

The light within...

People Dancing Associate Artist **Louise Katerega** continues her Voice and Presence conversations acknowledging, amplifying and celebrating women of the African Diaspora in participatory dance. Here she talks to **Louise Dickson**

Louise Dickson is a busy woman. A dance and movement specialist, health and exercise coach, dancer, choreographer and teacher she is founder and CEO of **Illuminate Freedom (ILF)**. ILF is a not-for-profit organisation delivering a range of dance and health and wellbeing projects across the UK for blind and visually impaired people and people living with fibromyalgia, chronic pain and chronic fatigue.

What signifies here though, is that Louise has fibromyalgia herself - as does her mother, who is also visually impaired. Louise, therefore, does not so much deliver her work as define it. She is the walking, talking demonstration for participants of the healing power of dance, no matter what barriers life appears to put in our way.



Louise Dickson, Illuminate Freedom's movement and gentle exercise class for fibromyalgia, pain and fatigue. Photo: Lisa Gilby @freshestframes

In this conversation, I hear how a unique personal journey led to a unique professional practice.

LK: Firstly, Louise, what is fibromyalgia?

LD: Fibromyalgia Syndrome (FMS) is a condition where you develop chronic widespread pain throughout the whole body, burning sensations, extreme tiredness; a whole host of symptoms can vary between individuals – muscle stiffness, cramps and spasms, ‘brain fog’, digestive difficulties. There is still mixed opinion on what causes it and it is difficult to diagnose. (Some estimates suggest nearly 1 in 20 people may be affected by fibromyalgia to some degree.(1))

LK: When and how did it show up in your life?

LD: In 1997, aged 18 after a footballing injury closely followed by a car crash. Just as I was beginning my (contemporary) dance training and about to take on the world! Life turned into endless pain, fatigue, hospital appointments, tests, operations and MRI scans. My list of ailments grew mysteriously. Doctors told me repeatedly, ‘it’s all in your head’, and ‘you’re just doing too much’. I was finally diagnosed in 2008.

LK: How did you find your way back to dance?

LD: This may sound strange... I just always knew in my heart dance was what made me happy and dance was going to help heal me. I tirelessly tried to find new manageable ways to keep moving, dancing, and putting some joy back in my life...

(Louise describes here a plethora of activities from hopping on crutches through Notting Hill Carnival, to changing to a less demanding dance degree course, to exploring complimentary therapies. She also created and performed with disabled and other long-term injured dancers and attended self-help groups.)

...but the standard physiotherapy, graded exercise and pain clinics on offer just didn’t seem to scratch the surface. So I began to design my own movement and gentle exercise classes. One big lesson was that too much was detrimental to my health and so was too little. But when I got the balance



Louise Dickson, Maria Oshodi (Extant), Mickel Smithen, Michelle Felix, Illuminate Freedom’s VI street dance class. Photo: Lisa Gilby @freshestframes

just right it helped me have more control over my body, relieved some of the pain and it began helping me heal my mind. I began to feel my joy for life returning.

LK: So how was Illuminate Freedom born?

LD: I was just about managing to work part-time, despite my condition, in arts admin and management roles. Feeling my experience with my Mum’s visual impairment would help, I applied to be personal assistant to Maria Oshodi, the blind Director of Extant, Britain’s leading performing arts company of visually impaired people. During my first two years working with Extant, I saw similarities between my own experiences of losing the freedom of movement and facing the daily battle of trying to manage and control mind, body and life. Maria put me forward to teach a street dance class for blind people in 2014. The participants couldn’t believe this was my first attempt to lead one: “If you start a regular class we will come”, they said. In that moment, I knew that my 17 year search to find a manageable career living with fibromyalgia was over. I started a whole company.

Such was the response to ILF’s work one year on, it was fully established with a plethora of partners from sport and leisure, charities, arts and

social venues. Louise has trained a small pool of teachers, assistants and volunteers to deliver work ranging from one to one sessions, dance/exercise classes and evening and weekend social events(2) to wrap-around social media support forums(3,4). Demand regularly outstrips capacity to deliver so ILF continues to actively seek new teachers and volunteers.

We talk about what distinguishes the work from conventional dance approaches, comparing and contrasting Louise’s studio practice with her two client groups. I learn that:

In fibromyalgia, chronic pain and chronic fatigue sessions:

- Pacing is the thing – active resting periods (‘you time’) strategically punctuates the class
- ‘Walking routines’ to music are an enjoyable way of re-doing the fundamentals of posture that have been lost due to long-term pain and fatigue (which is often “like carrying two invisible heavy buckets of water around all the time”)
- People share how they feel that day, “This came from the self-help groups I attended. You wouldn’t believe how healing three minutes of talking can be”, says Louise.
- Strength work only comes later in class when energy levels have built up
- Class ends quietly with meditation >>



Louise Dickson, Delene Gordon, Sayaka Akitsu with participants, VI Zumba at RNIB (Royal National Institute for Blind People). Photo: Arianna Carloni.

or 'you time' to build up to the journey home

- Participants universally report surprise at how much they can do in class, how much less pain and fatigue they experience later and over time
- The results are similar for the teacher, "I can tell if I haven't been teaching for a while. If my pain is on a scale of 1 to 10, with 10 being high, dancing regularly is the difference between living at a 6/7 and living at 8/9", Louise affirms.

When it comes to sight loss:

- Having fun and feeling free are the watchwords. The audio description is clear and concise and sessions help to build confidence and coordination, so the only thing left to do is to have fun.
- It's the freedom to move with no parameters like walls, broken pavements, dogs, canes – the movement of blind and visually impaired people is generally circumscribed by a hazard of one kind or another

- Participants report another freedom: not feeling a burden on others, an anxiety often prevalent in the class. Louise has always used assistants. From helping orient participants in the space, to opening lockers or ensuring there is water for guide dogs, needs are anticipated, so nothing is – or is made to feel – too much trouble
- This can extend beyond the studio to arranging meeting points to walk together to class/events.

For both groups:

- There is a degree of cross-over between classes as many participants with sight loss also need to move gently due to in-active lifestyles or age-related pain and fatigue
- Participants in both classes also express surprise at having dialogue with their tutors in contrast to other 'disabled' experiences. Louise offers an interesting perspective: "It's about empathy not sympathy. I have the condition but no one person is the same as me (or my Mum). It's about listening."

LK: So what are your current challenges, Louise?

Money generated through partnerships supports each activity, but we need comprehensive funding for what happens in-between; to grow ILF and keep me leading the company as a person coping with fibromyalgia. I have two amazing part-time assistants but I need them more and need to pay them more. We're very interested to hear from anyone who can help in these areas!

LK: And how would you describe your relationship with fibromyalgia now?

I am finally giving the fibromyalgia a chair to sit beside me on, instead of angrily slamming the door in its face. I am off pharmaceutical medications and manage my symptoms by trying to have a healthy mind, wholesome diet, manageable lifestyle and regular (appropriate) activity. I now manage it, instead of it managing me.

Post-interview, I ponder Louise Dickson's career as one that could only be possible nowadays.

The conventions, standards and structures of professional dance closed their doors on her and her physical struggles in the '90s. Yet, I would argue, inclusive participatory practices that were also flowering back then reopened these doors for her. Louise believes that: "Through the daily struggle that is living with fibromyalgia, dance and gentle movement is my lifeline to true happiness, health and contentment." Clearly, in the end, it's the label on the inside that counts.

Info

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www.spacehive.com/dance-in-the-dark
www.fmauk.org
www.pocklington-trust.org.uk

References

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