

## Transcript of The Last Custodian Podcast Episode 4: Matthew Sanford

Host: Stephen Lightbown (SL)

Guest: Matthew Sanford (MS)

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*:**

#### Day 129: Brighton

It has all gone to shit.  
I don't know which way is home.  
I'm using an empty packet  
of Quavers as a compass.

If [REDACTED] were here I would let  
her eat the needle.

I'd fill the empty bag  
with gravel if it meant I could  
share something with her again.

I look at the packet. Beg it  
to direct me back to the sofa  
with her, season three of Ozark  
and cheese dust.

### Day 138: Pease Pottage Services, M23

Everybody is busy being dead. But I see you, carrier bag caught in the branches of a tree grown with sorrow at these last-piss services.

Small twig fingers grasp your handles. Even you just want to be held. To feel the weight of being useful. You made it past the dead. Just like we were warned. A breeze catches, your plastic flutters like a sob.

I too take in air, behind me, for once too much to bear. Frozen as though a lost internet connection and I'm a glitch. I should have been a kite, you would say as you climbed free on the wind, and then: trapped. Back to bag.

I anchor to those images, buoys in the ocean. There will be more bags, caught in the embrace of a tree. Will anybody listen?

I reach for the tree  
Even here I cannot climb  
I swim from the buoy

### Day 140: Gatwick Airport

In lieu of a passport I wave a used plaster at the check-in desk. *I'm off to Wroclaw*, I shout at a recycling bin. I carry a suitcase through security, hold my arms out for a cold feet pat-down that never shows, my kills paraded in a clear bag. Breeze through duty-free, do not turn left. *Good day to you, impossibly smooth flooring.* I unhook the cart from the back of Chair. And push. I glide like a curling stone, imagine a pleasant chap in black pants sweeping a path before me. The remains of weekend revellers cheer, gate after gate. An empty airport is a ridiculous place. As many toilets as planes on a runway. I take a pilot cap off a corpse. I'm a pilot now, almost useful. Potentially respectable. *This is your captain speaking; we are beginning our descent.* I let that lie soar through Terminal 2.

Day 142: Somewhere on the M23

There is a callus for every landmark.  
So many points of uninterest, rest  
days become procrastination.  
Stonehenge in a rucksack. I stop only  
when my hand tells me to.

Mark my aching map with pins  
and needles. I stay when tomorrow  
looks pointless. Line of love, line of  
head, line of life.  
M3, M4, M5.

Tonight, I'll sleep in a layby on my palm,  
by a burger van with forgotten beef.  
Opening the pages of my hand,  
remembering the emptiness  
of fields.

My voice, unfamiliar as horses in  
a cinema. Somewhere along my thumb  
is an endpoint. I'll find it when the dust  
clears.

My wedding ring taps like a metronome.

Day 146: Clacket Lane Services. M25

The frame of a wheelchair, if drawn in lines, looks like a section of a flight of stairs. I notice this now for the first time as I take the wheels off to clear them of memories. When assembled, the frame has two wheels at the back, the size of dustbin lids (ones without wheels), and two wheels at the front, the size of the palms of my hands. The frame itself used to be a polished silver; now it's scratched, dull, held together with gaffer tape and hair ties. Chair has pushed past the remains of a country that only a year ago would have stood on two feet and thought I could not survive without help. How far would I have made it without this frame, these four wheels?

Day 148: Shoreham



Day 154: Swanley

Allen key. Tennis ball. Wrists, bent elbows. I wear pain.  
Connected like asteroids in orbit. The impact is their pain;

they won't let go. Hold it like a child's hand on a  
hard shoulder, *take two of these, it will help bear pain,*

and I want to sleep with the lamp on. It stays on the bedside  
table, unquestionable; at least some parts still share pain.

I dial the number for agony. Engaged, I bruise lines  
under jeans, left to right, back again, a secret, to repair pain

now out of reach, a dad in a wheelchair; beauty haunts  
my landscape. Small faces. Tears. They scare pain

with a single letter written on a stone, *U*, not just a capital.  
Become the past. A hill of scalpels to prepare pain.

Doorbell. Junk mail. Headstones. These towns are laden  
crematoriums. Luke, it's yours, a gift. Everywhere, pain.

Day 181: Rainham

Voices at the bus stop, idly  
chatting at an aloe vera baggage  
carousel in the Good Housekeeping  
waiting room, shouts of

well done, mate as I push up a hill,  
comments, jokes, rejections, the same  
*can you do a wheelie?* question  
I've heard four hundred and twelve  
times before.

And I hate  
that I miss it all.

I'd trade my cracked  
voice

talking with a family of stones  
for one tinder strip comment  
that would deliver rage.

*Do you want a hand with your bag?*

At least my breath would still  
exist in their world.

I'd barter it all  
for one last whisper, under  
the weight of an Egyptian cotton  
bedsheet from ████

*I see you.*

*I see you.*

Day 194: Barking

We clinked IPAs  
*to better things.*

I didn't believe in toasts.  
*U* did. We took a bottle top each,  
a memento of our pledge. Looked up;  
I was always surrounded by giants.  
Wrapped in blankets, wrapped in hope.  
I carried the bottle top. Held it  
against my ear. It spoke to me.

It said drink up the hope,  
made with fresh hope, hope  
on tap, you'll get addicted  
to hope, real craft hope, two  
hopes for the price of one,  
award-winning hope.

*U* said it tasted like  
clean clothes and optimism.  
It tasted like overpriced  
beer to me.

We had a drink to better things.

Why did the bottle top choose me?  
It told me to push.  
All those giants knew nothing.  
Where's their hope now?

I carried that hope for seven years.  
Buried it in the ground. Outlived it.  
I carry a stick now. Trained it to beat  
any remaining hope out of me.  
I'm empty. Bigger than the giants.



## Day 200: London

I understand.

Here, now, I can draw  
a zip around it all, the sky  
is canvas, this one-man tent  
of a world. I am alone, with every  
mistake I have ever made  
and no one to own up to.

(c)Stephen Lightbown *The Last Custodian* (Burning Eye Books, 2021)

**SL:** My guest today is Matthew Sanford. Matthew was paralysed from the chest down aged 13 following a devastating car accident. Now, some 30 years on, Matthew is a public speaker, healthcare pioneer, award-winning author of his memoir *Waking* and a nationally recognised yoga teacher.

**MS:** I am some combination of my personal story and what I've done. I'm an author. I wrote a book *Waking: A Memoir of Trauma and Transcendence*. I formed a nonprofit in 2001 called Mind Body Solutions and we help people transform trauma, loss and disability but we also help people live with trauma, loss and disability and their caregivers. We also train healthcare professionals. I also am a public speaker. I was injured when I was 13 years old. I was in a car accident. I'm a paraplegic at T4. I started yoga when I was 25 and I'm 55 so you can do the math. I've been doing yoga over 30 years and the last 20 have been working with Mind Body Solutions, the nonprofit I founded.

**SL:** I was listening to a podcast that you've done previously talking about trauma and the medical model and it's something that really resonated with me. I myself had an accident when I was 16. T9 paraplegic. At the time I was really grateful to the hospital where I rehabbed. They patched me up, sat me in a wheelchair, made sure I was physically okay and six months later I was discharged and actually maybe it was 20-25 years later when I'd started to really understand the new relationship with my body. I just wonder if there's a way that you might be able to expand a bit more on what you think about the medical model and if there's maybe a different way or an improved way that you think we could and should support people after trauma

**MS:** You know, in a way it's really easy to, say, talk about it or more clear to talk about what I think about that in relationship to a spinal cord injury but I think this is generalisable. One of the things that I think that occurs is that the knowledge that the medical model has is very much from their perspective. I know that sounds kinda funny but they don't know what it is to have... the caregivers; some of them have been through a lot of trauma, some of them haven't. Some of them haven't been deeply rattled within their mind-body relationship because what trauma does,

regardless of its physical or mental... It's got a lot of different effects. Or psychological. Trauma definitely affects the mind-body relationship at a core level, right? And in a spinal cord injury that's really easy to understand because my spinal cord was severed so the connection between my brain's thoughts—my mind's thoughts and if I go to wiggle my toes—my foot—my toes aren't gonna wiggle. That's an obvious... that's why it's a good example is that... and what's really paradoxical is that when you go through acute care in a hospital what I like to say is that the violence... They think the car bounced over my chest. I was in a car accident. Killed my father and sister and left me really quite injured and that the violence didn't end at the accident scene. It began.

**SL:** Mmmm.

**MS:** Okay, so once you're in acute care after a catastrophic accident in particular there's a lot of corrective violence going on. Right? Things that happened to me and I'm sure happened to you that were... Even surgery when you're under anaesthesia. When you get cut with a knife wide open, you're cut with a knife wide open! Right? It's just controlled violence. The paradoxical insight is that while it's traumatising to the mind-body relationship, you're also grateful for it. So, you're grateful for the perpetrator that's saving your life, right? So I think that there's an understated amount of trauma that occurs in acute care for all the right reasons. These are good people trying to save my life but the effect on the mind-body relationship, the rattling of the mind-body relationship—as I wrote in *Waking* I learned to disassociate from my body as a 13 year old boy to get through all the corrective violence that occurred so I literally disconnected from the senses. I think for a lot of people it's a survival skill built into human consciousness that we can disassociate from the body because the body will be the only core witness of everything that's ever happened to you. Your mind goes in and out of phase. Our hubris makes us think that the mind's in charge of everything. No; guess not! That's not what's happening. Your body is what stays faithful to living at all times and so I think there's an underappreciation of that kind of effect. I don't think that effect is just psychological; that they're issues that someone that comes through a catastrophic accident, let's say, that are psychological and emotional, cos that's all true.

I think that part of the mistake is an underappreciation—and I think it's changing now with neuroscience—is that we're beginning to recognise that the nervous system is much more robust than we thought and that there are ways that the mind stays—and the brain stays—connected to the entire body that don't just run through the frontal cortex, right? So what ends up happening is that because I had a spinal cord injury and my spine was severed, and they can't fix that and they feel bad because these are good people! Really good people that have saved my life and kept me alive. They feel bad but they think of the injury as a physical injury with psychological and emotional consequences, which is true. It sucks to be disabled. It sucks to have this type of injury. It sucks to go through that much trauma. That is all true, and there are psychological and emotional effects but that's not the injury I live with fundamentally all day long for the last 42

years. I live with the mind-body disconnection. Mine's just really overt but I think anyone that's gone through trauma loses connection to their body, or to his or her body. If you tickle the bottoms of my feet, I don't feel it. If I tickle the bottoms of your feet, you feel it and so I think that there's a... That because I live this mind-body disconnection there are psychological and emotional consequences but you've gotta help me reinhabit my entire body regardless of what's occurred; what the condition is. That's what I think the medical model's not doing. They see my mind-body relationship as fundamentally ending once my spinal cord's severed so they'd say things to me like: 'You have no sensation below your point of injury. You'll have to learn how to compensate for it.' I'm a T4 paraplegic which means I'm paralysed from my chest down, have to make my upper body really strong, and learn to drag my paralysed body through life, right? So a compensating model right from the beginning. Instead of 'How are we going to help you heal and learn to inhabit your body at whatever level you can?' So I think that rather than saying my mind-body relationship was over below my point of injury, that there was part of the rehabilitation process—and that's why I formed Mind Body Solutions—is to try to get me to learn how to live in my whole body even though it's not going to be the same as people that walk around, but that doesn't mean the sensation has ended. The nervous system is so robust and so more subtle than just through the spinal cord that *that's* the part that needs to be rehabilitated.

I know that's a long answer but my point is there's a fundamental lack of appreciation of how robust and amazing our nervous system is. It doesn't have to all run through one modal, one part of it and that's why we need to rehabilitate trauma at that level, on the level of how does... like, when I try to perceive into my paralysed legs I don't get what I would get if you tap me on the hand. I get a form of silence or emptiness in my experience of my body below my paralysed... my point of injury. That silence has texture and depth. My brain can start to pick up really subtle, important things from that level of presence. That's what they're not getting. And in fact I also think, for example, a paralysed body is an amazing teacher because it teaches you the experience of presence without control. You know what I mean? You can feel your legs on some level, right? But you and I don't get to affect it directly with our will. Talk about a spiritual teacher! <laughs> Right?

**SL:** I think the same thing. I've heard you talk about, whether it's a pin that they run into your foot or a pen that they run down your leg. I had that and so, so right. I didn't feel pain after my accident because I was in and out of consciousness, I was pretty delirious. I had a sledging accident where I was going backwards and I hit a tree. Maybe for the first few days I didn't really feel any pain. When I was transferred to the spinal unit and I had my lungs drained without anaesthetic, that's when the pain started. <laughs>

**MS:** Ugh!

**SL:** And the bit there I remember very clearly them doing the pen thing and saying ‘No’ and it was at that moment I disassociated myself from my legs.

**MS:** Right.

**SL:** And how then can I explain that when I’m lying in bed next to my wife I know when she is touching her feet against my feet?

**MS:** Isn’t that awesome?

**SL:** Yeah, and it is because of the mind being aware of the space that you inhabit.

**MS:** I think it’s an indication of how amazingly complex and subtle and evolved our nervous system is. It’s got multiple systems that can sense on multiple levels. You and I might call that spirit, someone else might not want that word but in fact—Guess what? We can sense emptiness and loss and bring it to life. Right?

**SL:** Yeah.

**MS:** And so you *can* feel. Like, I’ve built a whole yoga practice around exactly what you’ve just described: your wife’s feet into your feet and the change in sensation that you feel up through your whole body. That’s the level that needs to be recognised as what’s being revealed by trauma because someone that hasn’t had that doesn’t realise that that level exists.

**SL:** My epiphany moment—and I don’t want to kind of... You know, I’ve not just brought you onto a podcast to be able to say thank you for my epiphany moment! But I’d been practicing yoga in the privacy of my own home following online videos and things for maybe five or six years, came to it mid-30s. 2018 I was on a train from where I live in the UK to London to go to my first in-person yoga class. There were 200 people in the room and I was the only wheelchair user. On the train on the way there I was listening to you on a podcast and you said something about—and I’ll paraphrase so forgive me if I don’t quite get it right—but about ‘the voice in the legs is still there, it’s just softer. You just have to tune into it more’ and that sentence, it was like all the lightbulbs came on for me and having had... being told that I couldn’t feel my legs and being dissociated at the age of 16 I’d just ignored my legs. You know, I didn’t look after them, I wasn’t doing my stretching so my legs are now chair-shaped. They won’t go straight, they... a whole range of issues. I’d just neglected the care of them. I got off the train with this sentence buzzing around in my head, got into the class, was slightly overwhelmed by the fact it was my first yoga class with 200 people, went into a forward fold and in the forward fold—I was in a seated forward fold—something just compelled me to then just whisper to my legs and say ‘I’m sorry’ and there was something back... and I just started to well up and cry in that forward fold.

I'm feeling quite emotional talking about that now and for me that train journey; listening to you on that podcast and that yoga class, that's what changed my relationship to my legs and that's why I wanted to lead with that first question really because it was such a switch-on moment for me that has taken 20-25 years to get to that point. And I just think there's more that we could have done to understand that for other people in the same situation.

**MS:** Yeah, and that's... you're exactly why I started a nonprofit and try to train healthcare professionals because this is something that can be communicated and you and I can be trained earlier to sense this level of awareness that is connected and within the body. One of the problems is that the medical model—the paradigm in general—is biased towards healing as reversal. They try to fix the condition; they want to fix, fix, fix and the level of awareness—or consciousness I would call it—that we're talking about being able to recover and experience is never going to make us walk again. But what it's going to do is make us feel much more whole and connected both inside and out but at a level that's beyond just psychological. When you started to realise that you could live in your whole body and you whispered that 'I'm sorry' because I had the same type of moment. I write about it in *Waking* is that when I recognised 'Oh my God, my body's been the witness, my mind could not stay with what I went through' and that it was my champion as opposed to the thing that was letting me down, that level of forgiveness and then the other recognition when I first started yoga and the first time I practiced on my own I had this really intense feeling that my body had been waiting for me the whole time. It's like, it just sat there waiting going 'Okay, okay' and it stayed faithful. It ended up responding to me the twelve years later, right, but it had been waiting saying it wanted direction, it didn't just want to be left to wither even though it wasn't going to be able to lift weights. It was waiting for the sensations and the life force to be guided again just as if I were walking, so for us that means, you know, pushing in our femur bones and lifting our chest and letting energy and feeling energy move through the whole vessel again and, like the beautiful thing that our bodies are, it responded. It didn't judge me. It actually went 'Just give me some attention'.

**SL:** Because you start to appreciate just how unique your own body is to you. It's a gift, isn't it? It's special in that sense because nobody else has my body and no other body has fought as hard as my body to keep me alive and I need to be grateful for that! <laughs> I'm interested in terms of what led you, you know, you said you had your accident at 13 and came to yoga at 25? What was it that made that decision for you?

**MS:** I just missed my body! Like, it was one of those things where I was a super athletic kid and this is another part of what happens with the rehabilitation vision. They try to get across to us—which is good psychologically—'Look at all the things you can still do. You can still do this, you can still do that, you can still do this', right? I wish they would do that and help us live in our whole body at the same time, right?

So I did try to do some adaptive sports but I broke my neck—I don't know if you remember that from *Waking*—I broke my neck a year after the accident; after my first accident. My brother was tickling me and I fell out of my chair and I broke my neck so I was a quadriplegic for a while and then I was warned not to play something where I could fall out like that because it could happen again and so I went to my head more which is a natural thing. My Mom told me, 'Hey, you're a smart kid, you're gonna have to work with your head, you're not gonna be able to build houses with your body.' and so that led... I did that for 12 years, in fact so much so I went and became a philosopher, went to Graduate School in Philosophy thinking about the mind-body problem without fully realising I was actually thinking about myself, trying to wonder that there was something else going on that wasn't being captured by what I was told by the world. And so I started to really... I was unhappy, I started to have some shoulder pain but I just missed my body and I thought okay, I'm going to take this seriously. I had a body worker who got me to realise and feel—this is before I started yoga—that I had left my body behind and that I owed it a remarkable debt because it had continued me, I hadn't continued it. Right? And that made me go 'Oh my goodness, there's a whole...' kinda like your moment on the train where it's like 'I gotta do something' and then I thought 'Okay, I miss my body. What's a way I could reconnect?' And a different body worker said to me 'Hey, you should meet my yoga teacher.' That's when I was in—at that time I was in Graduate School and said what the hell? Why not pick a thousands of years tradition that's overtly about integrating mind and body and whatever you call spirit and give it a shot? I remember the moment I went up to the—kinda like your first yoga class was not 200 for me but for me I wheeled up to an Aikido dojo in Santa Barbara, California and I just happened to meet a fantastic yoga teacher one-on-one and it just clicked. That's part of why I formed Mind Body Solutions and I train yoga teachers from around the world. I want every one of us—the people that have gone through a big trauma—to find the right yoga teacher.

**SL:** The book that I've written there's a couple of things in there that I'm interested in talking to you about based on what I've heard you say before. One is around the effect of loneliness on movement and this person, if they are the last person, they take the decision to move, they take the decision to carry on moving and one of the things they talk about is if there's nobody else around, how can I be disabled because there's no-one to be compared to? And it's this—the concept of the word disability and I think I've heard you say before that is a word that has many issues in the sense that again, if I'm told I'm disabled then there's a psychological thing that starts to happen anyway rather than just focusing on just how great the body is and I don't know if there's anything that you felt maybe resonated there.

**MS:** One of the things that you originally said—I was writing it down here: 'loneliness and how it affects movement' and you're exploring what if the last person on Earth was a paraplegic? Which is interesting because it kind of gets to this idea here, giving a thought experiment: 'my body's not disabled, it's the world that I don't fit into' so it's kinda that I both agree and disagree with that. It's okay. I'm a little bit of the fact that guess what? Disability's not a swear word, you

know what I mean? It's actually the fact that I'm not going to be doing cartwheels anymore, so aging is a disability but God forbid this country, this world doesn't want to hear that. It's like, it is. You're not being as physically able as you used to be and there's nothing wrong with that. So I've a friend of mine and colleague, Kevin Kling who's a storyteller who also lives with a disability. He's a stunning storyteller. He said this to me that really made me rethink my relationship to what disability was. Talks about Dante going down in Dante's *Inferno* and talks about that, for Dante 'dis' didn't mean 'un'. Disability doesn't mean inability. 'Dis' actually means 'having travelled through the world of shadow and reflection'.

**SL:** Wow.

**MS:** Okay so, that I have wisdom, you have wisdom that's actually travelled through the world of shadow and reflection. It's actually earned ability <SL laughs> as opposed to taken for granted privileged ability. And I think that's part of how I want to reclaim the world. I don't wanna say no. I wanna say: Guess what? By the way I think our world right now is living in a chronic condition. We're crazy not to think of the environment as a chronic condition. We're crazy not to think that systemic racism is gonna suddenly be able to be fixed and go away. We have chronic conditions. Guess who should have the insight now? People that live with chronic conditions. The type of patience, the type of strength, the type of resilience, the type of... oh my God, I don't know about you but I am like... I just can't believe that people think that their individual freedom is constrained by whether they have to wear a mask. I mean... It's like, what... what are you even talking about? Talk to anyone with a fricking disability, dude! <both laugh> And it's like, that is nothing! That is not a constraint on your freedom.

**SL:** Yeah.

**MS:** Wait until you really know what a constraint on your freedom really is! And also for me, I mean, I obviously got vaccinated. You and I don't have the luxury of not trusting medical science. Even in rejecting a vaccine, that's such incredible luxury. It's unearned ability.

**SL:** If you were Luke in the story, so Luke who's the last paraplegic on Earth. If the last paraplegic on Earth was you, Matthew, where would you go?

**MS:** Okay, so, just so you know that question I've been wondering about because you gave me a little heads up on it and what's been so revealing for me about that question is how much it's made me know how I think. Right away I want—I'm so pragmatic. Am I the actual only last person? Are there a group of us? Is there a water supply? <SL laughs> I'm wanting more details. You know why? Because I wanna help whoever's left survive. So if I'm the very last person which I think is what you more meant—

**SL:** Yeah.

**MS:** That's a—that... I'll give an answer in a second but it was so funny to watch me go into survival mode, 'cause I actually think human beings have got—I don't know how many hundred years it is until we're done or most of us are done, we got, we're in survival mode so I'm all about the making choices, find where the water is, figuring out how to plant some stuff... That's my first level. Where I would go if I were the only person left... I would spend a lot of time apologising to the Earth. I would probably not travel as much if I actually could confirm what you're saying: that I'm the last and I'm a paraplegic. There's a lot of forgiveness that I need to ask for, for myself and for human beings and there's a failure to recognise that what we've done, we've done to the Earth. I heard on this podcast on a... I was watching the World Science Festival and they had this guy, this anthropologist who had just been with this Shaman in the rainforest somewhere and he asked his teachers there what message they wanted to give to this audience and the message was this—and I'm paraphrasing—Somehow, you, us, Western people have forgotten that your mind is the possession of Earth. It's an evolutionary by-product of an amazing system. Your mind was never your own. It's one of the culminations of the planet. Stop thinking it's about you. It gave the thoughts to us. It created the conditions. And with the time... think of the time it's taken for our minds to evolve. It provided the framework for that evolution and we sit there and have our own hands and our own underwear <SL laughs> and are all caught up in getting messed up about how important we are? So in that time, if there isn't a chance for me to save, I am going to sit and love and say thanks to what produced me.

**SL:** That is a great answer. Yeah. I think this feels like a really good place to bring that to a close Matthew, actually. I think that so much there has been just wonderful to listen to. I talked about having one lightbulb moment on the train listening to your podcast, I just had many more lightbulb moments taking part in this interview so thank you for that, and thank you for your time.

**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.