

# FROZEN LIGHT

## Frozen Light Podcast

### Episode 5 – Interview with Dr Nicola Grove from Surviving Through Story

- Lucy ([00:00](#)): Welcome to The Frozen Light Podcast
- Amber ([00:01](#)): A podcast aimed at staying in touch with the PMLD community in the age of corona virus.
- Jingle ([00:08](#)): (Jazzy music plays)
- Amber ([00:19](#)): Hello, I'm Amber Onat Gregory.
- Lucy ([00:22](#)): And I'm Lucy Garland, and we are the Co-Artistic Directors of Frozen Light, a theatre company that makes multi-sensory theatre audiences with profound and multiple learning disabilities.
- Amber ([00:32](#)): Thank you so much for joining us today on our podcast. Our one bit of Frozen Light news is that we are still looking for people with PMLD and their surrounding community to join us on our audience panel as we navigate through the next few months, and hopefully not too many years, of how theatres will be reopening. We really want to ensure that when audiences with PMLD are able to come back to the theatre, that we ensure that we are doing it in the best way possible. So please do get in touch with us at [info@frozenlighttheatre.com](mailto:info@frozenlighttheatre.com).
- Lucy ([01:08](#)): So on today's podcast, we are really, really excited to be talking to Dr Nicola Grove from Surviving Through Story. And we also have guest appearances from Katrina and Flo and Josh. So we are really, really excited to talk to them today.
- Amber ([01:28](#)): We'll give Nicola a ring now.
- Sound Effect ([01:30](#)): (Phone ringing sound effect)
- Lucy ([01:33](#)): So hello, Dr Nicola Grove, and welcome to The Frozen Light Podcast.
- Nicola ([01:38](#)): Thank you so much.
- Amber ([01:40](#)): It's so lovely to have you with us today, which is Thursday, the 25th of June. We've been really excited about having you come on to talk about Surviving Through Story, because we've heard so much about you and the program, both through Annie Fergusson, and Joanna Grace, who we really, really respect both

of their work. So we're so excited to be able to have you to speak to today. Um, could you introduce yourself to the listeners?

**Nicola (02:07):**

Certainly. Um, I want to start by saying it's a huge privilege to have been invited onto this podcast. It really is. I've been very excited looking at what Frozen Light does. I'm, uh, technically retired, I'm in my seventies and I started out life as an English teacher. And then I retrained as a speech and language therapist, um, back in the 1970s. And I've always worked with adults and children with severe and profound learning disabilities, they are kind of my great love really. I mean, I've worked across the board and I started out specialising in augmentative and alternative communication and my PhD was in sign language use. And then I got very interested in narrative and story and to cut a long story- story (laughter)- short I was then working, uh, at City University training speech and language therapists. And I left that when I got the funding to set up an experimental storytelling company for adults with learning disabilities called Open Storytellers, which is now a charity based in Frome. And I founded Open Storytellers, which is now very much thriving and doing really, really well without me. So I'm actually leaving that organisation as a trustee and leaving it in very, very good heart. Story in all its forms is something that I've been incredibly interested in ever since when I was working as a speech therapist, I noticed that in both day centres and schools, less in schools, but certainly in social care situations, people would tell stories about people with profound disabilities, but they never, never told them with them. And so I started exploring why that was, and out of that came this project called Story Sharing, which we'll be talking about later. That's a rather long introduction to me. Flo Hopwood and Katrina Arab are both Story Sharing tutors and absolutely inspirational teachers. And I'm just so lucky to have them on the Surviving through Story team.

**Amber (04:24):**

And we're going to hear from Katrina now.

**Katrina (04:26):**

Hi, I'm Katrina one third of the Surviving Through Story team and also a class teacher at Three Way School. And I am based in a primary class of PMLD learners. Lockdown has been an incredibly trying time for absolutely everybody in the UK. And speaking as a teacher, getting to grips with keeping in contact with my class of PMLD learners through a digital medium has been the biggest challenge of all. I am mostly using music and movement based activities, as well as Story Sharing on a one to one basis to connect with my pupils through the computer. And I'm having to fully rely on parent participation and enthusiasm. At Three Ways, we use Class Dojo to keep in regular contact with parents, and this has had a massive impact on opening up communication between parents and teaching staff, which has only deepened and strengthened my understanding of who my pupils are in and out of a classroom setting. Connecting with some of the most complex pupils via video conferencing has been pleasantly surprising to me. And I really held back from using this medium to connect for quite well because I foolishly thought that they would struggle to engage with so many barriers in place, but actually the first time I met with them via zoom, very recently, I got quite emotional from how much awareness

and recognition they had of the familiar songs and routines I had tried to bring back to them at home from school. One particular pupil who at the best of times has the most subtle of communication methods frequently looked at the screen and stilled when the session had begun, something mum even commented was rare for him to do. This was such a meaningful interaction. And it made me feel so grateful that this medium had actually worked and has opened up so many more opportunities to meet with my class online, especially because I've been missing them so terribly. Using Story Sharing with my class online requires lots of preparation and communication with parents at home to organise resources and get all of the information that's going to be the most significant to each pupil. Their stories have been about things that may not seem massively out of the ordinary, but they are still significant experiences, and most importantly, personal to each individual. I try to focus on multi-sensory aspects of the story such as if there was music playing in the background I want to know exactly which song was playing so I can try to replicate and emphasise their experience. What smells were involved, who else was there? What were they doing? What was the temperature or weather that day? The way it then works is that once I have been given that information from the parent who obviously knows their child, well, we'll pick the experience that is significant and personal to them. I then script it and use the Story Sharing structure to share live using video conferencing software whilst also providing guidance and instruction to the parent, to create that multi-sensory environment at home, as much as we possibly can. It becomes an incredibly co-active experience and that will then be repeated multiple times. My expectation of pupil involvement will be very personal to the individual and will depend on their chosen method of communication. And that can vary from eye contact to smiles, vocalisations upon sentence completion, to activating a Big Mac switch for repetitive refrains. Their participation in sessions progress over time, which is why it's so important to repeat and repeat and repeat.

**Amber (07:54):** Thank you Katrina and we'll be hearing from Flo a bit later on in the interview .

**Lucy (07:58):** During this COVID-19 pandemic, you guys have been doing Surviving Through Story. So that was started as a response to COVID-19. How did that come about and what are the aims of that project?

**Nicola (08:10):** When the pandemic hit, I started looking around to see, well, what's available for people with learning disabilities who are faced with this. I mean, it was, you know, it's bad enough for the rest of us, the shock of going into lockdown and what that meant and not seeing friends and family. And I thought, well, what's happening for people with learning disabilities. So I had a look and there was, um, people were amazingly creative in, in really getting out some good resources. I mention Books Beyond Words and, um, Mencap and various other organisations, but it was all about information. So it was 'What is COVID-19, how should wash your hands? What are the restrictions? What does that mean?' Photo symbols came up with brilliant, brilliant images for these, but I knew that the way that I was getting through it, and everybody I knew was getting through was by sharing these little tiny stories. So you'd go, 'Oh, I got

this delivery, but you know, I got all of these...' It was my next door neighbour actually, who just got this enormous turnip, she said 'What am I going to do with this turnip!' (laughter). So there were kind of little funny stories, which kept you going, but, uh, but also of course, very difficult ones when people were taken ill or isolating at home, or whatever. And I thought, well, where, where is where are the resources to help families and, and everybody to support people with learning disabilities to tell those stories. So I put a call out to people that I knew to say, is there anybody interested in developing this as a project. And Flo and Katrina immediately came on board. And so we then kind of formed a little team. And shortly after that, the Open University Social History for Learning Disability people got in touch because Craig who's the co-chair of that organisation, and who has a learning disability, had been saying right from the start, 'I want to know what's happening with other people. How are other people with learning disabilities, getting through this? How will they cope if somebody passes away? Where can I find out?' In many ways it was, it was Craig and his need for this and passion for it, which kept me going. And then The OU said they would fund a website and then Generate UK, which is headed up by the very wonderful Beverly Dawkins who used to be involved in the profound and intellectual multiple disability service at Mencap and Generate came on board, um, and they are in fact going to be administering it, and the website we hope will be going live next week. It's had to go through ethics procedures with The OU and that will be somewhere where people can load their stories, their art work, their photos, their memories.

**Amber (11:14):**

Amazing. Sounds incredible.

**Nicola (11:15):**

So we started out thinking about how we could turn our own, what we knew was happening with families,, into little sensory stories.

**Amber (11:25):**

Can you tell us about some of the different stories that you've explored with participants as part of the project?

**Nicola (11:29):**

Yeah. So, um, you'll see one, uh, one lovely one, which is actually on the Facebook site, cause it was a Facebook site we set up first, cause that seemed relatively straightforward. There's a lovely haircutting one where a lad had his, uh, had his hair cut by his mum, which is, is very funny and that you can see that, but we tackle more serious things as well- so, um, as somebody who's been coming to our training, who works at Lush has posted about Black Lives Matter story that, that she's been doing... Katrina developed one that was all around Um, 'Boris Says Stay Alert'. More personal ones as well. So a story that you're going to hear is a story from a little lad called Josh, which he's been telling since coming back to school and back into a bubble. In his family, his mother had to self-isolate with her, her own mother and this, this little lad was missing her terribly, but his father said how incredibly helpful Story Sharing was in enabling him to deal with that and process it because Story Sharing as a strategy has been used in Three Ways School where both Katrina and Flo teach for the last hmm since about 2011. And it's very, very, very well embedded so all of the kids understand how to do it, they understand the process. Flo certainly

said to me, it's the one, she's had to go back in and work with kids that she doesn't know. And she said, it's the, it's the one approach that has really, really worked because they all know how to share a story. And so, Josh is telling this story to, um, his classmates and you can hear in his voice how emotional he is about, about it. He still is, it's very, very live for him, those feelings of grief, but gradually as Flo talks with him and talks him through the story that he's very well familiar with now because of the way his dad scripted it for him. He kind of calms down and you'll also hear that what Flo does is she keeps quite a kind of upbeat tone, but when he talks about, uh, 'I want mummy, I want mummy.' She just, she echoes that and she echoes it in a slightly calmer away. But by doing that, she creates that emotional resonance, which means that he knows his feelings are heard and validated, and that's one of the kind of processes that we use in Story Sharing to make sure that people's emotions are respected, but also managed through the, through the sharing of the story.

**Lucy (14:22):**

That's just so key. I think often people with learning disabilities aren't allowed to have emotions or those emotions aren't recognised and validated and valued as things, so to be able to have a process where that is enabled, that's, that's um, yeah, really amazing. So we've got that clip of Josh and before we play the clip of Josh, we've got a little clip of Flo who just explains what they do and the process leading into it. And then you'll hear Josh's Story.

**Flo (14:53):**

Hi there, my name's Flo Hopwood and I am also a teacher at Three Ways Special school in Bath. Um, and I am one of the trio that created Surviving Through Story. Um, you're gonna hear a Story Sharing session with a boy called Josh who has just turned 11, today! So that'll be a few days ago when you're listening to this. And, um, I don't know Josh at all. So being a teacher at a special needs school, I've got a class that I'm trying to contact and stay engaged with online, but I've also got a different class. Um, we're all calling them 'bubbles' these days in school. So my new bubble has got this boy called Josh in, who is an absolutely wonderful, delightful young chap. Um, but also has been very sad because his mum wasn't very well and had to move out for quite some time from the family home. His dad has been very supportive in talking to us about this and helping Josh to understand when mum will be back. Um, and she is, she is now back with him, which is fantastic, but we did use Story Sharing to help him understand this change, really significant change with his primary caregiver, not being around as well as coming back to school, being in a different class with different students and different staff. So you're going to listen to this story, which we haven't practiced very much. It's still very early days, but you can hear the emotion in Josh's voice and how he's still coming to terms with the fact that mum's come back and that he will see her when he goes home. Hopefully you can hear some of the techniques and the way that we've enabled Josh, who is verbal, but has quite, um, low level comprehension to understand his feelings and be able to feel a bit more secure in this new situation that he's finding himself in.

**Flo (16:41):**

So this is Josh's story.

Josh ([16:46](#)): Vocalises.

Flo ([16:46](#)): In June.

Josh ([16:46](#)): In June.

Flo ([16:46](#)): When Josh was in Yellow Bubble.

Josh ([16:50](#)): No, I wasn't in Yellow Bubble.

Flo ([17:01](#)): (Inhales) He wasn't in Yellow Bubble! He was actually...

Josh ([17:01](#)): At home

Flo ([17:01](#)): At home! He was only with, oo let's find the picture we want to show everybody. he was only with...

Josh ([17:01](#)): Mummy and daddy...

Flo ([17:01](#)): Mummy wasn't there. There was only...

Josh ([17:01](#)): Daddy.

Flo ([17:01](#)): And...

Josh ([17:01](#)): Ben

Flo ([17:01](#)): Ben, who's your...

Josh ([17:01](#)): Brother.

Flo ([17:01](#)): Brother. Josh said 'Dad, I want...!'

Josh ([17:01](#)): Mummy!

Flo ([17:01](#)): Mummy! But dad said 'you can't see him, Josh'. She's...

Josh ([17:26](#)): At home.

Flo ([17:26](#)): She's at Grandma's home, cause she's...

Josh ([17:28](#)): Why I want to see her today!

Flo ([17:28](#)): I want to see her but dad said she was feeling a bit....

Josh ([17:28](#)): Sad.

Flo ([17:28](#)): She's a bit sad and poorly.

Josh ([17:49](#)): I want to see her today.

Flo ([17:49](#)): 'I want to see her today' Josh said. But this is what happened. Josh had to eat dad's cooking. Josh thought dad's cooking was....

Josh ([17:49](#)): Good!

Flo ([18:09](#)): It was good actually!

Josh ([18:09](#)): Yeah.

Flo ([18:09](#)): But Josh said 'Dad I want...!'

Josh ([18:09](#)): Mummy!

Flo ([18:09](#)): Mummy! But dad said 'No she's still at..'

Josh ([18:22](#)): At home.

Flo ([18:22](#)): At home with Grandma because she's still...

Josh ([18:22](#)): Not well.

Flo ([18:22](#)): She's not well.

Josh ([18:22](#)): I want her back!

Flo ([18:22](#)): 'I want to see her, I want her back' Josh said So with dad they went to see Jack and... Daddy and Josh went to see...

Josh ([18:22](#)): Horses!

Flo ([18:22](#)): Some horses! When they were looking at the horses Josh you said...

Josh ([18:22](#)): I want to go on the iPad.

Flo ([18:22](#)): You want to look at the iPad. But when you were looking at the horses Josh you said 'Dad I want to see...!'

Josh ([18:22](#)): Mummy.

Flo ([18:22](#)): But dad said....

Josh ([18:22](#)): 'No'.

Flo ([18:22](#)): 'No, she's...'

Josh ([18:22](#)): Poorly.

Flo ([18:22](#)): Poorly.

Amber ([18:58](#)): And a big, thank you to Josh and Flo for sharing that story with us today on the Frozen Light Podcast. Hearing you speak Nicola about emotions has also made me think about how we incorporate storytelling in Frozen Light's work as well, when we make theatre for audiences with profound and multiple learning disabilities. 'Why do you use stories? You could just explore sensory things.' And we've always an, our stories always have, uh, an emotional arc and a narrative. And we've always said, you know, our audiences who are coming to see our work have emotional experiences and are going on their own emotional journeys in everyday life and often have a lived experience, particularly for the adults, um, who we work with, have a lived experience that is longer than ours. So of course exploring emotion is, is so, so crucial no matter what, um, what your learning disabilities are. And I think that's really interesting coming from what you were saying about how you can use story in this situation.

Nicola ([20:04](#)): And there's often a perception, mm, and you know, I don't blame staff for this, uh, not, not in schools, but, but you, as a speech therapist, I saw first-hand how young people that I'd worked with in school, cause I crossed over between social care and schools. I've seen young, young people that I've worked with in school go into social care, uh, where the focus is not education it's, it's care. And so it's different sets of priorities and how they would lose skills that had been built up over years. They could lose their skills in a matter of weeks because of the problems of transition. This was I to say a very long time ago, but I think it can still happen. And very often I think that you get staff are frightened of unleashing emotions. So they will say, 'Oh, it's better not, you know, it's, it's better not to talk about that with them. It's better.' I've, I've, I've seen, you know, where somebody has died and nobody has, nobody has mentioned it because you mustn't upset them. Actually it's the staff of course, who were upset, and what I always used to say was, 'do you really think that just because you're not talking about it, they haven't noticed?' You know, those feelings are there. And all you're doing by not managing them is making sure that they just get banked down and cause all sorts of, of mental health problems and behavioural problems for those individuals.

Lucy ([21:46](#)): So how have you found connecting with participants through digital medium?

Nicola ([21:51](#)): Uh, well I know that for Katrina, she said it's been really, really hard for her, partly because the families are so overloaded with everything, with the youngsters, with PMLD it's obviously difficult to get their attention, um, to zoom. We've been running these different training sessions with Surviving Through Story. And so we've got a little group of people, including Annie Fergusson, and she's done some quite helpful things about putting backdrops behind the screen to make it more visually stimulating, uh, and providing



materials that, um, can be used by family members. Like, uh, I think this was with her, her own family member, Annie actually, um, sending through a jumper with her scent on it that could be held while he was looking at the screen. So I think that, I think people are finding immensely innovative ways actually of, uh, using this technology. And it's paradoxically been a very, very creative time. So I'm obviously not teaching, but I did get involved, um, with Generate, they run some young people's groups on Zoom, their use clubs. And I joined them to create online newsletters with screenshots and, um, comic strip, which I did through sharing the screen. And then they would say something and I would type it into a speech bubble we would kind of create the newsletter online and it was absolutely chaotic. But, um, again, you know, I just, I just learned a lot through doing that about how it is possible to be interactive on, um, on Zoom and the, uh, we've got a video on the site of little girl called Abby, telling uh co-telling the story of going to hospital with her teacher and the, the parent is there providing the props for this child. And the teacher co tells using story sharing techniques with this little girl, um, giving a message actually from this child about how it is possible to go into hospital and have a difficult time using, um, a mask and a ventilator, but actually come out the other end and remember it as uh, it's a story of resilience, which is, is really what this site is all about. It's how can we enable all of us really, but inclusively enable us to build resilience through memories is that we can share and feel proud to share. That's a term of Colwyn Trevarthen's, which I love about healthy mind builds strong memories in company with others, and that's how we get through things.

**Amber (24:42):**

And it really is an amazing video and we'll link that in our show notes as well so if you want to check it out, you can watch that. You've just mentioned doing some training. Can you tell us a bit more about the training that you've provided through this time? Who's it aimed at and what are the different things that you are exploring?

**Nicola (24:59):**

Yeah, absolutely. So, um, it's, it started out because, uh, Flo and Katrina wanted to do something for their fellow professionals about how they, how to use story sharing on Zoom. So we put together a webinar that was, that was focused on that. Um, but then we thought, well, why not open it up to some other people as well? And we had about 30 people for that first webinar. And then we thought, well, there's some other things we could be doing here. So we were incredibly lucky to get very, very generous people giving up their time. Um, the first one we had was on bereavement and loss, and that's a recorded one with Professor Irene Tuffrey-Wijne who's a leading expert on, uh, loss and death in people with learning disabilities and how to support people through this. And so that, that was the first one because it felt very, very critical to have that and we had a lot of people there. And then the last, the next three, we focused on creative storytelling approaches. So we started with Story Massage. Um, Mary Atkinson who has this lovely website, um, showing the principles of story massage and, uh, also Ashleigh Padden who's a very innovative speech therapist who uses yoga and movement as part of her speech therapy practice to enable people to vocalise and communicate and she works with kids with PMLD and that's, you know, really, really innovative. The next one we had was the Emma

Hughes who's co-director of the Soundabout Choir. And she was talking about interactive music on Zoom, which was just inspirational and how they were running the choir. And if you go and look at the Soundabout website, you'll see the amazing stuff that they've put together. Um, but she had also some sort of simple ideas for doing music activities on online with, um, people with severe and profound disabilities and Flo then also talked about how she, cause she's a music therapist as well as a teacher, but how she incorporated music in her storytelling and story sharing sessions. And then we've got one more of those coming up tomorrow, which is multimedia and storytelling and David Messa who is professor at The OU who developed one of the most useful digital apps for personal stories, uh, several years ago now, but it's just relaunched with the new version of it, which is Our Story Too. It's completely free app to download and it enables you to take pictures on an iPad and then link them into a very, very simple story framework and kids can create their own stories with it. Followed by a colleague and friend of mine Mascha Legel who's an incredible creative filmmaker in the Netherlands. Who's been running a project for about the past five years to train young people with complex needs as filmmakers. So she has an actual course, and she has young people who are, who don't have disabilities, who act as the kind of peer tutors and during the whole COVID lockdown, she's been coaching young people with complex needs in how to make their own vlogs. And it's called Cam on Wheels, really, really inspirational and she's going to talk us through that, and that will be followed by, uh, another Story Sharing training session. This time it's the foundation for a registered practitioner training called Story Sharing for recovery, which will focus on how Story Sharing promotes resilience. And then is followed by practitioner training, which is much more in depth. If you watch Jess telling that story with Abby, it looks really intuitive, it looks really easy, but I can tell you that it's, it's not quite as easy as all that, it was actually adapting your communication to refrain from the kind of question asking, which tends to dominate the way that we get stories from people.

**Amber (29:15):** And obviously it sounds like there's a wealth of information out there, um, through, through this training, how can people find out about it? Do you post it on the Facebook page?

**Nicola (29:26):** Absolutely yes. So there are a couple of posters about it on the Facebook page, and you can email me, I've set up, um, specific email account, which is nicolagrovesend@gmail.com. Um, and it's so if you're, and you want to register for any of those, you can either leave a message on the Facebook site, or you can send me an email.

**Lucy (29:48):** Are there any changes you hope will support people with PMLD in the future that may have been influenced by this time in lockdown?

**Nicola (29:55):** I would love to think so. Um, so when Flo and Katrina, were reflecting on this question, um, they felt increased training opportunities through the UK, and I certainly think that's the case. I think what everybody's familiarity now with online platforms means that there's just been an explosion of opportunities to

learn and develop your professional capacity. Now I think that's really, really exciting. What we'd, what we would all like to see is the voices of people with learning disabilities, including people with PMLD, being heard and out there, and that is absolutely not happening. And it's something that makes me, it makes me very frustrated actually. So the BBC covered the explosion in deaths of people with learning disabilities, because of course in care homes, they are so vulnerable, and they have died, excess deaths in that community has been huge. So the BBC covered this, but they always talk to families and carers, you know, you never hear them actually talking to people with learning disabilities themselves. One of the stories that, um, Sue Ledger from The OU group has sent is from a woman whose husband died and it's an incredibly moving testimony to their life together, but it also explains to people what happens in a funeral and what happened in the funeral there and how she had been unable to say goodbye to him. I mean, it's, she dictated it over the phone to Sue and it is one of the most moving things I've ever read and it deserves to be up and out there. One of the things that is there that you can see on the website is, is a young man called Terry, who is a member of Generate. And he sent us a story all about his reactions to lockdown and his reactions to Boris Johnson's message. I have to say that the clarity of Terry's thinking as compared to the kind of muddle that came across from politicians is, is really inspiring. You know, he's understood exactly what's going on. And he says, 'Just, don't go out, just stay at home. I don't know what being alert means'. And then he says, 'Nicola, if you can tell this to Boris Johnson, please tell the government' because we need to hear from these people, people like Craig, Terry, you know, they, they can tell us firsthand what's happening. People with PMLD through Story Sharing, through innovative use of technology, of images, of props. They can show you what life is like for them in this pandemic. They can tell you, Bev's work at Mencap with a project called Meet the People absolutely showed that people with PMLD can be involved in the conversation. They can contribute to public discourse and they should be able to, but we shut them out. You know, we shut them out in a group who are called vulnerable and it's shameful, it's shameful, and it should change. But at the moment, I'm not seeing the evidence that it is. Um, and I would really like to see a culture shift where we start listening to people, not just to families and carers, but to people with learning disabilities themselves about the kind of world they want to build.

**Lucy (33:40):** Absolutely.

**Amber (33:41):** And we often use 'Meet the People' in our training and we talk about it. But again, that was in 2009, you know, what's, what's happened since then? That entire team who worked on that project disappeared after Meet the People, and it was such a huge body of work. And sometimes now sharing those clips, I do have to say, 'Oh, they might seem a bit outdated' because things like technology have moved on so much and the quality of the filming and things like that. And you know, why aren't projects like that happening now?

**Nicola (34:11):** Yeah, absolutely. Well maybe together we can make something happen. I mean, the, so the website it's been a bit frustrating cause you know, we had the idea

such a long time ago, but we, it was so important to get the ethics, right. So that when people are posting stuff up, they know what they are consenting to. And we've got really robust consent process to safeguard what people are doing. Cause it's very easy to disclose sensitive information about yourself that's quite emotional and then see it kind of everywhere and not quite realise what's going on, but we're, we're very confident about our processes. So the website will be a kind of living archive of these stories. Um, there's going to be a page there, which is about celebrating lives. So that's where people can put tributes to people they know who who've died as well as, you know, creative projects that people have been doing as well as just their little stories about how, what they've been doing and The OU are hoping they're going to have a conference next year, hopefully- a real live conference! Um, but, uh, what we're thinking about is having a kind of events online, leading up to that. So something like an online exhibition and we are linking to some other sites like national voices. Um, and uh, there are some other groups like, Harrow Mencap are doing some really good stuff. So if you, if you know of any organisations that are doing innovative stuff, please get in touch with us. And, um, we'll send you the details of the website. Cause we really want that website to be full of experiences. It's quite interesting, I did a paper some years ago with my son actually about people with intellectual disabilities in war. I wrote it because there was this very, very shocking information coming out of Iraq of how people with learning disabilities had been groomed as suicide bombers. And I wanted to explore what on earth was happening there. Dr Sam Grove who's my son did some of the background research for it. And what he found was that during the Second World War people with learning disabilities actually worked as frontline workers. They contributed to the war effort. Um, they volunteered, they were, I don't know, I'm sure they weren't paid, but you know, they were, um, doing some frontline, very, very vital tasks that contributed to the building of a new society after the war. And that contribution has been forgotten, missed, lost. You know, so people with learning disabilities have been traditionally regarded as, as people who, who were takers, you know, who, who are in receipt of benefits and not people who are net contributors to our society, but they are, they have, people have, they have so much to contribute, because they're individuals like everybody else. And they can make us think in a different way about our lives and our priorities. And we need to record, we need to make sure that those memories and those sacrifices and those stories and that wisdom from that community do not get lost, but get used to help us vision where we want to be in the future for our children and our children's children.

**Amber (37:43):** So many people have been written out of history, and this is becoming more and more apparent in the world that we are currently living in. And it's about how, how can we find out about the lives of those people who haven't been included in the history books.

**Nicola (37:59):** Absolutely.

**Amber (38:00):** And include them now. So you've obviously started a whole new body of work through this pandemic, um, through the Surviving Through Story program,

which is the Facebook page and it's about to have this website and we've spoken about the training as well. Thinking about a future post lockdown and hopefully a post COVID future, certainly a post COVID future, as COVID as we know now, what's, what are you keen to take forward?

**Nicola (38:30):** We want a society that values how people work in community, values society, right? Um, but I think we're going to have to fight for it. I, you know, this is not just going to happen automatically. If you, if, if you want a new future, then you've got, we need to be campaigning. We need to be thinking politically, small p, and, and working really hard for that because it is not just going to happen. We are going to have to use a lot of creative energy to make that change happen. It's not going to be automatic.

**Lucy (39:12):** Something yeah. A real positivity that could come out of it if we work hard. And if people are really willing to change their mindsets and, and value people as human beings.

**Nicola (39:24):** Yes. Ultimately. Yeah, absolutely.

**Lucy (39:29):** I've had an amazing hour. Thank you. Absolutely fascinating. I feel like I've learned loads and now have a long, long list of more learning I need to go and do, um, and we'll link as much as we can onto the website.

**Nicola (39:44):** Well, I just like to say a very big, thank you for giving me, us, the opportunity to publicise what we're doing and to get that word out there. It really is about the message, Surviving Through Story, is not a kind of project which has an end point in itself. It's about, it's a tool to use, to enable people to, to survive and more than survive to grow and create. So thank you so much because I've really enjoyed talking to you, such great questions.

**Lucy (40:18):** I feel like I have just had the most fascinating conversation.

**Amber (40:24):** It was really, really exciting. And we've heard so much about Nicola's work before through other people we respect so much like Annie Fergusson and Joanna Grace, and it was amazing to meet Nicola in person via the internet, um, about the work that she has done. I think particularly in terms of the work that we do as a theatre company, we're so often questioned about why we use narrative in our work, why we use storytelling, why not just focus on the sensory experiences, but the way that she speaks about the importance of story and the importance of people with learning disabilities, to have the opportunity to access story and communicate with story through something like a global pandemic was really quite incredible.

**Lucy (41:13):** And also that real focus on emotion as well. I, I found really, um, interesting that allowing people with learning disabilities to be able to show their emotions and to have their emotions validated, it's really, really important. And I think with our work, we always try and take the audience on an emotional journey so that

people can see emotion reflected on stage. And so often, you know, we all use art and culture to see stories reflected and to look into that, and that's what we try and do with Frozen Light.

**Amber (41:50):** Also the whole reason that we've started this podcast, started in lockdown, was because we want the experience of people with PMLD in their community to be recorded during this time, because we feel so much that people with profound and multiple learning disabilities experiences aren't shared with the rest of society in the same way, um, that other peoples are. And, uh, what sounds amazing about the Surviving Through Story website, which is hopefully will have been published by this time, this podcast airs, but if not, I will still certainly keep a look out for it so we can put it on the show notes as soon as it is, is that it's going to be an amazing place to document people's experiences and to remember people who, who were lost during this time, and to also look at what people have been through and what their emotions are. And I think that's just an incredible resource.

**Lucy (42:45):** And I think with this podcast, a big question for us has been like, well, we're always talking to the family members or the people who support people with PMLD and actually what Nicola and Flo and Katrina have managed to do is create a resource where those voices of people that are nonverbal or have kind of limited verbal communication are actually able to share their stories and to share their experiences. And it's coming from them. And I feel like that's something that we haven't managed to achieve with this podcast. So for that, that to have happened and for Nicola's kind of generosity of saying that we can perhaps learn from her and start to be more involved in that I'm really, really excited at what that looks like moving forwards.

**Amber (43:30):** Up next week on the podcast we have Lucy Williams from Riding on a Star and Thomas, and we cannot wait to meet them.

**Lucy (43:40):** So if you have any questions, you're interested in coming on the podcast, you're interested in the audience panel do please get in touch with us. You can do that at [info@frozenlighttheatre.com](mailto:info@frozenlighttheatre.com). You can find the podcast on our website at [www.frozenlighttheatre.com/podcast](http://www.frozenlighttheatre.com/podcast). You can also find it on Apple podcasts, Spotify, and all the other places where you usually get your podcasts. Please do rate, review and subscribe.

**Amber (44:14):** You can also find us on Facebook at [facebook.com/frozenlighttheatre](https://facebook.com/frozenlighttheatre) and on twitter [@frozentheatre](https://twitter.com/frozentheatre) and on Instagram [@frozenlighttheatre](https://instagram.com/frozenlighttheatre). Please do get in touch. We're really enjoying getting to know people throughout this period. So we love to hear from you.

**Lucy (44:32):** Thank you very much for listening today and we look forward to bringing you the next podcast.

**Amber (44:38):** Thank you. Bye bye!

Jingle ([44:38](#)): (Jazzy music plays)