you would usually want because of that transmission risk. Is there another way that isn’t that hands-on care that you would feel supported as a family?

**Thomas W:** (Vocalising)

**Lucy W:** I think it’s just like being having the information really of like, you know, the professionals that are kind of doing the – not the researchers obviously, but kind of find out more and advise us more about the risks to Thomas if they can through like their connections. Other than that, you know, like I say, we’ve had the contact checking whether we want the respite care, and we get contact from the hospice again checking on us, and they’ve sent activities, school have sent things through. The physios, you know, we had a call from them as well to check on that and if I’m happy

with doing the physio exercises. I don't really know what else actually, but it is just really the respite and just it not being full-on, just the time to sit down and like take a break, that's been the difficult bit.

**Lucy:** Yeah, there's just been no time for you and your husband to have a rest.

**Lucy W:** No, not really. Like we go – you know, one of us walks the dog each day and one of us goes for a run, but then it's just trying to cram it all in because my husband finishes work at half-past-four so then he might come and take over with Thomas. I go and get changed, go out for my run, have a shower, I've got to them cook, do dishes and so on. Then, you know, we have the evening to spend some time with my daughter. And then I think she's been struggling, I've been spending a bit more time with her at like bedtime stuff as well, so I haven't even – like early on I was getting into bed and then having a little bit of a read, but now I haven't even been doing that either as much, so it has been a bit full-on.

**Lucy:** And you run as well? This seems to be a theme in our podcasts. Everyone we interview is really into running.

**Lucy W:** Yeah, I started a couple of years ago, so it does really help. And, again, I've blogged about that and how it's helped with my mental health and getting that me time and so on. So, we've kept that up, both of us, trying to fit that in, it's the one thing that we do try and make sure we fit in.

**Lucy:** Oh, well, amazing. It's been so lovely to talk to you, Lucy. I think we also have to mention your amazing backdrop that you've got going on there. There's like blue and pink swirls, and butterflies. This is amazing. Where are you?

**Lucy W:** This is one of – well, Thomas has kind of got two rooms, because he's got his bedroom which is quite small, and then this is the room the lift comes into where we do his physio, and he's got his other bits and bobs. So, his wall design was created by his sister, she drew it in pencil.

**Amber:** Amazing.

**Lucy W:** And then she – I think, yeah, she chose the colours, and we've got florescent paint through the colours, and then we have a UV light.

**Amber:** Oh.

**Lucy W:** So, then we can turn all the lights out, do the blind, or put the blind down, and shine a UV light on it and it all glows.

**Lucy:** Thomas, that is really cool. We all need this in our room. So, thank you so much, Lucy and Thomas, for talking to us today, it's been really, really lovely to meet you.

**Amber:** Thank you.

**Lucy W:** Well thank you very much for talking to us.

**Lucy:** Bye.

**Amber:** All right, bye.

**Lucy W:** Bye.

**Lucy:** Thank you so much, Lucy and Thomas, and it was really lovely to have Thomas in as part of that Zoom call.

**Amber:** Yeah, it was really great to hear from them and hear a perspective. I particularly liked it being across the border in Wales because there's been so much conversation in the news about the restrictions being slightly different in different areas of the UK, so that was quite interesting.

**Lucy:** I think it came through, and I think this has come through a few episodes, of peoples real lack of information being given to them, the fact that Lucy and Thomas never received a shielding letter and so therefore was stopped from getting any support or information that they really needed.

**Amber:** Yeah, and that's not the first guest we've had on who have expected shielding letters and never received them because they think services have kind of presumed someone else would do it. And obviously there's been a huge amount of people to be contacted throughout this process, but that is fascinating.

**Lucy:** And I also thought what came through on that, when talking to Lucy about the Eye Gaze technology, is how much she's had to fight for Thomas to have access to that. And I think that's stories that we hear time and time again from our audience that perhaps the contribution of people with PMLD just isn't valued, and therefore people don't get access to things that could greatly improve their quality of life and their ability to be able to communicate their needs and desires and give them a sense of autonomy and independence.

**Amber:** On a positive note, it was great to hear about Thomas' photo shoot for the bubble advertising campaign, and to hear about their experiences of playing with bubbles and using them, and the photos taken, and again brings us back to what Joanna Grace was saying earlier on in the podcast about "if people with profound and multiple learning disabilities were visible in society, then perhaps society would be better at listening to their needs."

**Lucy:** That's one of the reasons at Frozen Light that we tour our shows to theatre venues is to increase the visibility for people with PMLD, because only when people are visible does society get any better for them. But during

this time in lockdown, we were like but we're not able to do that. So that's why we started this podcast to hopefully help to support that visibility.

**Amber:** I'm going to take it back to the bubbles for one more second because the bubbles were so exciting, but I also thought it was great about how the product wasn't at first accessible for Thomas because they couldn't put an entire bubble over his wheelchair which was the entire concept of the product, so they went away and they had to change their product specifications to ensure that they'd be able to do that, which I think is really, really great.

And again, it just shows that if you have people with different needs involved in these campaigns and using these products, then you actually see what's necessary. You can see how society needs to change and adapt.

**Lucy:** Yeah, and I wouldn't have thought that was very hard. They just took an existing product and made it slightly larger, and that came about through Thomas being visible. And through Thomas' visibility to them, they went "oh, great, actually we can market this to a bigger group of people." Ultimately, it's like going to be financially better for them that they've done that.

**Amber:** Yeah, really cool. So, that was great. And next on the podcast, we have the Disabled Children's Partnership who we were really keen to speak to because they've been doing a lot of research during lockdown about families experiences of this time. So, we can't wait to speak to them next week.

**Lucy:** So, thanks for listening everybody. You can find our podcast on our website at [www.frozenlighttheatre.com/podcasts](http://www.frozenlighttheatre.com/podcasts). You can also get it in all the usual places you'd access your podcasts, Apple podcasts, Spotify, Google Play, and all the other podcast platforms.

**Amber:** And you can get us on Facebook at [www.facebook.com/frozenlighttheatre](http://www.facebook.com/frozenlighttheatre) and at Twitter @FrozenTheatre, and on Instagram @FrozenLightTheatre, and on our website which Lucy previously mentioned, you can get an episode, transcript, and all of the show notes, as well as a photo of the guest.

**Lucy:** Please do rate, review, and subscribe to the podcast, it would really help us out. And do let us know if there's anything you'd like included, or send us any feedback with any of your thoughts to [info@frozenlighttheatre.com](mailto:info@frozenlighttheatre.com)

**Amber:** Thanks for listening everyone. Bye.

**Lucy:** Bye.

**Jingle:** Jazzy music

[End of recorded material at 00:35:17]