Transcript of The Last Custodian Podcast Episode 5: Nwando Ebizie

Host: Stephen Lightbown (SL) Guest: Nwando Ebizie (NE)

Transcript by Elizabeth McGeown

Introduction:

SL: Hello, and welcome to The Last Custodian podcast. I'm Stephen Lightbown. In this podcast, you'll hear my latest collection of poetry *The Last Custodian* read in full, as well as conversations I've had with other creative people to discuss process, disability in the arts and other topics.

Stephen Lightbown reads from The Last Custodian:

207: London, The British Library

The ceiling rises upwards as if the year escaped the first day. I've traipsed my finger along a spine from Bristol.

I don't know why I'm here. She watches, her back to the box office. She's assumed control. I have to decide if I'm returning or borrowing something.

It's a bit bigger than Waterstones. That was the best I could do. I'd wanted to see a face, her face, the Librarian.

I'm trying to build the world with books. And here you are, you made it, you followed? Now what do you do? She had spoken through pages. Brought me here to show we would not start from scratch.

High-rise stories and no one to listen.

I can't flick to the truth.

It's OK, she says. In amongst everything we got wrong are all the things we almost got right. It won't be easy; it never was.

Day 211: London

I've started writing assistance on my shopping lists. There are words without lines through them. Cake, gingham curtains, pity.

From before. When I wheeled through a door I collected disappointment. My differences clearer than lifeboats at a rodeo.

I recall their questions, not faces. *Do you need a hand with that?*

I'll let you know.

Now. I see myself in the gradual revolutions of fusilli pasta. I clear shelves, my hands reach to write messages in cards no one will read.

In these bemused aisles, can I be disabled if there's no one to compare me to?

Day 216: London, Piccadilly

The Coca-Cola lights are forlorn. Bereft of shoppers, bumping shoulders in cashmere wishlists. Like dogs that keep eating as long as there's food.

Fattening bags with empty gestures that won't be acknowledged by New Year's Eve. Every house I've been in seems full of plastic declarations.

Christmas Eve, and I'm searching for something that will make tomorrow different. I throw a street cone through the window of Fortnum & Mason,

take a basket. A cured glazed ham covered in promise, honey-roasted cashews, three bottles of solitude remover. Dinner. I will light a Cohiba Talisman for making it this far.

Day 220: London

That she's had a haircut is distressing. There is a white band between hairline and skin. It laughs at me like a crooked smile along the south. When I woke this morning I didn't think to make an effort. Wasn't being *here* enough?

My matted hair of bungalows feels like bramble to my fingers. If you were to find cabbage, I'd bare my neck to twelve nibbling hamsters if it meant I could have a trim.

There's a hint of a fade, product, sculpting, artistry. I want to hang her head in the Tate. It still surprises what can make me unsettled.

I point, my finger a divining rod, her hair water on Mars. *Not now,* she says. *Listen*.

Day 228: London

It is ten years since we lived here.

1.

A spray-painted hedgehog on a locksmith wall. A lane of bricks takes us east. We walk towards unpronounceable cocktails in a repurposed petrol station.

2.

U lean down to kiss me at London Bridge. A tourist ignores the skyline to capture our embrace.

3.

Underneath a blanket, on a sofa. A secret screen. James Stewart told us how wonderful it was.

4.

Kicked out for doing backstroke. We were trying to eat the rooftops in London Fields like Pac-Man chasing ghosts.

5.

We crashed a party for those who passed the bar, now asleep on the bar. Waiters dressed as elves served eggnog and wished only us a Merry Christmas. 6. Just off the Strand, the *Lion King* poster looks at me again. Watching as I touch the exhibits.

Day 254: London, The British Library

I stroke the cover of every book she has given me. I'm tugged to the ones with the broken spines, wonder if they've spent their lives trying to prove they are still books.

She hands me a copy of *Madame Bovary*. *Give this to the Bibliothécaire*.

She tells me I can come back, that, now I know there are others, I need to understand if this is it. Always expectations. I want to ask why this isn't enough. I want to thank her for guiding me. I want to hold her, feel the warmth of someone other than me, but don't.

I accept the book, draw an L on the gift with my Sharpie. She takes the pen from me. *You don't need this.*

She points at Chair. Stop pushing from your reality.

Day 255: London, Kings Cross

 Gustave Flaubert.
 Madame Bovary, 1856.
 We screwed the earth, so it bit back. We didn't understand it was language that separated us from nature. So it was taken.
 I'm here because we still need custodians. There is a debt to pay. A single note: Luke is not brave, or sent to inspire. He knows how.
 The Librarian.

2. Andy Weir. *The Martian*, 2011. I am Watney, trowel in hand, ready to grow potatoes in my desperation. Perhaps everyone left me behind. *Hello*. A single note: *When you are ready*, *come. Find the frequency;* I am listening. The Librarian.

3. Elmore Leonard. Unknown Man No. 89, 1977. Year I was born. On the counter of WHSmith. Admirable man, under stress, adrift, becomes whole. Never get personally involved. A single note: Move on. The Librarian.

4. Edwidge Danticat.*Everything Inside*, 2019.I saw the beacon.Approached, cautious; I only creak. Laid out like kindling, eight copies, eight stories,

coming to terms with a dance between old, new. A single note: *It seems so big, yet each journey is intimate. The Librarian.*

5. Regina Porter. *The Travelers*, 2019.
Interconnected. Resetting.
Generations driven by memories.
Barriers, pain, love, family.
This is not one story.
A single note: *The pages will come together. The Librarian.*

Day 267: London

Trouble in the distance; it can wait for now. Sea, take me as I am. Erode the desire from my bones. Let the salt scrub me clean.

Day 273: Somewhere on the M20

You stop to admire the horses, beyond the SOS phone.

You imagine they are sleeping.

Some freedom, ahead.

Day 276: Somewhere on the M20

Things I did not expect to see today.

1. A man.

To be precise, a naked man running with a pair of sandals threaded through a leather belt round his waist.

He was on the other side of the central reservation. In the outside lane, a few years short of seventy.

I twitch towards the knife gaffer-taped to Chair.

He gets nearer, whistling a tune I can't quite make out.

How are flashers still a thing?

He sees me. Without missing a stride, he vaults the barrier between us. I wince.

That tune. Louder. Clearer. Aerosmith, 'I Don't Want to Miss a Thing'.

He comes to a standstill. Everything static; well, almost. He looks like a grandfather clock with a pendulum cock.

Tattooless. Hairless (goatee aside). *Chatty. Greetings to you.*

I mean you no harm,

just out for a run.

Mate. You don't know the danger you are in.

What from, where to? I ask.

Nowhere, just a run.

I have to know. *Why no clothes?*

The serrated edges of the knife call to me. Only gaffer tape is saving him.

Look around, my good friend. I'm the least of your worries. (c)Stephen Lightbown The Last Custodian (Burning Eye Books, 2021)

Interview:

SL: My guest this week is Nwando Ebizie. On her website she describes herself as 'a constellation point for a spectrum of multidisciplinary works that calls for radical change'. That is definitely something to ponder on and explore further in this episode. but first, here is Nwando to tell us more about her work.

NE: My name is Nwando Ebizie. I'm a multidisciplinary artist. I work across a lot of different media. I work in installation, performance art, sonic arts, music. I work with ritual, I work across science and arts and I just try and create numinous experiences to give people access to themselves and reveal new perceptual realities.

SL: Yeah, I think I've really felt that through exploring your work a bit more. One of the things I've been doing in preparation is listening to a podcast that you've hosted called 'For All I Care' which I think debuted in November last year. And I would really recommend people go and listen to that. It's a fabulous podcast which I've really enjoyed. I listened to episode 2 and it's an episode on touch and it explores touch and it is just incredible. It resonated with me on so many different levels, particularly as someone who is paralysed from the waist down and has no access and feeling to my legs, touch is something that I've really thought about a lot over the past few

years. I didn't touch my legs for a long time after the accident that I had and through yoga and massage I've really started to benefit from touch again and touching my legs and reconnecting with them. And I wondered if your perception of touch changed at all after recording that episode?

NE: Yeah, definitely. One of the things that came up during that episode was the idea of touch hunger and that as a scientific term and that is something that—at the time when we made that episode we were in lockdown. Yeah, it was quite the depths of lockdown in my recollection and I was alone during a lot of lockdown—for the first time ever living on my own—and I really deeply felt that idea of touch hunger and yeah, this is one example that my ideas around touch changed. So we're on a video so you can see I'm holding this stone and that actually came from making the podcasts. There was always a healing section in the podcasts and one of them invited us to take a stone and to hold it and it was a real revelation for me. I love stones. I'm obsessed with rocks and at some point I went and picked one of these rocks from the hills around me. So I took this stone and I held it and ever since then I've really… I've just loved holding it. It's hard to describe what it does but I think it definitely helps with anxiety, it helps me just… it gives my fingers and hands something to do which somehow helps my brain which makes me feel more comfortable. And yeah, that's quite an interesting example of touch being this thing that can just change my perception of reality; it can just change my perception of where I'm at in a really unconscious way.

Also, I've been working with ASMR for quite a few years and there was a really interesting experience connecting with ASMR in that episode. The idea of connecting to your space in a new way. If you're locked down or you're somebody who can't leave your home, how do you awaken the senses and get useful stimulus to the senses? ASMR is—in case anybody doesn't know—it stands for Autonomous Sensory Meridian Response and there's scientists studying it at the moment but it's one of these really interesting things that have grown up on the internet, in that people have talked about their perceptual experiences of something and coined a term and shared it and proliferated it through the internet before scientists have been connected with it and now have the opportunity to research it. ASMR is really quite a sonic, it's quite a visual thing. It's quite cross modal in that it's about the feeling that some people get: you get a tingling sensation in response to certain sounds and certain ideas like somebody playing with something crinkly <lowers voice to a whisper> or certain mouth sounds or somebody whispering to you and there's a neuroscientist who I work with and her idea was that it's possibly an associative thing. It reminds us of those kind of close, delicate whisperings that somebody might do and that we have an association of that with touch.

So yeah, it's interesting that there's something that can be sonic and sometimes visual for people but then can give us a sense of touch, can give us a tingling sensation, a kind of internal touch and so that's something else that can be used if you're somebody who's isolated. Obviously you can connect to it online but I can also connect to it in my home, I can find different objects that can give me that kind of sensation and even if I don't experience ASMR I can find different objects just to touch. How often do you consciously go around just touching things? And especially after the pandemic where there's a fear of catching a virus. It's like, you know, touch isn't so safe anymore. Yeah, doing that podcast really connected me to lots of things I'd already thought about but opened me up to new things and helped just reconnect lots of things.

SL: I think that's absolutely beautifully put and I wholeheartedly agree with ASMR. I've actually... In a previous episode I talked to Matthew Sanford who's a paraplegic yoga teacher and we had a conversation about the energy in the body and the softness of that energy and how it can still exist even if maybe you become paralysed. One of the things that maybe I've wondered about ASMR is if that kind of—the ASMR voice or the noise that you hear is somehow connecting with that softer energy inside the body and that's also also where that connection comes from, and that's something that I've been exploring a little bit with different sensations and sounds as well. I think it brings me to another question because some of your work explores all of the senses and I've just been watching your *Distorted Constellations* project and again, found that really intriguing about how you describe living with Visual Snow Syndrome which, if I'm honest, was not something I'd heard of before but it provided a real way into learning a little bit more about that. I just found it a really fascinating piece of work and I wondered if maybe you could explain a little more about that?

NE: So Visual Snow Syndrome is-I think it's really fascinating because, like ASMR, it's something that I think couldn't really have been studied by scientists until this particular age, the internet age where people are comparing perceptual worlds online across continents. It was only 'discovered' (in inverted commas) in... was it 2011, 2014? They were the first couple of studies that were written about it. Before then it was considered a part of something they'd call Persistent Migraine Aura so if other people have migraines, maybe they know what a migraine aura is which is like these flashing lights or black spaces they get in their vision before, or not before, a migraine headache so scientists thought it was part of that. But no, Visual Snow Syndrome as far as we know—and definitely in my case—that people are born with it quite often, who have it. It's all the time, it doesn't stop, it's not like a migraine aura that comes and goes. It's just the way that I experience the world. It's part of the way that I experience the world. It's neurological as opposed to in your eyes so I have very good vision but I also have what I like to describe as a kind of augmented reality which is one of the reasons why I've been drawn to working with immersive tech and things like the video that I made and using augmented reality and exploring virtual reality because I think there's something really analogous to the way that I experience visual snow to the idea of putting on a VR headset or more likely using-like seeing augmented reality: the way, like, Pokemon Go works where you can see something laid on top of something, or an Instagram filter for example, which is why we also made an Instagram filter as part of the project.

So the symptoms of Visual Snow Syndrome are mostly visual. That's where the name comes from. The one that was the first categorised and most famous in the literature is the symptom of visual snow. I'd describe mine as a bit like having a transparent pointillist painting overlaid on reality and there's also lots of other visual symptoms like seeing starburst from lights, which is seeing more points of light from light sources, seeing after images which is also called Palinopsia, so lots of objects in your field of vision and people and all kinds of things and I'll see an inverted kind of after-image of it at the same time as seeing the thing. And then there's lots of non-visual symptoms as well. It's a condition that can be really debilitating for people and it can be very shocking for people who get it later in life, I think. I think there's something quite different about being born with it and getting it later on, because your perceptual reality's your perceptual reality. You only realise it's different to other people's if you question it and I'm the type of person who's just always questioned it so that's how I've ended up researching it and putting it into my work and opening it out to other people because I question things. I'm also autistic and I've found that quite a lot of autistic people experience Visual Snow Syndrome and I wonder if it's higher in the autistic population which is a population where people do have a lot of perceptual differences, a lot of sensory sensitivities so I think that kind of overlap's interesting. I think if more people could understand this way of seeing the world, the way that I see the world, that our perception is unique and goes into building the way we understand ourselves and others, I would hope that that could help people question their biases, their prejudices, it could build empathy, it could help them at least understand that 'Oh, somebody else literally has a different view of reality than me. What could that mean for how we can communicate and accept and learn from each other?'

SL: I wonder if there's any great examples that you might have of where you've performed somewhere and access has been done really well?

NE: I think the idea of doing access really well... It's so hard. I'm always trying to make my work more accessible and it's a constant failure and I think that's one of the reasons why it's almost like that stops some people and some organisations. It's like, 'Oh, it's just too hard. it's just impossible!' or, you know, going, 'We put a ramp in. Done. Done!' <laughs> Because that's way easier than facing the truth which is that, yeah, as you've pointed out, people's access needs are contradictory and they're unknowable sometimes. I worked with a really amazing director called Rachel Bagshaw on a show called *Midnight Movie* and one of the amazing things about that was that most of the creative team were disabled and it's that classic thing, you know, if we're there, if disabled people are present in the creation of something then we will work and people really fought hard individually and advocated for their own particular disability to try and make it accessible. And also, the director, she just had a really amazing way of thinking about it so that people with different access needs would have, kind of parallel experiences and their experiences might be prioritised so a D/deaf person's experience might be prioritised above a

hearing person's experience at some parts of the play and the hearing person would never know because that was just something, like a secret little thing in there for the D/deaf person and just how amazing that can feel when normally the world is just not for you, to know that you've been considered. I mean, it's kind of sad when you think about it that way as well, that you should even have to feel grateful for that and you shouldn't have to feel grateful for that. That's how things should be. But I think there's something very special about that production and I think that's the same with all the work that she does. I think she's always considering that and there's something exciting about it to me and I know to that group of artists who made that show. It's exciting to think 'How do we make a sound something that a D/deaf person can experience? How do we make this work for somebody who has chronic pain?' That to me is just the beginning of creativity.

SL: Thank you Nwando. I've really enjoyed that and I think that seems like a good place to bring it to a close and how we tend to bring each episode to a close is by asking every guest if they were the last person on Earth, if they were the last survivor and you found yourself in an apocalypse; where would you go? What would you do?

NE: <laughs> I've been thinking about this so much! Yeah, I've been reading your poems and I've been listening to your podcasts and the very strong feeling I have is that I do not wanna be the last person surviving after an apocalypse! <SL laughs> So the question... it might be a bit of a boring answer because my answer's just no! No thanks!
both laugh> But if I could change the question and just go anywhere, oh God, could it be... Could I make the type of apocalypse that it is? Could I make it... How could I make it...?

SL: This is your apocalypse! Go wild with it, yeah!

NE: Okay. Could it be an apocalypse where, I don't know, there's, oh, maybe there's just really cute animals left like some deer and someone was talking about butterflies, <SL laughs> yeah, someone had butterflies left in their apocalypse? I don't know... and also some, oh! Aliens could come! And they're really cool aliens and they're aliens from maybe an Octavia Butler novel and they've been watching the planet and they were just waiting for the apocalypse to happen and then so I'd be, maybe I'd be the last person left on Earth and I'd be like 'Okay, I'm not doing this. I'm not being the last person left on Earth,' and they'd turn up and be 'Whoa, whoa, whoa, hold up! It's okay, we're here now!' and I'm like 'Cool'. Okay, so I've just made my apocalypse to be completely peopled by really cool aliens and the aliens have some technology which means we can leave the planet and go and explore space. Yeah. And some time-travelling ability. Oh, I don't know. I'm just making it into an episode of Doctor Who! <laughs>

SL: No, I think you definitely win the award for wanting to travel the farthest then in this apocalypse. So you're wanting to travel into planetary space and back through time so—

NE: And! Could I also go sideways? I'd quite like to go, yeah, maybe some alternate realities and view some alternative versions of Earth.

SL: I mean, that feels like an incredible place to leave it. We will leave you to travel sideways, forwards, backwards through time and say thank you very much. <laughs> We'll let you travel with the deer through space and time!

NE: Amazing! <laughs>

SL: Thank you Nwando.

NE: Thank you!

SL: I've really enjoyed that! Thank you.

SL: Thanks for listening to this episode of The Last Custodian podcast. *The Last Custodian* was written by me, Stephen Lightbown. This series was produced by Rowan Bishop with many thanks to all our guests and Arts Council England for funding the series. If you enjoyed the episode please consider subscribing to the series wherever you get your podcasts to be kept up to date with the latest episodes and feel free to leave us a review on Apple Podcasts.