Linda Rose is the founder of Music for Life and a member of the reference group for the Music and Dementia project. Kate Page (née Newell) is project manager of Music for Life and Wigmore Hall trainee animateur. Kate is also a co-researcher on this project. We interviewed them in May, while they were in the Netherlands to talk about setting up the project Music and Dementia.

Q: Linda, you are the founder of Music for Life. How did you first conceive the idea of music for people with dementia? Is it original, or did initiatives like this already exist?

Linda: No, it didn’t exist, but it’s a project which evolved. It started by developing work that was already happening at the Guildhall School of Music and Drama in London, a performance and communication skills course in which students were encouraged to work in schools. And I was doing some work with older people at the time, for the first time. I’d been working as a teacher and education advisor before that. And it struck me that there was a whole sector of the population that was not being addressed at that time, we’re talking about 1990, 1991. The population was clearly ageing, but there was hardly any work going on in that area. And so I managed to set up a module to work with students working in a setting with older people in a day care centre.

Q: At that time, was it already about working with people with dementia?

Linda: No, it didn’t begin in that way. A key turning point came in the mid-nineties, when The Community Care Act came into force in the UK. This meant that more people were staying in their own homes, and going into residential care at a much later stage, when they were much more confused and frail. And that presented all sorts of challenges for managers of homes, and of course also for our musicians.

Q: Was it challenging for the team of musicians? Could you name five of the most important skills musicians need for this work?

Linda: It was very challenging for the musicians. One of the things they needed to understand was the pace at which they needed to work, which was much, much slower. Many of the musicians were used to working with children, and here the pace had to be very, very slow. Also it was very
important to make sure musical textures weren’t cluttered when three or more musicians were playing. People could focus maybe on one or two musicians playing. They had to be careful about dynamics, be aware, because maybe people’s hearing might be impaired. They had to understand the kind of space you could use, be aware of how near you could go to a person without worrying them, use a lot of eye contact.

Q: This would not be for all musicians I imagine, you need to be a special kind of person

Linda: You do, it’s about the person behind the musical skill. But quality also matters, because the music has to have great musical integrity, all the time. In the early days we had musicians who were less experienced than those we have now. But it is essential to have absolute top quality musicians who also have great improvisation skills. Even if it’s just one note, it’s got to be absolutely beautiful, the best they can do.

Q: How are musicians trained?

Kate: We go through a special recruitment model, where musicians play as a group. We look at how they improvise, how they communicate, what they are like personally, how they interact within the group. Then during the training they receive a presentation from a dementia expert, from Dementia UK, who tells them what dementia is, how it happens, and the stages of dementia. It’s kind of scientific, but very personal as well. They tell how they see aspects of dementia being addressed through the project. People are helped to express themselves, and to feel safe and comfortable as part of a group. So there’s that side of things, but our lead musicians also work on improvisation skills and the kind of musical exercises and activities you can do to strip back the improvisation so they are context-specific. They do a number of exercises like that and a discussion as well, which Linda and myself are involved in, really an open forum and a debate about the work. And then there are development days as well. For our existing team that regularly works in the project we have two days a year dedicated to the team coming together. It can be an open forum for discussing elements they need to talk about together, but also for trying out some musical activities.

Q: There are different degrees of dementia. Is everyone suitable to work with, or do people have to be capable of certain things?

Linda: There’s a strong selection process, a discussion that happens with the managers and the staff in the homes. And very often actually the people they think would not be responsive to the project, are the very people we want to work with. The people who they may find are difficult to manage for all sorts of reasons. Perhaps they are frustrated that they’re not allowed to do certain things they would like to do. Or they may be very, very withdrawn. There may be people who constantly want to get up and go to the toilet or who want lunch at any time of day. But we’re very happy to work with anybody if the staff are happy to agree to that. And we see big changes in people’s behaviour and demeanour. It’s very easy to talk about behaviour, but we’re talking about the person that emerges through this work.

Q: Could you talk about one the most striking things you have experienced?

Linda: Just one? There are so many. But this is an example of something which happened last year. There was a lady who staff were quite concerned about, they weren’t sure that she would be responsive. Tended to swear at them, to throw things. They didn’t know whether she would stay,
whether she would disrupt the session. We talked about it with the workshop leader and the staff, and we said, ok, we’ll give it a go. See what happens. So the first of eight sessions, this lady is brought down the corridor in her wheelchair, shouting and swearing. Doesn’t want to join the circle that we work in. And so we agreed that she would just sit, on the edge and nobody would demand anything of her. If she looked as if she wanted to be acknowledged, we would acknowledge her, otherwise we would just let her be. If she would stay in the room, then that was the start. So, that’s how it began. I was sitting next to her at the time, observing. She shouted for a cup of tea and I thought any minute now this tea is going to go over me. It was quite a strong reaction to the session. She started to move her wheelchair forward and shunting herself into the lady sitting in the circle. And she had a little toy rabbit, which was very important to her, she always had that with her. She picked up the rabbit and threw it across the circle. This was session one. Each week she was brought in and bit by bit she allowed herself to be brought into the circle. Again, not paying a lot of attention to her, because she would have reacted very strongly. And then about session seven, for the first time she allowed a musician to come near her and play to her, he knelt. He was an oboist, and the workshop leader. He knelt in front of her and asked if she would like a piece to be played for her in a way that she would understand. He didn’t use words, but he gestured, ‘would you like me to play?’, kneeling in front of her. And he started to play to her, which she tolerated. Most of the time she was looking down, all those weeks she was looking down, not making contact with anybody. And she looked up at him, and the rest of the circle was absolutely silent at this point, she looked up at him and she started to giggle. And she started looking around the circle. And it’s like she suddenly realised actually she was part of this, and she giggled and she laughed and one by one all around the circle, everybody was laughing with her and all of us who were observing caught this. The whole room was just laughing with her. And it was just the most magical moment.

Kate: Session seven out of eight sessions for something so magical to happen. That makes it all the more sweet, it makes it very, very poignant. And hats off to the musicians who work so very hard, and the times they are thinking, goodness, I’m not getting through. It’s this absolute determination and perseverance that there is potential there to really engage with someone, which is so very important in this work.

Linda: And leading up to that you kind of see the process happening. You could see the day she might let go of the rabbit. Musicians need those kinds of skills to notice how important these things are, which are not overtly musical things, that people are giving back to them. They’re giving them signs of growing confidence, and that’s what they’re building on all the time. They have to recognise this growing confidence in the group, with the staff as well.

Q: Is it specifically music that has this kind of effect on people, or could you do it with different kinds of activities as well?

Kate: I think music’s special. It has a different way of reaching people. In the UK there’s a number of arts-based activities, with drama or visual arts, memory boxes, that sort of thing. But I think with music, there’s something about it that can touch where people are at. We find that because the setting is so very open and the pace is so slow, that we can tune in very much to how people in the group are feeling. And then to create music that taps into that, acknowledges that, and say, it’s ok to feel sad today. Or if someone feels joyful that we can celebrate that with joyful music, I think that
that's where it really is different from other art forms. Music makes no demands on people to do anything.

Q: The lady with the rabbit was able to move outward a little bit, and make contact. Is this something that is a lasting change? Is it possible, for example, for the staff to reach her more easily afterwards?

Linda: That’s the big question. That’s where the staff development strand comes in. Staff are given a better understanding of the people they are working with. During another series of sessions there was a breakthrough with a man. The staff had not been able to approach him, had not been able to touch him. And in working with people with dementia touch is very important because of the personal care they have to give. This man spent all his time sitting in a seat in the entrance hall, not really communicating with anybody. And after his Eureka experience in one of the projects, a member of staff reported in the debriefing that something had been happening that nobody knew about. Which was that, after the project finished, this man tolerated being touched. He tolerated his hand being touched, which meant that if she could hold his hand she could lead him somewhere. And she was able to lead him out into the garden. It sounds such a small thing but it was life-changing. And it was life-changing for her as a carer as well, who was now able to make that communication.

Q: How do you measure the effects? Is there an evaluation with the musicians, or with the residents? How does this work?

Kate: A project is eight sessions of one hour every week. The workshop itself is one hour, but we’re in a home for three hours. We have an hour’s preparation and an hour’s debriefing. And there’s always an evaluation debrief about a month after the project. So we do start to get a bit of a sense over time as to what that culture shift is in a home. And just how far it is spreading to other staff.

Linda: And there’s a lot of contact with the staff development workers. A lot of informal feedback as well as formal feedback. In a way, we’ve described this as a kind of ongoing conversation, the project itself is a piece of action research all the time.

Q: How are staff selected?

Kate: We talk to the manager about what support we need, and there is a certain amount of support and collaboration that is needed from the staff to really make it work. But we do like it if staff can self-select, so we have staff that really want to be there. But then of course care home managers might have their own ideas like, say, someone new has come into the setting and they want to use it as an opportunity for that person to really get to know the clients. So, it’s kind of a mixture of all these things.

Linda: In the debriefings there’s a lot of discussion about work with the staff, because we want to build relationships with them and help them build relationships with the residents. So, it’s a very, very important part of the work.
Q: If a home should decide to take on this project, do they need specific facilities?

Kate: We set quite a number of constraints for a home, actually. Basically we need to have a controlled environment and a protected space. And we have to make sure the people in the room aren’t interrupted during the session. We know when we’ve succeeded in protecting the space when there’s quiet around it.

Linda: Yes, it’s not a thoroughfare, you don’t want doctors or manicurists or anybody knocking on the door saying, I need to see this person now. The managers absolutely have to protect the session and nobody must interrupt. There has to be a consistency of staff; if five staff are selected for the project or volunteer for it, those five staff have to commit to eight sessions. We also need safe locked storage for equipment, very important, space to debrief, space for the musicians to debrief, for the staff to debrief, uninterrupted. And availability of staff for two full hours. Which is a big ask for a home, actually.

Q: I imagine that this is important for the quality of what you’re able to deliver as well.

Kate: Yes, definitively. We want to be part of the community. While we’re delivering the project we’re trying to make friends with everyone in the home as much as possible, to create a wide support base. Because the project can affect a whole community, and bring new energy to it. For us it’s a sign of success when staff we’re not working with don’t look at us and feel a bit worried, but actually say, ‘Ah, the musicians are here! Oh, great’. Or when you hear them singing down the corridor.

Q: Musical workshops have been given in the UK for over 20 years, and now they are going to be set up in the Netherlands as well. Will they be different here from those in the UK?

Linda: We expect they will. But Kate and I don’t know what the context is here yet, what the structure of the homes is like. We don’t know, for example, to what level person centred care is a philosophy, is fundamental in the homes in the Netherlands. Musician training and development is something that is obviously going to be looked at. In the UK there’s a kind of apprenticeship scheme, and our more experienced musicians will support and mentor the new musicians coming in. Logistically how that will work across the two countries, we will have to look at.

Kate: Yes, we’re essentially building a new team, from the ground. So there will be lots of things that from the outside will look different, but I would hope that the values and the integrity of the project would transfer and remain central to the work, even if that manifests in a slightly different way. We know from the people that we’ve met that we share those values. And if it’s in a different format because things are structured differently here, then we will set it up in a way that suits the context here best.

Interview by Annejoke Smids, 21 May 2010