

‘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 granddad  
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 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.*