

Laura: Hi, everyone, and welcome to our safeguarding podcast today. My name's Laura Thorpe. I'm our safeguarding adults manager at the Ann Craft Trust. I am really pleased today to be joined by Daniella Smith and Jess Johnson from our dementia choir. They will be singing at and performing at our conference this year in November, which we're very excited about. And it's wonderful to meet them, to talk to them today just about what they do and what we should expect at the conference. Okay, so, hi, Daniela.

Daniela: Hi, Jess.

Laura: Nice to meet you.

Jess: Hi.

Laura: Hi. Do you want to start off by just telling us a little bit about the dementia choir, how it started? What, you.

Daniela: Yeah, no problem. Thanks, Laura. So, the Our Dementia Choir – Vicky McClure's Our Dementia Choir – started in 2018 as part of a BBC documentary about how music basically is medicine and helps the lives of those living with dementia. Since the documentary, we have become a registered charity and gone on to do some credible things, proving that music really is medicine and people can live well with dementia. I mean, we've performed on the NTA's, on telly, we've had other series since then. We've performed at the cabin club with some pretty cool celebrities and it just. There's no stopping the choir. They're going from strength to strength and they are amazing. We like one big family. It's great.

Laura: Thank you so much. It is incredible and it's so heartwarming to see how important music is. Roughly how many people are in your choir at the moment.

Daniela: Crikey. I think now, Daniella, you might want to correct me, but I think if.

Jess: We've got about 35, we've got 35, yeah. And all of them perform constantly. They kind of. Obviously, depending on the different levels of dementia or where they're at within their journeys, some of them perform at everything. Some of them have had to retire because we've got early onset dementia, so they've had to retire and the choir is their life. So they come to everything, every rehearsal, every performance. Some just come during the day. If it's a daytime performance, some come if it's an evening performance and make a night of it and a social event of it, etcetera. So it does depend on average, I'd say we have around 15 to 20 at most performances. But, yeah, it's a very fun, lively choir and they love it. They do enjoy the performances, I can imagine, as well.

Laura: Obviously, the actual performing and the music is incredible, but the social interaction and being part of that group must be so important to people.

Jess: No, massively, it's a huge. That's the bit that has the impact for the carers. It's a time for them to speak to other members of the choir and the other carers and maybe just

share some of their experiences. For the. The choir members, they light up when they sing. We've had numerous comments from carers saying things like, for days afterwards, after a performance or even a rehearsal, they're just alive. They're coming back alive and they see glimpses of their loved ones. And it's very special. We've got members who struggle communicating and struggle stringing more than one and two words together, but they sing every single song word and it's just beautiful. It really. Something magical happens every performance and every rehearsal. We're very lucky to work with them.

Laura: That's so powerful and so touching to hear that just from a personal point of view. My grandma had dementia and she loved to sing quesara and, you know, all of the old sort of wartime songs and she did. She remembered all the words and I think it's so powerful.

Jess: Yeah. What we tend to do, we have. I mean, they've got. There's various songs that they absolutely love. They do like the more lively songs. We find that. But also we're doing a lot of medleys at the moment, so I think it's the case for everybody. We start off by knowing the first verse of a song, don't we? We sing along on the radio and the second and third long, everyone's a bit like, oh, I'm not quite sure about that. So we're doing lots of medleys at the moment where it's a verse, a chorus into another song into a verse and a chorus. And the choir just love those. They really come alive when. When we sing. The medal is. And it's great for the audience, too, so. And they favorite songs are things like Sweet Caroline and some very, very lively ones, but at the same time, we've got. We do some Beatles songs at the moment because we're working towards big performance at the Cavern Club. And in my life is one where we kind of commemorate the members that we've lost and think about the members we've lost. Stand by me is obviously a very slow one and it's kind of. It's proven to be our song. It's one of the first ones that we did. And so, yeah, it's a real mixture, but at the same time, they'll learn. We learnt a modern song by Tom Grennan, completely from scratch, performed with him. And they're up for a challenge. They're such a wonderful group and nothing's kind of out of their reach. We kind of. Yeah, we do a complete mixture of.

Daniela: Everything and touching on the medleys as well. It really helps because I don't know about you, Laura, but when I listen to the radio, I tend to only know, you know, the first verse and then the chorus, and then when the second verse comes on, I haven't got a clue what the lyrics are. It really does kind of help doing the medleys because we kind of do a burst and a chorus and then move on to the next song. So it takes that pressure of kind of. Crikey, what are the words to the second 2nd verse? It's a lovely way of doing it. And Daniela does them great. They're really cool.

Laura: That sounds like a really good idea. And I think a lot of us as well, we realize that we missed remembered lyrics anyway. You know, the songs that I realize I've been singing wrong for 20 years, you know, so. But I guess it's just. It's not about the words, is it? It's about the enjoyment.

Jess: This is exactly it. It's about having fun. I can tell you, no two performances are ever the same. I'll plan. I work with choirs in my day job and I'm working on perfection. For those with the dementia choir, it's all about having fun.

Daniela: It's beautiful. Chaos.

Jess: It is years, but that adds to it.

Laura: That's a brilliant.

Daniela: We always, always encourage the audiences to get up, dance, sing along. It's very kind of relaxed. We want them to have just as good a time as we are.

Laura: And I will be doing that at our conference. I will be busting some moves. Definitely.

Daniela: I'll hold you to that.

Laura: Have you noticed that some people have sort of improved a bit or improve while they're with you?

Daniela: Definitely. I mean, this morning was a prime example, really. We had ex Forest football player Paul McGregor. He brought his mom to rehearsal this morning and it was quite emotional walking through the door for them because it is like a family, honestly, I can't tell you, like, the supportive feeling that you get from being in the same room as people, living through the same thing as you are. You don't feel on your own, you know, it's all right getting this diagnosis and then kind of you're left to do your own thing with that. And the help and support is very minimal. So walking through a door of a room full of people who are. Who get you, who understand what you're going through is priceless and blessed. Joan got up and she was a bit nervous, I think, of starting to sing, but after a bit of encouragement and the choir members went and took her hand and said, come on, we can do this together, which was beautiful. She started to sing and just relaxed into the whole thing and her partner was emotional and her son was emotional because they'd not seen that joy in such a long time. And she was given kind of a new lease of life through that music. And even when we'd stop singing, because we like to have a game of bingo, we have lunch and we do a raffle. So it's the full shabam at rehearsals. It is a beautiful. It's a full experience. Yeah, that's it. But even through, like, the bingo and everything, you know, because they're vibing so much of what they've just done and, you know, everyone hypes them up, everyone claps, everyone cheerleads. For everyone in the choir, they're given that buzz and it carries on throughout the day and often on to the next day and the next day. So, yeah, it's powerful.

Laura: I think one thing I a lot in our roles in safeguarding and working with organizations is we see that isolation and loneliness is a really big vulnerability factor or issue when you think about safeguarding. So I think any community project like this, that, like you say, helps people meet people in similar positions, not feel quite so alone, is just so important and it helps build people up, create resilience. It's just incredible.

Jess: It is about the carers. We need to get to know them really well, we need to get the quiet, know the choir members really well, and that's our priority.

Daniela: And, I mean, with dementia, no two journeys are the same. Once you've met one person with dementia, you've met one person with dementia, everyone you meet is. Is different. And that's why it's so essential to kind of get to know their background. Get to know what my upset them. Can they listen? Can they understand our pictures better? You know, that kind of thing is so, so important because everyone's journey is different.

Laura: Of course. No, no one size fits all to anyone. Is there really our own human beings? So if you. In terms of the families, is there, do you support the families of people that come as well? Is there any offers, help that you support them with?

Daniela: Yeah, we do quite often. Sorry, Danielle. We do quite often get industry experts in, you know, to kind of sit and have a chat with our carers. We like to do that, to kind of offer that support and we have kind of group sessions where you can support each other. We also have done quite a few social activities with just the carers. We had a bit of a painting workshop for the carers, just so they get a little bit of time to themselves. Because if you care and someone with dementia, you know, or if you're a carer for anybody, it's so important to care for yourself, to give that person the best possible care that you can. Because if you're not looking after yourself, how do you expect yourself to look after someone else? Because you are also very, very important in this situation as a carer.

Laura: Yeah, I completely agree. And, you know, we often talk about care for carers or, you know, support for those who were supporting, because, as you rightly say, if you're not strong in yourself or you're, you know, missing out on things in life, it can put you at risk of harm as well.

Jess: Yeah. Who us with? I think the heart of safeguarding for us is personalised care, whether that's with a choir member or a carer. It's. We've got to really understand somebody's needs and how we can best meet them and understand also what is in our scope and what's not. We don't want to promise them the world. We've got a duty of care, but we don't want to promise the world and then not be able to kind of follow through with that. So it is for us, the start of safeguarding is to get to know those individuals, whether it's a choir member, like I say, or a carer. So there's often situations that come up and we can't support everybody, but we can certainly assign those. Them to different things and help them. Like Jess before we are. We really are a family and if we can do what we can do and make it as comfortable and easy for anybody who's able to come.

Laura: Yeah, that sounds brilliant. Sounds like it's a whole family sort of approach. It's a really good point that you raised, though, about sort of professional boundaries. We talk about that quite a lot at ancra trust, that in that you can't promise the world, you can't. You know, there are some things that you may not be able to personally solve, but signposting and helping people find the right place to go is just so, so important in

safeguarding. How important is safeguarding? One working with adults with dementia? So that was the next thing I was going to ask.

Jess: Yes. So people living with dementia will have a level of need that's constantly changing. This is what we found. So we need to be able to assess where they're at, think about their needs as they change and what measures need to be put in place. This is essential for us. So, again, it comes back to really knowing that person and being with them on their journey as their dementia changes and being aware of what we can do, support them within our limits, and if not, we need. We can get that additional support. Again, this is, it kind of all comes back to the same thing of getting to know that choir member as.

Daniela: Best we can and also trusting them to kind of be honest with us as well and keeping us kind of informed on the journey. And by having that family feel and kind of, you know, having that. Just spending the time with people kind of one, on a one to one basis and getting to know them as an individual, you build up that kind of trust in the relationship. So therefore, if there are changes within the dementia, you know, they're able to come to us, let us know, and then we can kind of help them along the way and making them kind of realize as well, we know that situations change, things change. You might be coming to every performance one week, but the next week you may not be, and that's absolutely fine. So it's, you know, taking that pressure off them. There's no judgment. There's no. We're an open book. We get that dementia is unpredictable. It's, you know, it changes on a day to day basis. If you're having a bad morning, give us a ring and don't come, that's absolutely fine. But without that trust there, you know, people feel that they can't necessarily come to you and update you on new. New scenarios that might be occurring or medication changes that might affect them during choir. So, yeah, the trust thing is really important. Important.

Laura: I think, really, to me, you describe in what we talk about an open and safe culture, you know, like this open, non judgmental culture, and I think that's vital. It sounds like, you know, that's really at the heart of what you do. I also think that with people with dementia, I'm often led to believe that anything that's time pressured is quite stressful for people, isn't it? So with you saying, you know, we don't want to put this extra pressure on you. This is an activity to have fun. You know, that's what the onus is on, fun. And that's, you know, the best thing that you can do.

Daniela: It is.

Jess: And also with our. With our rehearsals and with our performances, rehearsals, like just said before, it's a four day event. It's not. They don't just come and sing for an hour. They have tea and coffee when they arrive, they get a chance to chat, they do the rehearsal for an hour, then they have lunch, then we do bingo, we do raffle, we have fun. It's a full performance. But again, with rehearsal. Sorry, with performances, they have time, they have refreshments when they get there. It's not. They don't get off the boss and go straight on stage and perform. I have found that it's no good rehearsing and then doing a performance. So we're better just to have some time in a quiet room before we go on.

Because if we rehearse, a lot of them feel that that's the performance done and they don't want to do it again or get agitated. So there's different ways. We found that work. We've changed. We've had to change as we've gone along with things. Certain things haven't worked and we've kind of looked at that and thought, actually these choir members were affected by that. So we need to change what we do and this works better. So again, with performances. Now, it's not just. We don't just turn up and perform and leave or turn up and rehearse beforehand for 2 hours and then do the performance. We do it to tailor the choir at the centre. And what works best for them is how we go with it.

Daniela: Exactly that as well. And we're constantly changing and learning because like I said before, no two people are the same. So someone may come through our doors. That kind of, you know, makes us think about, right, could we do that in a better way so we're not fixed to regime, you know, one year might be completely different to the next year and we're forever learning about dementia along the way. I never. I think that people cannot learn enough, do you know what I mean? Every day is school day. And it's keeping that openness to change because one person's needs is completely different to another person's needs. And if we're as a charity, setting our ways with how we do things. No, we go this time, you get off the bus, we do a rehearsal, you know, it's never going to work. So we're constantly growing, changing, adapting in to fit people's needs.

Laura: Brilliant. I think for me, you know, a good charity is set up for the purpose of the beneficiaries and the people who use it, you know, and that's what you do. And constantly adapting to what is right for them and not necessarily right for you as an organization. And so it's all about person centered support, isn't it? Sounds wonderful. What can people do to support the charity and the choir?

Daniela: Well, you can head on over to www.Dotadmissions.com and you can find everything that you may need. There's information about hiring us for a performance if you've got like a conference or anything coming up. Like you guys, we've performed every kind of event that there is, really. And also you can head to our socials, all of our social media pages. You'll find like, share our things, like our posts, and also kind of just shouting about the power of music. People fundraise for us in many different ways. We've just done the Robin Hood half marathon and then Robin Hood mini marathon. Hopefully next year we'll be getting places for the London marathon. So people have done skydives for the real daredevils out there, or like a cake sale or any kind of donation is always welcome because we are a self funded charity, so we do rely on the amazing support that we get from the general public. And without them, they're at the center of it. Without them, we, you know, we couldn't do what we do.

Laura: Yeah, I think that's amazing. I think that dementia has touched many of our lives. You know, statistically, it may touch all of our lives at some point. And music, it's just such a great, you know, brings you together, doesn't it, everybody? You know, it brings out memories, emotions. I think it's such a good tool to use.

Daniela: 100%. We say that kind of, you know, obviously we're a dementia based charity and we'll sing and shout from the rooftops that music is medicine for people living with

dementia. However, it's medicine for us all. Like, if I'm feeling grumpy one day and I put some great tunes on, you know, it really does help and uplift your spirit. So if everyone can just spend two minutes of the day, get a song on, have a sing in the shower, you know, while you're doing your drive to the school, run, anything, get the music going, you know, teach your kids, get your kids involved, you know, it is medicine.

Laura: I'm a big fan of a kitchen dance, actually. Kitchen dance and a sing. I'm sure my neighbours must hate me, but, yeah, it's so powerful. Isn't it? Just, if you're feeling low, some song that you love, a dance and a sing, it just blows off the cobwebs.

Daniela: That's a challenge. For all the listeners out there. After you finish listening to this podcast, go and play your favorite song, have a kitchen dance, and then let us know how you feel.

Laura: I think that's excellent. That's everyone's homework. So shall we just go finish sort of with. I was going to ask you, do you have a message for people during safeguarding adults week?

Jess: Yes. So we understand its legal aspect of what we're doing when we're working with people living with dementia. But what we believe safeguarding to be is excellent personal care and really understanding that individual.