

FROZEN LIGHT

Frozen Light Podcast

Episode Ten – Interview with Carole Kelly founder of Jolly Josh

- Lucy:** Hello and welcome to the Frozen Light podcast.
- Amber:** A podcast aimed at staying in touch with the PMLD community in the age or coronavirus.
- Jingle:** Jazzy piano music
- Lucy:** So I'm Lucy Garland and I'm one of the Co-Artistic Directors of Frozen Light.
- Amber:** And I'm Amber Onat Gregory and I am the other Co-Artistic Director of Frozen Light.
- Lucy:** And Frozen Light make multi sensory theatre for audiences with profound and multiple learning disabilities which tours all over the UK. And at the moment due to coronavirus our touring is on hold so we started this podcast with the aim of keeping in touch with our audience and increasing the visibility of people with PMLD during lockdown.
- Amber:** And we are loving staying in touch with people. So if you have any questions for us or you're interested in our recruitment of new trustees for our board, or being on the audience panel please do contact us on info@frozenlighttheatre.com.
- Lucy:** And on today's show we are talking to Carole from Jolly Josh.
- Amber:** We'll give her a ring now.
- Phone ring:** Phone ringing sound effect
- Lucy:** So hi Carole, welcome to the Frozen Light podcast.
- Carole:** Thanks for having me.
- Lucy:** You're welcome. And can you introduce yourself and Jolly Josh to the listeners?
- Carole:** I am a mum of three, to Sophie who's just turned six, Oliver who's just turned one and Joshua who would be four now but he passed away aged 15 months in 2017. I'm a wife, a daughter, a friend, a teacher and the founder of Jolly Josh. Jolly Josh aims to help families to connect, support and thrive and we aim to inspire inclusion for those with a loved one with

additional needs, complex needs and PMLD.

I volunteered at the local special school after Josh passed away just to gain a sense of what his education might have looked like had he survived to school age, and years later I acquired a job there as a teacher of children with PMLD. So I teach at that school now and also voluntarily manage Jolly Josh.

Lucy: So busy, really busy.

Carole: Yeah. Very.

Amber: That's amazing though that Josh introduced to that school and that's where you are now. How amazing.

Carole: Interestingly I was a play worker many moons ago in my, the sort of beginning of my career as a one to one support assistant for a play scheme in the school holidays so I already knew that it did sort of interest me, and I love working with children and it's come back round now.

Lucy: That's amazing.

Amber: Wonderful. And how did you make the decision to start Jolly Josh?

Carole: So I really wanted to connect with other families who had a disabled child. Joshua was born healthy, he was meeting all milestones and then after his four month immunisations he began to regress. We know now that they triggered a disorder thought to be mitochondrial disorder which is actually currently a storyline in Coronation Street.

He developed extensive brain damage and then just one week after his first birthday in May 2017 we were given the devastating prognosis that he had weeks if months to live which was a huge shock to us all. There was a massive gap in the system. A lack of support from similar existing groups especially from those in a position to empower my idea of Jolly Josh, they really didn't.

And actually that just made me all the more determined that the concept was needed and not just for me but for others too. I took Sophie and Joshua to almost three groups a week and never met another disabled child until I met Lorenza who became a friend and now is a family supported by Jolly Josh.

She actually features in our photography project as family B on our website. Both of our children at the time had nasal feeding tubes and we just made a beeline for each other across the room. We may as well have like thrown every mother aside to get to each other and I asked her so many questions.

I was new to tube feeding and I just bombarded her with questions.

And I think I came away with the confirmation that Jolly Josh was needed. And we wanted our families to connect. I wanted for Sophie to meet other young sibling carers but professionals follow confidentiality policies and they really couldn't link me with other families however they did really support the idea of Jolly Josh, so much so that they agreed to become trustees on the group.

So I started planning. I used our time in the Manchester Children's Hospital and Derian Children's Hospice to plan really. Joshua passed away in August 2017 aged 15 months. He didn't manage to attend a Jolly Josh session as we'd hoped for but we opened exactly one month after his passing.

And it really was a way for me to direct my grief into something positive and create a legacy for him as well. And then a year later in April 2018 we became an official charity with registered status so it kind of went to grander schemes than I ever imagined really.

Lucy: And that must have been like ah, it's just moving fast.

Carole: Yeah, it really did move fast but I think that again proved the need for the group, you know, we were becoming bigger than our expectations and it really did just clarify the need that it wasn't just me that needed it. There were a lot of other families that needed to access such a service.

Amber: And it sounds like an incredible journey to have been on both with Josh and with the organisation. You mentioned Corrie earlier and how Josh's condition is currently a storyline that they're exploring.

Carole: I already follow the Lily Foundation which is a charity that supports families with supports families with children with mitochondrial disorder so they're sort of the place where you go if you have got a diagnosis or symptoms of mito. So I was already following the Lily Foundation anyway but they've managed to really support Coronation Street with the storyline.

I won't be watching it. I haven't watched it but I fully back the story and I believe from what I'm seeing that Jane Danson who plays Leanne Battersby is doing a phenomenal job in portraying our stories if you will as the mother of a child with mitochondrial disorder. So I do lots of tweets to her on Twitter in the hope that we can also raise the awareness of Jolly Josh as well.

Lucy: Yeah, and I think that's just like what soap operas can do so well because they sit with people in their living rooms. If you're really into a soap it feels like you're part of the family.

Carole: I did write a blog for when Coronation Street becomes your reality. I read a lot online of people saying “Oh it’s only a soap opera” lots of comments on social media “It’s only a soap opera” and I thought no there are absolutely hundreds of thousands of people living out this similar storyline. It might not be the exact storyline but we’ve lived it, we’ve walked those characters shoes albeit a different journey.

But it’s real and I’m really pleased that it’s raised awareness of the disorder because when we got diagnosis in 2017, well we still actually don’t have diagnosis, no formal diagnosis, it was the symptoms that provided the diagnosis but we’ve not had formal – but when we got that prognosis in 2017 we’d never heard of it.

Nobody, you know, nobody in our family or friendship circle had ever heard of it hence the reason why you get in touch with the Lily Foundation. They’re the experts in the field and they support the families out there with that prognosis.

Lucy: Moving on a little bit but also we probably should have put this in the beginning, can you just explain a little bit about what Jolly Josh is now and what it does?

Carole: At present Jolly Josh, well prior to COVID because everything is so changed now, but prior to COVID we were running weekly stay and play sessions at the school where I work which is Springside with Hamer Learning Community School in Rochdale and one morning a week we were holding sort of a stay and play session.

I really wanted to make it easier for people to access so that we have all Joshua’s equipment there and obviously some donated equipment for seating support. So when I was accessing groups I had to take Joshua’s specialised seat in because he couldn’t sit up to access play. So it just means something else that parents don’t have to bring to the session.

They don’t have to lug around with them. They can arrive knowing that our venue and our sessions are accessible, so they just literally turn up and enjoy themselves. Joshua was supposed to be having a gastrostomy but we never got that fair but had he have done that we’d have been shown on a doll more likely the peg feed.

But at Jolly Josh pretty much most of our children have a peg feed and I can’t even count the number of times that mums have just lifted up their toddler’s top to show another mum who’s due to go to surgery with their child what it looks like, what they do, how they attach the feed, how it runs. So I think it really is a peer of group of reducing anxiety, bringing about knowledge and understanding.

And learning together. And then in addition I wanted us to meet professionals in a less formal manner in that they visit Jolly Josh. So every week we timetable a different professional. In the first year I think we had 23 different professionals visit so they ranged from nurses, GPs, dietitians, OTs, physios. The scope is huge.

But what it means is they come alongside our parents as a group. So they have a little bit more confidence. They're in their own zone. They're not having to go into clinic and the conversation is a lot more relaxed. The children are happily playing in our provision.

But also I think what that does is Joshua had 23 professionals working around his care I think. Although he might not have needed those professionals at the beginning we ended up needing them. So I think if your child doesn't need that professional now but in the future you can always think I've met that person at Jolly Josh.

I've got a face to the name. I've got a bit of familiarity so that when I do go to clinic it's a bit less daunting. So that's what we've done so far with Jolly Josh but the scope is due to change. We made an announcement in November 2019, so not so long ago, as a total surprise to our families and to myself at the time.

But in September we celebrated our second year anniversary, so we're still only a really small newly established charity but we were given the huge opportunity to develop our own venue. It still doesn't seem real. A home for Jolly Josh thanks to two incredibly generous local businessmen; Dan of Kerf Developments and Pete of PGC and the construction started in November so it was a bit of a whirlwind really.

We're really proud that we're housing a changing places facility and a hydro pool.

Amber: Woo!

Carole: Our families are absolutely over the moon, it really is huge for us and I do need to pinch myself that it's actually happening but it has been a huge journey already. It's been so stressful and challenging at times especially because Oliver was only two months old when we took on the build, and my husband James is the volunteer architect for the project.

So we've both not only invested an unsociable amount of time into the build but also it's, you know, it's been emotional for us and it has quite often questioned our sanity at times. But we're really proud. It has come at a high price and that's not just the price of the construction.

We've sacrificed a lot of ourselves to the venture but we just know it's

going to work, and we know it's going to make a huge difference to Rochdale and to our families. And hopefully the wider community. I think people will travel to reach us.

Lucy: So when do you reckon it will be open?

Carole: I think COVID has got a lot to answer for as it has for everything. It's had a big impact on the construction in terms of lockdown and our fundraising, and our access to bids as well but we are very grateful that a lot of businesses and people have got behind us in Rochdale. They've donated services, their time, their equipment, their efforts into creating an inclusive accessible centre for us.

So we do now have the shell. We did announce an exciting year for Jolly Josh because I think we were hoping to have opened but obviously we have been hampered but we're just so pleased that the vision is still progressing, and anybody who is interested can view the photographs on our website.

The hydrotherapy pool is in. The plasterboard is up. The shell of the changing places is there ready to be kitted out. So, yeah, in terms of the fact that this was only a decision made in September to know that we've got this far already on the back of volunteers and people and local businesses who have just given to Jolly Josh.

I think because we are all volunteers at Jolly Josh, we don't have any employed staff members at present, we've obviously had to do this alongside our work and our families, and now it's just a case of wait and see when we open really. We just keep ticking along but I think we're all impressed with the speed we've gone at so far really considering the decision was only made in September to build.

Lucy: I think it's incredible. I can't believe you've achieved so much especially like during a pandemic.

Carole: It is amazing when you think how much has been given to us, you know, there are businesses out there that have donated all of their time, all of their services, it is going to be very special for our community.

Amber: You talk about the charity and Jolly Josh with such energy and passion that I can totally see why you have so many organisations and people wanting to back the organisation, so that's just an amazing thing to have as an advocate, you know, that's what advocates need really.

Carole: I think we're very lucky, very lucky.

Amber: In episode two of the Frozen Light podcast Joanna Grace talks about the need of images of people with PMLD to be shared across social media, and

in episode six we met Thomas who is a model for a bubble production organisation which is amazing. During lockdown you've created a portrait of our families during lockdown 2020, can you tell us a bit more about this project, and actually it was this project that made us aware of Jolly Josh and of your organisation.

Carole:

Yeah, I've listened to the podcasts and I think it really does emphasise how much power our photography project has within representing our families within our community and society as a whole. Unfortunately they're not often represented. For example, I took Joshua to an event within our borough for parents and carers with disabled children and this was prior to his terminal diagnosis.

At this point we knew he had extensive brain damage but I was told by one person who was in a position of power and influence, and had the ability to support our family, that most disabled children are at home with their parents. And it really angered me. It suggested to me that I should stay hidden away with Joshua and it really would have been the easy option for me to do.

Joshua needed specialist equipment everywhere that we went. He needed 15 medicines a day in between his tube feeds and suction and then due to his condition he was sick more times than I could ever count. So staying at home hidden would have been the easy option but we wanted to be social and Sophie was almost three so I felt the real need for her to mix with peers.

And more than anything I wanted Joshua to experience and explore the world especially when we got terminal diagnosis. I paraded him around for the world to see. I think the idea of the photograph shoot came to me whilst watching This Morning actually. They were doing a feature on the Duchess of Cambridge and she'd revealed a project called Hold Still which was a portrait of our nation during lockdown.

And I decided that we could make this relevant to our charity and to our families and that in doing so, like you say, it would be a reminder to the public and the powers that be that our families exist behind our closed doors. They are shielding vulnerable loved ones and that we need to be considered within the guidance that they're creating.

And also it really enabled us to reach out to social media, to create awareness, like you say that's how you heard of our charity. And also the hope was that in seeing our families other families in similar circumstances would be encouraged to access our charity and again it allowed us to provide an insight to our sponsors, our supporters, our fundraisers to better understand where their support is going when they do support Jolly Josh.

So the project was huge really. It allowed us to do so many things within the one project. The images are incredibly emotive. Asha Burrell is an award winning photographer and she volunteered her time to create the gallery for us. She was actually our wedding photographer in 2017 and I broached her with the idea of creating this project and she jumped at the opportunity.

She was amazing. Our families were all very excited to do the photo shoots and I think are really grateful that we helped them to capture these memories. Also the gallery portrays helpers and heroes. Two of our Jolly Josh trustees are photographed in their professional capacity whilst they're out supporting our families in lockdown.

So the gallery was just for us a really wonderful project that was able to reach the wider society hopefully and represent our families out in our community.

Lucy: And they are really, really beautiful photos so do go on the Jolly Josh website and check them out, they're lovely.

Amber: And we'll share them on our podcast show notes as well.

Carole: Yeah, please do because they are incredible, very moving.

Lucy: So that's one that you've sort of stayed in touch with families during lockdown, are there any other ways that you as a Jolly Josh community have managed to stay connected?

Carole: Yeah, so like I said we are all volunteers at Jolly Josh. We've got no current employees. We ourselves have all continued to work throughout lockdown as key workers and NHS staff so it's been a difficult time for us behind the scenes as well but when our current weekly sessions had to close due to COVID it was crucial to us that our families were able to still connect and support one another.

So we created an online chat network for that to take place. It doesn't of course compare to the personal and physical engagement that they were getting at our sessions but it has provided a means for them to continue to connect, and they have, it's been amazing to see.

In addition we were really grateful to be supported by Rochdale Soup Kitchen throughout lockdown. They've supported 10 of our families with weekly food deliveries whilst they're shielding and we also provided a six week workshop which was delivered by Beyond Psychology called Dealing with Distress when Supporting Others.

And that was really interesting. It became really clear that lockdown

wasn't the only cause of anxiety for our families. The real source of our anxiety actually now relates to the easing of lockdown and how they transition into the new normal, and begin to really risk assess entering that world with their vulnerable loved one.

Lucy: And I think that's what we've heard from lots of our guests, you know, when it was, like everybody felt they were in it together and now it's sort of the world is opening up and actually becoming more dangerous for people with complex health needs.

Carole: Yeah, hugely, hugely and I think everybody's circumstances differ so much that it really is now individual risk assessments for each family and trying to venture into the new normal when it's safe and when you're ready to do so.

Amber: And we're recording this currently on 16 July and the current date for shielding ending as the Government keeps putting it is 1 August but Lucy sent me a link yesterday from the NHS website which was advice for people who are vulnerable to COVID about what steps they should take after the 1 August and it didn't use the word shielding but the steps you should take are basically to continue to shield.

So even though it's saying the last day is 1 August actually the NHS advice is to continue to keep these steps that we've all got in place now.

Carole: And I do think many of our families, you know, they've got some huge decisions to make and we've just got to respect everybody's personal opinions when it comes to stepping out into the new normal.

Amber: And the motto of Jolly Josh is the #connectsupportthrive. Having spoken to you now I can completely see where that hashtag comes from. You live and you breathe it in everything that you've created with Jolly Josh. One of the key things we keep hearing from people when recording a podcast is how isolated the learning disability community has felt during lockdown and we've just been speaking about this too.

How do you think we can connect and support each other more as a society particularly after experiencing a global pandemic?

Carole: Well it's really interesting because when lockdown began to ease and public places opened many of the toilets remained closed and of course it was criticised greatly by the public but this toilet issue has always been problematic for our families. Society has never really understood nor showed any real empathy until now when it's impacting them.

Our families have been changing their loved ones on urine soaked toilet floors because there's been no other option for so long. Changing places

and campaigners have voiced the need to be able to toilet with dignity and thankfully I think that we are starting to be heard, and obviously we're really proud that Jolly Josh will have changing places.

But with regards to Jolly Josh we've allowed parent carer voice to be united. We've become more powerful as we join families together and created a community. We hope to empower our families with the knowledge, with understanding, and with the determination to connect. It's really important to us that our families are represented.

That they're seen, that they're heard and hopefully our photography project has gone some way into helping that, but also serving as a reminder to society that as they do begin to ease out of lockdown there are in fact many people who can't and who will remain shielded. I think as Rachel Wright said in her podcast episode it's to be hoped for that society now has some form of empathy and understanding for our families.

For whom isolation is unfortunately the norm due to various factors. Perhaps some of those being judgmental faces, rude whispers and stares, which I know all of our families experience, and we really do need to break down the barriers and help our communities to include our families. To perhaps teach them how to communicate and interact with our loved ones and that can simply just start from a smile rather than a stare.

So I think it's to be hoped that the world will be a kinder place as we enter the new normal but there's that word again, hope.

Lucy: Yeah, and I think this keeps coming up as well in the podcasts, like we have a real opportunity to look at that and to have some empathy through everything and hope that things get better. I'm trying to remain hopeful about it.

Carole: Always, always.

Lucy: On that note are there any changes, you've touched on it a little bit, but are there any changes that you hope will support people with profound and multiple learning disabilities and complex health needs in the future influenced by this time in lockdown?

Carole: I think really the key is the empathy and being represented. Really it was touched on by Joanna Grace. Our loved ones with PMLD – maybe it's because there's not the inclusive accessible venues so our families don't travel out because at the end of the day they can't toilet their children. So we're not seen in society. We're not represented and we're sort of just hidden away behind closed doors most of the time.

And maybe that does stem from the confidence of the parent and carers.

You've got to be quite thick skinned to go out and to perform suction in a cafe and restaurant, to have the whole place turn around and look at your noisy machine whilst you're delving in with the suction. You've got to be quite thick skinned to do that and I am, you know, I am thick skinned and I wanted to parade Josh round for the world to see.

But we have many parents at Jolly Josh who aren't and who have received verbal abuse if you will whilst sat in a cafe tube feeding their child. So we did start the summer socials at Jolly Josh which is a weekly visit to a different park and what that allowed was our parents and carers to become one for those outings.

So that they didn't feel subject to those stares, to those judgmental looks, to the quiet whispers. It's a lot easier to handle when you're within a group of peers I think but hopefully society will be a kinder place and show a little bit of empathy towards us but we shall see.

Lucy: Yeah, and I think it's a really good point people with profound and multiple learning disabilities are not visible because society doesn't allow that to happen and it's not just physical access, you know, the changing places and not having those available is a massive thing but it's not just that. It's people's attitudes and the way people are treated.

And they just need to be kinder to each other and allow everybody to live how they want to live.

Amber: And that links so much to the social model of disability and creating a world that is accessible for disabled people.

Carole: It starts with a smile rather than a stare for me and I think a smile has a huge impact doesn't it?

Lucy: Absolutely, and that's kind of one of the things we always say at Frozen Light to people, just smile guys, just be nice.

Carole: That's it, if you don't know what to do, you don't know how to interact with our loved ones just smile and it just shows that there's that bit of acceptance and puts us at ease when we're out and about as well.

Amber: Brilliant. Well it's been amazing talking to you. I've loved every minute. It's been really wonderful and, you know, energy for Jolly Josh is really incredible and I really look forward to following your journey.

Carole: Thank you.

Lucy: And I feel like we need a trip to Rochdale to see this new venue.

- Carole:** Yeah. Hopefully, so you can stay in the loop on our website and our social media and I can't wait to open, I can't wait to welcome our families.
- Lucy:** Do you want to just let us know your website address and social media, we'll put them in the show notes.
- Carole:** The website is www.jollyjosh.co.uk. And we are on Facebook, Instagram and Twitter @jollyjosh1.
- Lucy:** Amazing, well thank you so much Carole, it's been brilliant.
- Carole:** Thank you. Thank you so much.
- Lucy:** Well I don't know about you Amber but I really, really enjoyed that podcast interview.
- Amber:** Yeah, it was just brilliant. I think just the energy and passion that Carole has for the organisation, it just shows you how much someone can do in such a short space of time when they have a cause that they just believe in just so so strongly. The amount that they've done as a such a young organisation so far is really, really incredible.
- Lucy:** I mean to have been set up for two years, two and a half years and become a charity, have a building nearly ready and built, it's phenomenal.
- Amber:** Yeah, it's amazing to see what people can do to change the world really and particularly when during this podcast we've just been hearing so much about things within the system that aren't working. People not getting shielding letters. People feeling unsupported by the community and you just feel like you're banging your head against a brick wall and then you meet someone like Carole and you're just like "Oh can't everyone just have that energy and passion. I want to create change as much as you do because then I just feel the world would be..."
- I feel like it would become more accessible in a much shorter space of time.
- Lucy:** Yeah absolutely and just that horrible fact that Carole was saying that every one of her families that she's met has experienced some form of discrimination and horrible comments when they've been out and about, it just makes me really sad.
- Amber:** Yeah, and again that whole smile not stare, it's just such a simple but powerful message and we always say in our shows again, and no matter what's happening on the show, just to smile and laugh, and have that enjoyment with people as human beings. It's so lovely to have laughter in shows and just have laughter with people that you've just met. And again smiling is just such a simple thing that we can all do.

Lucy: And I think you hit the nail on the head there, it's just we're all just humans and I think if people can remember that we all share this basic humanity and we just need to be kind to each other I think the world would be a much better place.

Amber: I also love that she took that photo idea from the Duchess of Cambridge and transported to the community that she supports, I think that's just such an awesome idea and it just really, really fits with what we've been talking about along the whole way on this podcast. Everyone feels so isolated and invisible, how do we make people visible and something like a photography exhibition is just such an amazing way to be able to do that.

Lucy: And they really are beautiful photos, and again it's that commitment to quality as well in creating these really quality photos, they really feel like a piece of art and we'd never heard of Jolly Josh, and we just came it across it through this photography project on Facebook so it really is reaching people in a way that other things maybe aren't.

Amber: And again just to hear of an artistic idea that someone has achieved in lockdown I mean I just feel envious.

Lucy: Oh God, so starved of art.

Amber: I wish I'd done it. It's amazing. It's really, really great. Really starved of art but also just I feel starved of ideas. You know this time in lockdown when we're just spending so much time on our computers and just staring at a screen. Just to have those innovative ideas that I feel we would normally be having in the rehearsal room surrounded by a team of creatives.

I feel it's been really, really difficult and, yeah, I just feel really inspired by hearing about other projects that other people are doing. It's really, really exciting.

Lucy: And I think also I really liked Carole talking about Coronation Street doing this project. That is the power of art and it's so important because they sit in people's living rooms and they really have the power to let people know about these issues and to know them really – dig into it on a deep level so that people can understand it and hopefully start changing their attitudes.

And again that's just art, that's just culture, that's just the power that the arts have I think, and nothing else can do that. With the arts you mirror what's going on in real life and you let people know that their stories are important.

Amber: Yeah, really, really great stuff.

- Lucy:** Up next on the podcast we are talking to Reflect PMLD which is a service for people with PMLD based down in Taunton and they've been really active during lockdown so we're really excited to talk to them about how that's been during this time.
- Amber:** And we came across Reflect PMLD when we last toured to Taunton, to Tacchi-Morris Arts Centre, and we actually found out about them after we had toured there so I've been meaning to kind of get in touch with them ever since but we haven't really had the opportunity to this is going to be a great chance to get to know more about them and hopefully they will be a future Frozen Light audience.
- Lucy:** So thank you so much for listening today. You can listen to the podcast on all the usual places you would find your podcasts. You can also find it on our website at www.frozenlighttheatre.com/podcasts. Please do rate, review and subscribe.
- Amber:** And you can catch us on Facebook, on facebook.com/frozenlighttheatre. On Twitter @frozentheatre and on Instagram @frozenlighttheatre.
- Lucy:** We really look forward to hearing from you. See you next week.
- Amber:** Thanks everyone. Bye.
- Lucy:** Bye.
- Jingle:** *Jazzy piano music with scatting*