

‘Stories of Power’

Transcription poems
by
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From the words of Jess Thom

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But first, a word from the tics...

*I love beans. Hello cat.
Trigonometry killed the radio star
but it didn't kill mother's kitten.
Beans. Fuck it. I love cats.
Fuck it. I hate cats.
Biscuit. Hedgehog. Biscuit It.*

Primary

I struggled in my first primary school
because I moved around a lot,
fell over a lot, relatively.
I was relatively disruptive in lots of ways
but not intentionally.

As a neuro-diverse child in the '80s,
I've got some very early memories
of failing as well, teachers talking about me.
I think certainly my school life
up until the age of nine or ten
was mainly characterised by a feeling of failure.

One of the other very strong memories I have
is being taken by school to the Tate Gallery,
when I was about six or seven,
going up a spiral staircase and sitting in a studio
in a big circle with my classmates
and a man in the middle introducing himself as an artist.
And it blew me away, because I didn't,
didn't know that artists were alive people,
I didn't know it was an actual job you could do.
And I think from that point on I knew
that that was gonna be the job that I did.

Creativity has always been
an integral part of my life,
partly because I was encouraged to draw
instead of doing anything more substantial
for the first years of my primary education.

Shame

I had tics since I was a child
but they were much less noticeable
to other people then.
My parents were very accepting
of me and my range of
very unusual chaotic behaviour,
and I felt very accepted exactly as I am,
but I did feel that there were aspects of my being
I didn't understand
and didn't feel like I had space to talk about.

That is something that I say to parents:
just because a child looks like they're managing
or their tics aren't that noticeable,
they will know, and to a certain extent
not talking about the tics
can make people feel that they're embarrassing
or that there's shame.
And that process of shame
as a disabled child, young person, adult,
that process of shame starts really early.

Finding Out

I was a disabled child
I received specialist education,
I had a number of different diagnoses
that didn't lead to Tourette's
definitely understood in the context of neurodiversity.
And I remember when I was at my first primary school
which means that I would have been under eight,
looking for information around the things that I was experiencing
in the children's library.
I remember bringing home a book called 'Mentally Handicapped',
it was such and such is mentally handicapped,
it was a book for children. And using that language
and talking to my mum, 'Is this me?'
So I was looking for that as a child.
What I didn't get was any good answers
or good representation.
That's not necessarily the fault of my family,
because I think there was a lot of openness and discussion,
you know I had lots of things explained to me really well,
but it was around what was wrong with me
rather than anything about the sort of barriers
that I would encounter in the world.

Lots of parents, when they first receive diagnoses,
what they worry about is the future and for me,
when parents say they're worrying about the future
they're worrying about their children living full active lives
and being able to participate within their communities.
Obviously it's different for different conditions
but I think that there's an element where I'm curious
if we change those first moments,
if we change the way children and families receive diagnosis,
we can tweak some of those early encounters
including making sure parents understand the social model,
potentially including parents understanding
their role as advocates,
and being given skills and resources to do that
and being honest about the challenges which they face,
I wonder if there is a, if there is a welcome
rather than a sorrow around diagnosis
or a sort of here you go, go and get on with it.

I feel like we could drastically change the outcomes
for the children who will then go on to be disabled adults
and then become the next generation
of disabled makers and creators.

My sister

I have one sister, who I am really,
really close to and she's a doctor
she's five years younger than me,
and was on the receiving end
of a lot of unusual behaviour as a child.
I realised a few years ago
that she's the only other person in the whole world
for whom my tics have always been part of their life.
Whereas other people have to get to know them,
or get to know my body
or get to know how my mind works.

And so she has an acceptance and a response to that
that is so deep and supportive
that it almost defies description.
That sort of unconditional acceptance
of the reality of the situation
and that being a fact,
the fact about me and my body,
amongst many other facts and is interesting,
because in lots of other areas of my life
it's something that people have to learn
to be with, to cope with,
whatever language you wanna use.

And certainly, you know,
my parents are very supportive of me.
I think they really struggled at various times
to know how to help me grow into
an independent and happy person.
They've done it but I don't think
that's a straightforward journey
for anybody raising a child who is neuro-diverse
and likely to encounter barriers
that are invisible to other people.
I think some of the physical barriers I encounter
are really easy to explain to people
and I think people can understand
some of the attitudinal barriers,
but the experience of constantly being problematised is hard.

Special School

I left my first primary school when I was eight or nine
and did two years in a specialist setting
for young people with specific learning disabilities,
it was a setting that was designed to take
young people who were struggling at school
and work with them intensively
to a point where they would be able to go back
into a mainstream system.

And so I had lots of input there
but the most important thing I think that they did
was rebuild my confidence.
I don't think it would have ever occurred to me
in lots of ways to,
to go in a performance direction,
I think that's an amazing opportunity that educators have
in terms of recognising talent and nurturing it
and helping people feel confident
about aspects of themselves
particularly if you are used to being talked about
in terms of deficit and in terms of problems,

I'd definitely started to feel like a problem
and had been made to feel like a problem in school lots of the time.
They experimented quite a lot at that school
and a couple of classes were given computers,
they were taught how to touch type
using a sort of specialist programme
were able to use computing and computers in their lessons.

I was not part of that group,
I was part of a group of children
that got to walk around the hall
with a hula hoop round their middle
trying not to bump into each other.

My Grandparents

I had a very close relationship
with my maternal grandparents,
I lived on and off with them at various points.
And it was my gran that persevered in terms of my education,
I think she was probably the only one,
only person who ever managed to properly teach me anything
as in a sort of one person
teaching another person directly something
and she did that by a combination of bribery and repetition.

My granddad was quite an obsessive,
I'm sure that there's an element of Tourette's
that links to that obsessive compulsive behaviour and there's definitely,
you can trace that back in the family,
One of the things that me and my grandad
used to do together in an evening
was walk around locally and identify broken lampposts
and take down their serial numbers,
and then once a week he'd go and report them all to the council
and we'd have to stand in line while he did his weekly report,
and he'd get very frustrated
if the same lamppost continued to be out of action.
But that's funny now to me in, that was a very, a lovely like
I really enjoyed those walks,
I'm now reflecting back on that,
that's not a natural activity,
there aren't rambling associations
that do that as part of their routes.

When I moved into this place,
there's a lamppost that I can see from my bedroom window
that my tics have a very strange relationship with.
So I brush my teeth, get into my pyjamas,
get into bed and then go on to the lamppost
about the brightness of the moon
and talk to a TV aerial.
I think one of the things that I've really come to appreciate
(and actually writing every day as part of the blog,
the Touretteshero blog, helped me get to this point)
was really valuing the relationship

that Tourette's gives me to the world around me.

I notice details, or my tics notice details
that the conscious part of me wouldn't,
and then draw my attention to them
and everybody else's attention to them,
in often very funny ways.

The Fortunate Geranium

My friend Matthew got given a geranium.
And the moment it appeared in his house
I started swearing at it
and sticking my finger up at it,
essentially bullying the geranium.
But I'm sure that plant would not have survived
and would not have been kept alive
had it not had that impact on my tics.
So I feel like I might have been
being quite mean to the geranium,
but I feel like it owes me its life,
because there's no way
Matthew would have looked after that plant
and kept it alive
if I hadn't been regularly shouting at it
and he found that funny.

I notice the themes,
like Tourettes will often notice the seasons
before I do and will start chatting
to the tree or to the sky.

Secondary

I didn't have a diagnosis of Tourette's in secondary school,
I had a diagnosis of other conditions,
but I was lucky in that I was my behaviour was I think
always understood in the context of neuro-diversity,.
I went through a phase at secondary school
of running uncontrollably into closed doors,
which was probably quite a large thing for teachers to manage.
But they did and I was never told off for that.

I talk to teachers, I often talk about an experience
where my whole year group was in the gymnasium
and we'd all got basketballs in front of us.
A male PE teacher was standing at the front
and told us not to touch the balls, the basketballs.
And I just picked the one up in front of me
and hurled it at him
and it hit him square in the face.

He ordered me out of the gym in a rage,
and the humiliation that was written over him
and the fear and the terror that was in me
of having done something
I definitely didn't feel like I had chosen to do.
It had totally shocked me in terms of what had happened.
He ordered me out of the gym
and he came to speak to me and he asked me why I'd done it.
And I said I didn't know, and said
I hadn't chosen to do it and it had just happened.

And he believed me, and he understood me
and he did not punish me, and he did not go on about it
and I now feel that that
would have taken an incredible amount of strength.
If you're humiliated by a child
it's very easy for teachers to react
on a very impersonal level, but he didn't.

I was sent on errands all the time.
It had not occurred to me that I was being given
carefully structured movement breaks.
So there's certain things now

that I know were there.
I was being looked out for.

Remember, remember.

I was in all the bottom sets and I didn't find school easy
from an academic point of view.
But then about six weeks before my GCSEs,
I don't know where or when but I suddenly realised
that the teachers basically knew
what was gonna be in the exam papers,
or had a fairly good idea,
that we just needed to remember it
and I was furious.

Why did nobody tell me
that all I needed to do was remember it,
like remember stuff? Because I knew
that I could make myself remember it,
just couldn't do it in a way that they were trying to teach me.
I was trying to know this stuff. I don't need to know it,
I just need to remember it.

So I created myself loads of big posters,
colourful posters with all the key information,
and I put them around the house,
and every time I walked past them or used the toilet
I would make myself read them from start to finish.
That was utilising that obsessive part of my brain
to acquire information.
It's exactly the same strategy that I use now
when I'm learning lines.

The reason that I can do Samuel Beckett's 'Not I'
is because of that exact same process
that I worked out when I was fifteen.
I then did much better in my in my GCSE exams
than anyone was expecting.

Camberwell

I didn't go to agricultural college as planned at sixteen
and do a land-based industries course.
Instead I stayed on
and suddenly got art in a way that
like suddenly got that,
that I could make art in a way that I wanted.
And I think that that's, there was like a,
that it wasn't about being good at doing a specific thing,
it was just about that I needed
to let myself be creative and that would work.

And so that was exciting
and then I applied for art college.
I went and did a foundation course
at Camberwell College of Art
and then stayed on, did a BA in drawing.

And I was lucky that the course I did
took a very broad view of what drawing was
and understood it as a process of creative thinking.
And I think that that sort of thinking creatively
and the process of trying,
testing stuff out and solving problems,
definitely had been enhanced
by my experiences as a disabled person.
As disabled people we are very good at adapting.
It means that we can find amazing solutions
to problems and barriers.

I started to understand
that we have to make the right adjustments.
And it can be very easy to adapt to inequality
rather than make some of the adjustments
necessary to equalise opportunity.

Particularly on public transport

Particularly on public transport
I have had loads of amazing conversations
but also really difficult experiences.
My right to be in public space
as someone who behaves in an unusual way
is often something people have opinions on.

When I was a child
people had opinions
on whether I should be in the classroom
or whether I should be in a mainstream setting.

As a young adult,
travelling by public transport,
as I wanted to go to art galleries or theatres,
people had opinions on whether
I should be on the bus or not.

And I think I had been inadvertently taught,
by the system of how we like to educate
and raise young people as a community,
I had been taught that other people's rights
trumped my own.

And that there were certain places
that weren't for me because I couldn't behave
in a way that was appropriate for those contexts.
It didn't occur to me as a child to question that
or as a young person to question those contexts.
That's why it's important to do that now.

Play Work

Working with children and young people
has always been an absolutely integral part
of what I want to be doing as a creative person.
Some of that is because playing is fun
and it's exciting to make things happen
and kids are really full of imagination and joy
and go with the process in an exciting way.
Part of that is because I believe that
those positive experiences are protective
and that they give children and young people
stuff to draw on and feel proud of
when things are inevitably tough
when they hit barriers.
So inclusive play
and working on adventure playgrounds
for disabled and non-disabled children
is where I think I learned to be a performer.
I certainly didn't go to drama school.

Charlie Chaplin Playground

All the time of my creative education
I was also working as a play worker,
in an adventure playground
for disabled and non-disabled children in Camberwell.

I needed to earn some money,
I needed a summer or weekend job.
I'd grown up on adventure playgrounds as a child
and was going past one that looked good
and actually saw an advert for jobs there in the Big Issue.
And so applied and started working there.
That was actually a place called
Charlie Chaplin Adventure Playground.
Matthew and I have a big relationship with that
and it's where we met.
It's where we started putting on
participatory events for the children there.

‘Something out of Nothing ‘

We decanted the whole of Charlie Chaplin,
eighty kids, to the South London Gallery,
they’d given us the space, the main space
when they had a gap in their programme,

The idea was to do an event without outcomes
where we had no expectation of what the outcome would be.
It was not directly funded by anyone,
so it meant that we weren’t worrying
about it having to do anything.
It was an experiment.

We created a space where there were
costume-making practitioners,
musicians, live musicians, digital artists
who had computers and projectors set up
and DJs and painters and collage artists
and there was an accessible ramp
catwalk style platform ramp
that went down the middle of the gallery
that was fully accessible.

Every child when they arrived was given,
and every adult, everybody in fact
all the staff working in the gallery that day,
every single person was given
a white paper dust suit
and the invitation is that this is your starting point,
you can use any of the resources
or any of the things here to create whatever,
to make something out of this nothing.
And our hunch was that
the imaginations and energy of the children,
we could trust in that,
we didn’t need to do anything else.
It was an absolutely brilliant event
and it ended in a parade
along this ramp of all of these costumes.

And that was definitely
one of the first events

that Matthew and I had really
created and designed
in a cultural space rather than in a playground.

It did some good stuff
both within that institution
and in terms of the opportunities
for young people we were working with.
So we just started doing that more and more.

Sceaux Gardens

I'm a play worker and an artist
and I did a residency for the South London Gallery
in a barber's shop on the Sceaux Gardens Estate.

I worked with the children and young people on the estate
to map and research and investigate their play
through a load of creative things
and we turned the barber's shop
into a sort of three dimensional map of their play on their estate
and also it was a centre for playful responses
to the world around them.

And then that was also a challenging time
because shortly after that residency
there was a big fire on that estate
and lots of the children witnessed that.
It was quite a difficult, traumatic time for the whole community
and two of the children who'd been involved with that project
died in that fire, which was the Lakanal House fire.

I had that relationship with lots of the families
and was a play worker and recognised that in those traumatic spaces
the needs of children are often missed, not deliberately missed
but not given attention where people are trying to cope
with losing their homes and their possessions and finding housing
and the distress of that, the trauma of that.
Doing play work in the middle of that felt important.

Catching the Moon

Matthew often talks about a beautiful moment
at the South London Gallery
when one of the technicians was repositioning a spotlight
and the children noticed that and started following it
and trying to reach for it and jump for it.
And then this game emerged
between the technician and the children
where he was moving the light around
and they were jumping around and reaching for it.
It was like a sort of amazing
trying to catch the moon.
Nobody had planned that,
nobody had defined that, designed that,
it's about understanding
that you just go with the flow.

And then within Touretteshero going with tics,
and they were some of the first creative experiments we did where,
rather than have a conversation like this
where we largely ignore the tics,
instead we went with them
and let their unusual stories unfold.
Within our practice now, some of what we do
that I feel most excited by
is where we use tics like my neurology
to generate involuntary text.

And partly why I think I relate to the 'Not I' text is,
part of my progress as an artist and as a human being
was understanding that Tourette's was part of me
and was coming from my brain and my tics.

Before that I would always talk about them as the tics, the Tourette's
and lots of like accepting how you live with a voice
that you don't have control of
and words that aren't communicative straightforwardly
is a really challenging place to negotiate,
particularly as an adult,
because of the variety of responses and judgements
that that then comes with.

And the lack of anonymity and the standing out in public space
and, you know I don't feel like,
I'd often feel talking about Tourette's
and talking about my impairment
and talking about disability
isn't always a choice.
It's a tool for living.

And in a way being a performer
and doing that on stage
or doing that in public speaking,
it's just you hit more people at the same time.

I value conversation deeply but I also recognise
that talking about Tourette's has changed my life
in terms of having the confidence to do that
and explain what I need and ask for help when I need it
and understand that that independence
isn't about doing everything for yourself,
but about being in control of the decisions.

Becoming disabled

My tics had been intensifying from my early twenties.
By 2006 they were enough of an issue
for me to have sought diagnosis.
I knew I had Tourette's long before that
and that is probably the point where I was,
they were having significant impact on my life
and my visibility in public space.
And I'd come across things like BBC Ouch!.

I feel a great sadness that we've lost Ouch!
as a disabled-led platform, the way that it used to exist,
because it allowed me from the safety of my home
to read and access the voices of disabled people
with a range of different experience and impairments
to engage with disability culture
in a playful, funny, really accessible way.

It meant that I could build my identity as a disabled person quietly
and then get to a point
where I was able to articulate
and express that with the language of disability,
rooted in the language of disability activism.
And that's also why I think online space is really crucial,
I don't think it's the only way,
because I think also for example,
it was through BBC Ouch! that I found Liberty Festival.

Liberty Festival

At that point I had been increasingly restricting my life.
From my late teens not staying very long in places,
constantly having to manage the impact of my impairment
without feeling like I could share that with anyone.
Well you know I did share it with,
I did share, I did talk about it,
I certainly found it very difficult to talk about,
it was an upsetting part of my life
rather than now it feels like a very positive part of my identity.

It was through Liberty Festival that I saw people on stage
and saw the depth and richness of the disability arts scene
and started to be introduced to disabled artists
who then shaped my expectations of myself,
seeing, you know, Mat Fraser and Liz Carr at Liberty Festival,
watching Katherine Araniello, the Disabled Avant-Garde videos.
I found it very hard to find
experiences of Tourette's and disability reflected.
Part of the reason we started TourettesHero was because
there wasn't anything that reflected the humour and surrealness.

Keeping it Global

I started to understand
that we have to make the right adjustments
as individuals and as a community.
And it can be very easy to adapt to inequality
rather than make some of the adjustments
necessary to equalise opportunity.

Because I have had an opportunity to travel internationally,
I understand, I've got the chance to understand
and see how the expectations of disabled people
are so very much shaped by the politics of where they live,
the politics of the place or systems.
'Crip time' was talked about in Canada, for example.
It's a way that some activists and academics
talk about disabled people's experience of time,
the assumptions that they made
about the control people had over their lives.
Hearing people talk about the way that
they crowdsource their care and manage that.

I'm really keen to keep trying to have
a global and international perspective on our conversations,
because otherwise we can't see the barriers
that are just part of the system that we're living in.
It's really easy to miss the barriers
when you're being restricted by them,
but often on our side I will be like,
you don't need different time,
you just need accessible public transport.
And obviously, some of that is simplistic
but I do think the politics of place
and continuing to find way
to have conversations across borders
feels essential, crucial, now more than ever.

Abuse

I'm used to having all sorts of weird experiences
on buses and public transport. Had so many,
whether that's laughing,
whether that's nice conversations,
curious conversations, aggressive responses,
I've had all of that in response to my tics.

But what happened at the start of last year
was so different, and it was based
on me being a wheelchair user
rather than my tics. And, straightforwardly,
it was ten minutes of the most
personal abuse that I've ever experienced,
targeted abuse, and abuse that,
they were really wanting to make sure that I knew
that the horrible things that they were saying
were directed at me and were directed at me
because I used a wheelchair.

Nobody else on the bus did anything
and the most upsetting part of that
was the silence afterwards
rather than the horrible things that were said to me.
My instinct was to minimise it,
was to like, to feel like, to not say anything,
to rationalise why that happened.
I didn't stop the bus, didn't tell the bus driver,
didn't ask my PA to ask the bus driver,
didn't do anything to take action about it
other than make some notes about
what was being said to me and where.
But that, that's sort of the natural instinct,
to just explain things away was so present,
and it was only with the support of friends,
it was like this does need to,
I do need to talk to the police about this,
I do need to go through all these steps,
but I also wrote about it
and had a creative network to draw on,
had a way of making that experience
visible to other people and processing it.

I know that my response five or six years ago
would have been totally different,
and I wouldn't have felt
that I had any sort of resilience to that.
That would have probably limited,
had a big impact, limiting impact on my life.
So the idea that those creative tools and networks are powerful
was very tangible to me at that point,
as was the idea that you have to make sure
that we're not just adjusting to shit.

Blog

I did feel like the humour and weirdness of my experiences weren't being reflected.

And so I started writing, we tried Touretteshero, we started talking about it as a website.

The main goal was to share tics for other people to make art in response to and we had a go with hundreds of images and poems, and you know these lists of musicians who've responded and film makers, so that was the intent.

And so Matthew's saying to me you should start practising writing.

You should start writing a blog to give the context of lots of the stuff that we're doing, to give the wry humour and to make sure that people understand about sitting in the right place.

I had obviously had a relationship with writing that was not always good. But it became an incredibly important part of my life. And particularly important because it helped, I think before that I would have always drawn from the negative experiences. I'd be able to talk about the times people had hurt me and discriminated against me and the challenges of that they were all instantly available to me.

What writing every day helped me realise was all the spontaneous support in conversations, beautiful moments as well as the challenging bits, and I was able to see them in a new way.

And difficult experiences, I would be thinking, 'well I'm going to be able to write about this and how am I going to do that?' And again, it gave me opportunities to reframe those and feel strong at points where things were hard.

Independent Living

In 2011 I started experiencing increasing episodes,
tics that affected my mobility, tics that affected ,
that meant I would suddenly lose complete control of my body and speech.
I had a support worker two days a week
and I had no social care
and I was living in a flat up six flights of stairs with no lift
and with deteriorating ability.
I felt very trapped.
Then I was supported to apply for Access to Work,
my employer was brilliant and I got to experience
being managed by a quiet, strong female manager
very supportive and gentle.
I learnt a lot from her.

And Access to Work and the inclusive environment at Oasis
allowed me to keep working
and doing the job that I loved
at a point where that felt impossible.
I didn't think that was possible at the beginning,
but I was supported to see that that could happen.
For a long time I was much more independent at work
than I was at home, couldn't take any leave
because I had Access to Work supporting me at work,
but at home I was put upstairs
by a support worker on the Friday night
and then had to stay there until somebody
came to take me down on a Monday
unless friends or family came and got involved.
So I think then suddenly realising
that it was time to think about accessing support.
It's really hard to know
at what point to make those decisions,
and how to do that. I was very lucky
in that I'd worked in those professional settings,
but still doing that for myself was a very,
I didn't know how to do that.

Lots of those systems are really invisible to people
and invisible to people who need them.
And I don't see that that's going to change from a structural level
so I think with disabled people as communities

we need to share the knowledge about those systems
and to keep doing that and challenging that
and doing that in as broad a way as possible
to try and catch some of those people.

There is a large amount
of institutional discrimination
that is not acknowledged
about who accesses what and how.

I certainly think that there are some local authorities who,
certainly in recent years,
basically divide up support not on needs
but on the risk of people taking legal action,
how able someone is to assert their rights to certain services.
And that's not on.

The era of the first two years of the cuts
as a disabled person was very unsettling,
watching equalities being rolled backwards.

Making Connection

You know I was taught publicly
over and over again about this sort of moment
where I felt a real change in my own attitude to my body.
And it was in a conversation
with the co-founder of Touretteshero, Matthew.
We've worked in playgrounds together since 2000.

We'd had lots of conversations in that time
about my changing tics
and the impact of that on my work
and I'd always up until that point got upset,
and I couldn't talk about Tourette's
or any of my experiences relating to them
without tears.

We'd have lots of conversations about creativity
in relation to that, but I heard,
I heard this conversation differently.
And the key part of that was that he described Tourette's
as a crazy language-generating machine,
and told me that not doing something creative with it
would be wasteful.
And it was the combination of those two things,
it's the combination of imagining it as a machine,
as a sort of fascinating producer of new ideas and language
and churning out words that I was really drawn to.
I was able to understand that maybe
that access to that spontaneous creativity that Tourette's gives me
has value, and didn't just have value for me
within my own practice,
but potentially I could record the things that I said
and gift them to other people
to be used as sort of springboards for their own creativity.
And that was the birth of Touretteshero
but also the first time where I was able to really connect Tourette's
to my professional understanding around disability and play,
actually bring it into my own life and live it,
rather than just feel on the side of it.
Does that make sense?

Memories are Made Like This

One of the ideas that underpins Tourette's Hero
is the idea that positive memories are protective,
that if we give disabled people, particularly disabled children,
positive experiences in public space
then they have something to draw on
when they inevitably hit barriers.

Words like resilience have been politicised
and used by other, by the current government and the polit..
You know some of those things are about
putting it back on communities
to manage without the right support.
But actually there is also I think a really important role
of making sure people have the tools
to withstand the barriers and keep going.
Because that is hard.

Positive experiences are key for me.
Being able to feel connected
to a network of other disabled artists
having the tools, skills, resources
to communicate my experiences
has meant that I've been able
to process and manage changes or challenges
that would have at other points in my life
really floored me.

Working with Tourette's

We were recently discussing our aims as an organisation
and absolutely everything we do
goes beyond Tourette's as a specific impairment.

I totally subscribe to the view
that disabled people don't need to talk about their impairments
and people don't have a right to know about my impairment.

However one of the interesting things about Tourette's
and how we've chosen to work with it
is it feels so intrinsic to my practice
and that collaborating with that part of my neurology and makeup
and using the things that are the product,
that essentially would be described in a medical context
as symptoms of a condition
as springboards for creativity
and catalysts for making art
means that I feel like I'm acknowledging my impairment
in a particular way that isn't about educating others
and is much more about using
the creative force that's within me.

Stories of Power

Our first event as Touretteshero
was in December 2010
and was on the snowiest day of the year.
We had 300 children invited from all over the UK,
with and without Tourette's, to a secret superhero lair.
We'd made a video
that was about Touretteshero
doing an emergency broadcast
which was about this impending dull wave
and the character called Bureaucrat
who was threatening to overwhelm the country with dullness
and make us all conform.
He was obsessed with checking best before dates
and making sure people's shoelaces were tied.
So we did this callout saying that
we needed the energy and creativity of children
to come and create their own identities
and come and save the world from the dull wave.
You'll be pleased to know that they were successful.

We use narrative within lots of our events
so that children have a way of buying in.
There's often an underpinning ethic.
For example we did a big event in 2014
called 'We Forgot the Lot' which was a collaboration
with Tate schools and teachers team at Tate Britain.

It was a national event
and we worked with eleven artists
who created activities and installations and things
that the children could engage with,
based on the idea of changing your environment
to meet your individual requirements.
So the idea of changing space to meet your needs
was the underpinning theme of the event.

That wasn't spelled out to the children
but there was this narrative of Tate needs,
Tate has revamped all of its gallery spaces
but it's forgotten how people would look at art
and how people would move in galleries,

so we need you to come and help us.
We invent the way we look at art,
so it was get involved with the artist
and make sure that nothing gets forgotten.

So increasingly I suppose the way
that performance crept into our practice
was through the role of narrative
in communicating ideas, in getting children excited
and feel like they have power within the particular space.

Understandings

I think when we started Touretteshero we had no idea
how other people with Tourette's would respond.
But we've had incredible support.
There's been very little difficulty
and misunderstanding of our position.
I think that that is because of
where the laughter sits
and how careful we are
about how we then communicate that externally.
That doesn't always work,
we talk a lot to journalists about language
and you get brilliant articles
with the headlines written by someone else.
Can then be pretty bleak.
But the thing about lots of stuff being online now
is that you can sometimes get them to change
where it expressly goes against
something that we've been specific about.

One of the great things
about Touretteshero being an organisation
rather than me as an individual artist
and being part of a team is that some of that work,
some of the real emotional labour of that
can be held and taken on
by people who care about it and understand it
on a really deep level
it doesn't have to be me all the time.
Which is what's made the way that Touretteshero works sustainable.
And it's very much an equal collaborative project.

Matthew's contribution is often
not understood as easily
because he's not a public face in the same way. But it is,
there's definitely this synergy
between our individual practices
that means that together I feel
that we can both be better artists
if that makes sense.

Unrelaxed Performance

I had this difficult experience at the Tricycle Theatre
where despite having done loads of prep beforehand
and Mark Thomas introducing me
to the audience at the start of the show
I was still asked to move at the interval
and sit in the sound booth
because people were threatening to not come back
unless I left or was moved.

And it was obvious that Mark
wasn't comfortable with that happening at the time
and by the time that had been asked of me
I felt I had no choice but to move.

And it was a deeply humiliating
and upsetting experience
and I sat and watched the rest of the show
in floods of tears
in this sound booth behind glass.
I made a promise to myself
I would never set foot in another theatre again.

'Backstage in Biscuit Land'

We basically did the big project with Tate
in March or April 2014.
And then immediately afterwards,
the weekend afterwards
we launched the kickstarter for Wellcome,
'Backstage in Biscuit Land',
which was made with Jess Mabel-Jones.

Me and Matthew co-devised it
and we also got funding,
a research and development award from UnLtd.
I think our background in play meant that we
and our lack of knowledge of how you made theatre
and of more formal arts funding
meant that we made the whole show.
We missed out the research and development bit,
made the show and took it to Edinburgh
made a finished thing on five grand.

We were then supported
to develop it more
and be able to tour it,
which was phenomenal.
I saw more theatre in my first week at Edinburgh
than I'd seen in my life to that point.

We knew in making 'Biscuit Land'
that we wanted to take a show
that talked about Tourette's,
my experience, more broadly
but also particularly talked about theatre
and our belief that making art inclusive makes it better,
makes it stronger, richer, deeper art
and makes the experience of it more interesting for everyone.

I think within TourettesHero
the idea of art as a catalyst for change
and the idea that you can use creativity
to present stuff in a way
that then changes people's thinking
was something that we very much believed in.

'Backstage in Biscuit Land'
is a really great example
of what that means in practice
and how wide that reach can be.
In terms of drawing people's attention to those barriers,
and people wanting to make work,
other artists making work in different ways.

All of the performances were relaxed,
which meant that wherever we toured
we would do a load of work
with those venues about what that meant.
Matthew will often describe our work
as a Trojan horse and I think
that's quite a good way of thinking about it.

What I Do

There's so many people
assume I can't work or don't work,
and I liked having a job
that was a project management job
that didn't straightforwardly relate to my impairment,
that challenged those assumptions really easily.

It took me a long time after leaving Oasis
to really be able
to confidently answer the question,
'what do you do?'.
'

I didn't know what to say.
Do I say in terms of Touretteshero?
I worried about what that meant for my identity,
particularly something
that related so closely to my impairment.

But I also realised that loads of that
was about my concerns
about other people's perceptions
rather than what I was actually doing as a job.

I think that was a, that was a,
you know, even feeling very, you know,
identifying as a sort of politically disabled person,
it's interesting how sometimes
other people's language and ideas
can really easily be internalised
and get into your thinking.

It takes a lot of energy and attention
sometimes to unpick that
and work out I feel this way
not because that's inherent in what I feel
but because I've got all these concerns
that relate to other people
and not to me
It's hard sometimes to separate the rubbish
from the real feelings or perspective.

'Broadcast in Biscuit Land'

In 2015 we made 'Broadcast in Biscuit Land',
which was live from Television Centre,
which went out on BBC Four.
And to go from being asked to leave a theatre
to being live on TV
with a choir of people in cat t-shirts,
giant inflatable cats and dogs and biscuits,
I mean that was quite a,
that was a really just mind-blowing moment for me.
And just before,
just as Kirsty Wark introduced us
and just before we went live
I led the audience in a chorus of
'Don't fuck it up, fuck it up,
fuck it up, don't fuck it up'.
And then we did it!

'Brewing in Battersea'

We held an event at Battersea Arts Centre
called 'Brewing in Battersea',
the last few days of the summer holiday.
We did daytime activities for children and young people,
then cabaret on one of the evenings
celebrating disability culture,
with an older young people and adult audience.

I was watching children come in to
the beautiful auditorium,
the beautiful dome at Battersea,
I don't know quite what you call it,
but there's an amazing stained glass dome
with light coming through
and we'd created this amazing,
my designer'd created this amazing installation
full of potions and mixtures in the middle
and it was covered in 'Fragile' stickers.
But then there were play workers
encouraging children to touch it
and get involved and move the liquid away.
And I watched children, families come into that space
and I was very aware
that there were children coming into that space
who in every other environment in their lives,
I could instantly see from how their behaviour
and character and energy was presenting itself
that it's like you are going to have,
you are going to be made to feel like a problem
in lots of different areas of your life.
There's very few places
where you will be accepted in this amazing way
that you are with this amazing imagination
and sort of force behind your being.
And I felt really proud to be part of
creating spaces where people and specifically children
get to be themselves exactly as they are.
But the flip side of that then feels very sad.
I was very aware that the majority of these children's experiences
would not be like that.
And it was so simple to create that.

I loved the mix of a very intricate fragile-looking sculpture
with their absolute permission to reshape it.
I did feel really connected at that point
to those young people
in relation to my own experience
but also in thinking about how we create
a future where different minds and bodies are considered
and more people are gonna feel free and safe
to be themselves exactly as they are,
because what that then added to that event,
in terms of the amazing directions,
playful directions that we went in
because those children were in the room
and that they didn't work, their brains don't work
in conventional normative ways,
it just made for humour and joy and creative routes
that I don't think anybody would have got to otherwise.

'Not I'

Matthew had introduced me to 'Not I'
years before Touretteshero
when my tics had first been intensifying
and so it had been a reference for us for a while.
And it came up within a discussion with another theatre company
who were asking me to get involved
with a project that they were doing
which was around a classic text.
Within that conversation we mentioned 'Not I'
and someone around the table said oh you'd never get,
the Beckett Estate would never let Jess perform that.
And I think that was the point that my fate was sealed.
'Cause Matthew came out of that meeting
and was like, 'So, "Not I", I wonder how that works with the equality act'.
He became fascinated by that side of things
and as to whether we would get,
who gets a say in performance work
and in what roles.

And for a long time we thought
well if they don't let us perform that
I would make a show
that would put a question mark on the end
and be 'Why Not I?'.

But the more I read it and the more I looked at it,
the more interested we became in demonstrating,
modelling how you would
make a really intense piece of theatre accessible at every level
without reducing its intensity,
and to really challenge the cultural curation
that was happening round relaxed performance.
The idea that, relaxed performance,
it was alright for the Lion King to be relaxed,
but nobody would do a Beckett play
as a relaxed performance.
So it's like alright, we'll do that.
and actually the Beckett estate were very supportive of us.

Talking to Edward Beckett

We were very careful in how we made the approach,
we were lucky in being really well supported by the Beckett community,
the academic and scholar community around Beckett's work
were incredibly supportive of us
and we did a lot of talking and thinking
about the approach to Edward Beckett and the Beckett estate.

I wrote an email.
It was a very simple response.
He said his sole interest was in
Samuel Beckett's work being performed as it was intended.
If we felt we could honour that
then he was happy for us to proceed.
And then we met him personally,
had more detailed discussions.

One of the interesting things was that actually
it was not the text being performed
by someone with Tourette's
that needed the most discussion,
it was the integration
of the British Sign Language,
because I just don't think
that they had been asked that before.

I think we felt a real responsibility
because it's like if we get this wrong,
then that could potentially be a barrier,
a more fixed barrier
for loads of people in the future,
if we get it right
it's potentially opening that up.

But we very clearly identified Mouth
as a disabled character and neuro-diverse character
and felt that it was right
that she was performed by someone,
by a performer who identified in that way.

Creating the Performance

Beckett's famous quote was
'for god's sake don't act',
which was a relief
because I can't act.

One of the things that makes me laugh
when people call me an actor
is that actually Tourette's makes me really rubbish at acting
because I'm very bad at pretending.
I will call it out straightaway.

But it's working with those. That's how
Tourette's becomes our collaborator,
because it's those creative constraints
that I think become really interesting.
And that's definitely what we had with 'Not I'.

Previously in other productions,
how it had been presented historically became the guide
rather than Samuel Beckett's initial directions.

So we went back to those and we thought
"how are we going to make this work for my body?"
And I liked that because that also fits with
the social model idea that
it's not right to expect us all to do things in the same way
because that's gonna mean that some people don't achieve stuff,
not because they can't but because they need to do it in a different way.

There's an element where it's very hard I think now,
well I hope it's very hard
for a performer or director to turn round to me
and say it's all very well
doing relaxed performances for light comedy shows,
but you could never do it for serious work.

I performed that monologue
while six or seven other people
shout very, very brilliant things in the air.
And it has made me concentrate harder.
It's meant my performance was better.
All the things that I said,

it was like 'oh that's actually true'.
I do believe that,
particularly within theatre, that live environment,
the great thing about relaxed performance
is that it, it really makes theatre live, or can do.
It's then supporting people to feel confident.

Making it Relaxed

Working with Battersea Arts Centre in a really collaborative way
we wanted to develop a methodology
that flips that assumption
rather than it being a case where
you have performances that have
the traditional rules and expectations
sort of uptight, very normative idea
of a singular normative body
who is the audience member.
And with occasional relaxed or accessible performances.
We just wanted to flip that assumption.
What happens if you say that all our performances,
all of our programme, takes a relaxed approach
and will meet the seven core elements of a relaxed performance?
Unless there is a clear creative rationale why not. That's sort of a simple,
it's a simple flip with a more complicated lot
of chatting and learning and adjusting
that needs to happen underneath, underpinning it.
The hope is that that is a methodology
that is flexible enough to go across different organisations,
not just theatre but also usable within a museum or gallery context.
And that it's also designed
to be able to be stepped through
by really small organisations with no resources
or bigger organisations with a load of resources.
Because some of the principles remain the same.
What you can invest in it
obviously makes a difference in terms of the impact.
But I think that there are some small steps
that cultural institutions could make
that would make a radical difference in terms of access.

And what's frustrating is that often
it doesn't feel like there is that willingness to change.
I just feel a bit fed up with excuses.
Because actually it isn't that hard
and the knowledge isn't that difficult to find.

Working conditions

Why do we go to theatre
and expect not to sit
next to a learning disabled person?
Why are people with conditions like Tourette's
having to make shows to occupy space
or to have to actively advocate
for their inclusion in these spaces?

One of the things that frustrates me
is that companies say that not all directors
are into doing relaxed performance.
Well you get to make the work you do
but you don't get to say who gets to see it.

If you are not prepared to do relaxed performance
then list who you don't want in your audience,
tell me who you don't want.

I think that that is the difficult thing
about the exclusion of disabled people
because there's this perception that,
for so long the idea was that
you gave access as a charitable act, as a gift.
It was a nice bonus that you did for people
rather than the right of everybody
to be able to access our shared cultural space.

We're chipping away at that
but it definitely hasn't been smashed to pieces yet.

And finally...

*Hedgehog. Sausage. Bucket.
I love dogs.
I love Tellytubby tits. Biscuit.
This is a poem about bears.
The bears fucked an octopus.
The octopus had gloves on. Biscuit.
Nobody smells of wee
but everyone smells of smiles.
Fuck a goat. I love pitta bread.
I actually quite like pitta bread, don't like cats.
I don't mind cats. Fuck the cat.
Solidly indifferent to cats.
Sausage.*