[Narelle] Good morning! And welcome to The Digital Access Show. My guest today and I met at the Brisbane Disability Expo, and we had a really great conversation... ...about communication. And I'm really thrilled that Bianca said yes straight away, when I said, would you come on the podcast to talk about it? Everyone, please meet, Bianca Saez.

[music playing]

Bianca, thank you for being on the show. [Bianca] You're so welcome, Narelle. Thank you so much for having me here. [Narelle] Bianca, tell us a bit about yourself. [Bianca] So, I've had severe Tourette's Syndrome my whole life, from the mddle, the age of four, diagnosed at five. Pretty sure after that, we worked out, that was I was one of the worst

people in the world with Tourette's,

when I was younger.

But as I've gotten older, my

Tourette's has kind of calmed.

Still got see Tourette's, but

it's calmed to the point where...

I can walk down the shopping aisle without ticing,

and breaking things with my

Tourette's like I did as a kid.

So I've had a big, big life

with Tourette's Syndrome,

all different avenues of things

that have happened to me,

but as I've gotten older,

all I do is just want to work like everyone else.

But no one would hire me because of my swearing.

So I'm like, "Alright, let's make my own job".

So I just decided...

to do stuff on my social media platform, which was amazing.

But previously, back in my childhood,

I've got three 60

Minutes stories in it,

60 Minutes Australia to be able to boost my career,

so that I've been

on social media.

After that, created a platform

for disability advocate.

And then after that, I got a job at a place called Designer Life,

that basically wanted me to talk to their students,

to uplift and tell them what I had to do before I come to work,

trying to uplift so they get jobs too.

And then from there,

I found out that I have a passion for motivational speaking,

but also it's the educationa; of side of Tourette's that I need...

to get across to people.

Like un, another person in my

Tourette's community...

went and took

himself to the park,

just so he could be away from other people,

so he could tic freely.

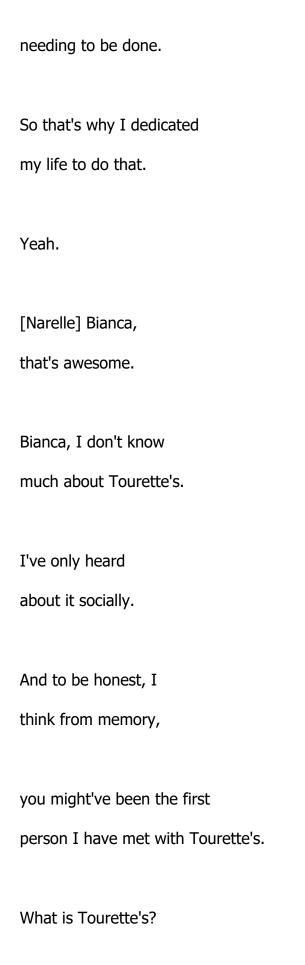
And then there was a

lady and a child there,

and there was police,

and she went over,

and complained to
the police about him.
About him being too aggressive
or yelling or something. So.
And the way the
police handled it.
They don't know how to approach
someone with a disability,
or how to go about it.
There's so much education needed
done in all walks of life,
from hospitals,
ambulance staff, police,
teachers at school.
There's so much education



[Bianca] So Tourette's Syndrome is a neurological disorder, characterised by controllable movement, and vocalisations called Tourette's. So basically, our tic is like, someone says, stop your Tourette's. It's like saying to them, stop breathing or stop blinking.

Tourette's Syndrome is more common in boys too.

You don't come out as baby, but it comes out later.

You could be 21 and you could wake up with Tourette's,

or you could be any age and develop Tourette's, you know?

[Narelle] Oh my gosh.

I didn't realise.

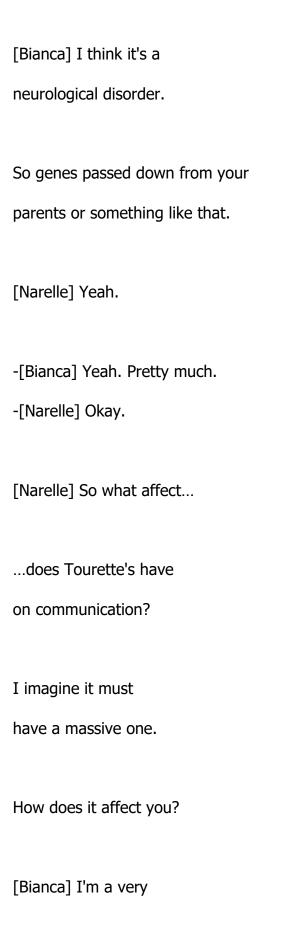
[Bianca] it's very rare in older people.

But yeah, there's people that I know who've had...

been 21 and woke up and started ticing and it never stopped.

[Narelle] Can people get it through having strokes,

or other conditions like that?



good communicator. It's just people in public that don't understand. So, a couple of Saturdays ago, I was at a pub with friends, just having some drinks and some dinner. And then I decided to go home early, around 6:30, 7. So I organised the courtesy bus to drive me home. Then not even two minutes down the road, I tapped the window. This man said, what are you doing?

I said, remember, I

have Tourette's Syndrome.

He goes, I know. Do it again, and

I'll have to kick you out of my car.

[Narelle] Oh my gosh.

[Bianca] I couldn't help doing

it again, and so I did it again.

He goes, that's it. I'm boint to put

you out on the side of the road.

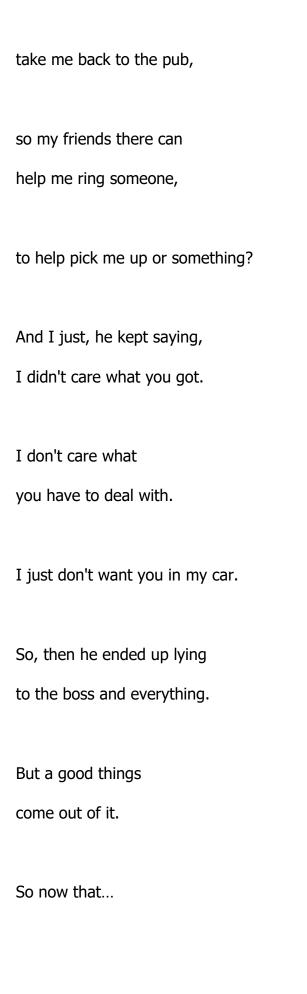
I said, no, please,

Like, I, I'm, I have a disability,

and I'm worried

about getting home.

Could you just please



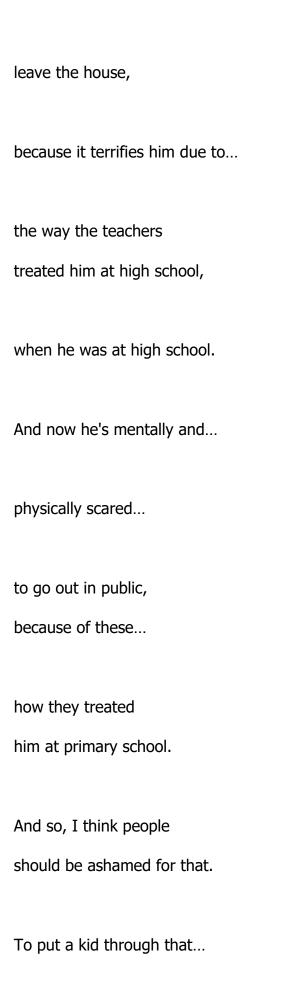
something's been happening in that place, I did a video on it saying, hey, I was just trying to get home. Anyway, now this place has done disability training, and they're going to get me to come and have a chat. So, it's really good. So, now that awful thing that happened to me, now, good change has come out of it. People have realised that they need to be...

being there and understanding about people with disabilities, so this pub will be much better, better equipped in the future, after my encounter. [Narelle] That's awesome. What about as a child at school? I mean, children with Tourette's must have a hard time at school. [Bianca] To be honest, a lot of people in my Tourette's community have... awful times with

teachers and stuff.

from kids my whole schooling career. But other than that, the teachers were so good with me, and so understanding when I was at school, which I was lucky enough to have a good experience. But a lot of people don't. Another friend of mine has now been traumatised. He has fear of open spaces, that he can't...

I had bullying...



[Narelle] A big issue with all of this is... lack of communication about Tourette's, and that is the bottom line, isn't it? If people knew it was just something you can't control, accept it for what it is, and it's just everyone has the education about it, which is done by communication. -[Narelle] We'd be a lot better off. -[Bianca] Yeah.

[Bianca] This is, this is what makes me really sad.

I'm lucky enough to receive NDIS funding,

but my community can't receive anything,

because Tourette's is classed as psychosocial.

So it's with schizophrenia, bipolar and stuff.

So it's not classed as a proper disability.

It's in the psychosocial tab.

So, if the NDIS isn't listening and understanding,

how are we supposed to help people?

The Tourettes Community,

The NDIS doesn't want to...

...give people funding to help them. You know.

[Narelle] Actually, I didn't realise it wasn't on the NDIS.

[Bianca] No, it's not. It hasn't been ever on the NDIS.

Cause, I was in the disability service before the NDIS came about.

So I think that's why

I went over to NDIS.

I think we need to communicate with the government and stress,

I'm not saying for every person with Tourette's Syndrome,

that has the tic disorder, but for people in my situation,

that was when I was younger.

I destroyed my parent's homes.

Every aspect of daily life gets affected.

So, if you got one tic, you don't necessarily funding for that.

But people in my

situation where...

they're breaking

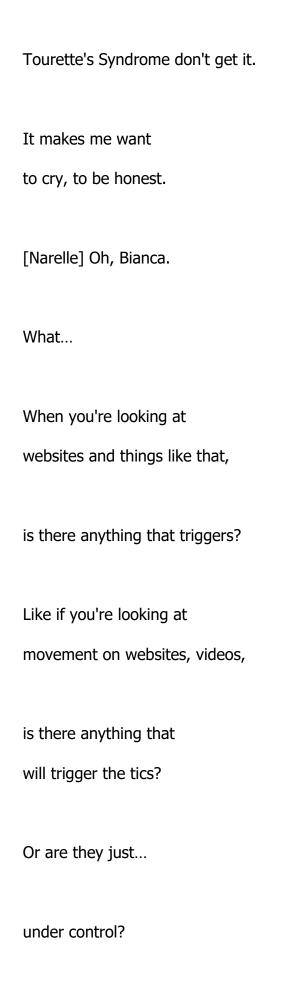
homes, suicide attempts,

all these awful things happening. A lady came to me in the expo a couple of years ago, and wrote something to NDIS to get... her client funding and the stuff that she wrote was horrendous. And the NDIS said, no, you don't get it. You don't need it. [Narelle] Yeah. [Bianca] So, that's what I'm trying, and why people with severe

why they can't access NDIS funding, because it benefits my life so much. I have a better life. I get to do so many amazing things, and without my NDIS funding, I wouldn't be able to do the motivational speaking and the educating that I've need to do in this world. So, NDIS makes my world go round and have a better life.

And I can't believe people with

Tourette's struggles every day,



[Bianca] So, with my

Tourette's Syndrome...

So, with my Tourette's Syndrome,

I can't use computer mice, keyboard or computers,

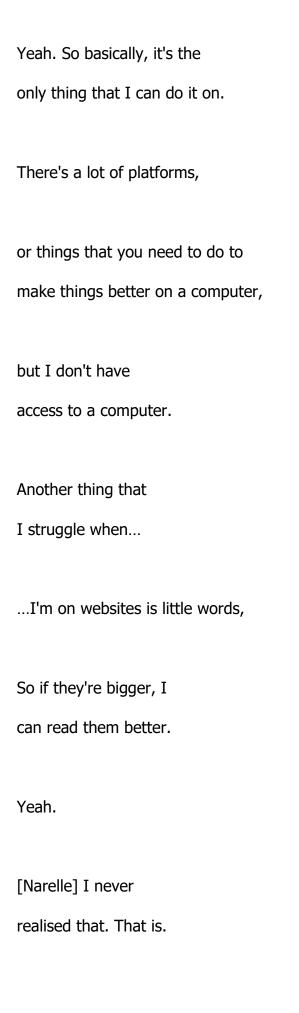
because I've just broken so many over my life.

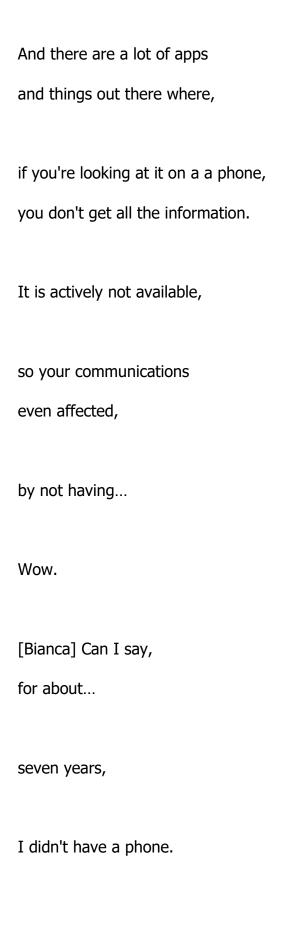
[Narelle] Okay. Yeah.

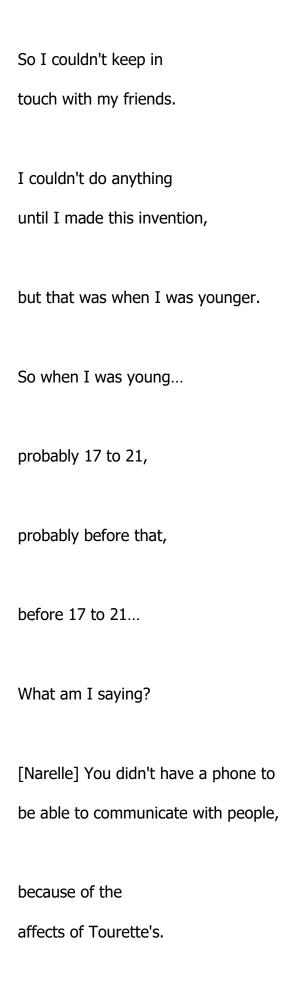
[Bianca] Or I can only use on my phone,

because I got a, you saw my pillow invention that I made,

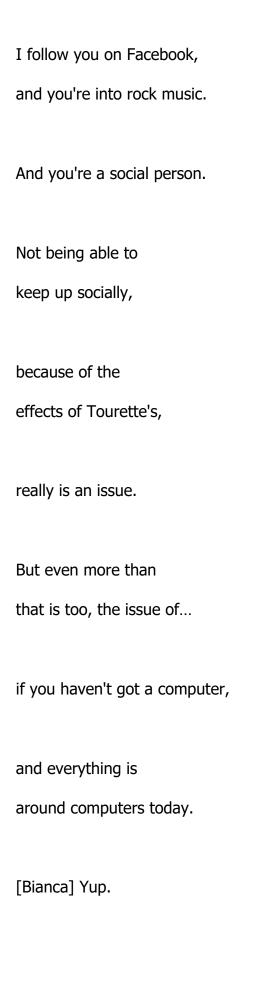
to put up my phone so it stops breaking my phones?







[Bianca] Yeah, so I didn't have a phone, so I couldn't keep up with anything. I couldn't see where my friends were or what was happening. So that was incredibly debilitating, and being cut off from world, not knowing, because I just kept breaking phones. [Narelle] Yeah. And you love rock music.



[Narelle] You're reliant on a phone.

Oh my gosh, what are you missing out on?

[Bianca] Imagine in the future,

if they start to put things inside our body like...

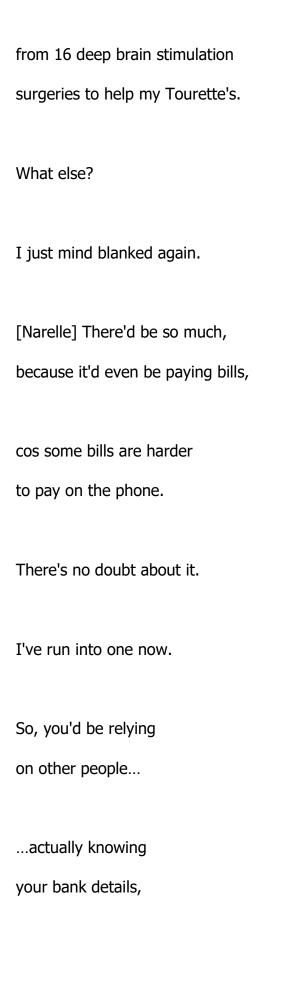
There's this movie that they put a phone inside their hands,

so all they have

to do is do that.

So in the future, if things start to happen like that,

I can't have things inside my body due to my staph infections,



so you can pay bills.

[Bianca] But I got really good when I didn't have a phone with directions,

and where the car was parked.

So yeah, actually I adapted, and it made me...

more equipped to find my way around and stuff,

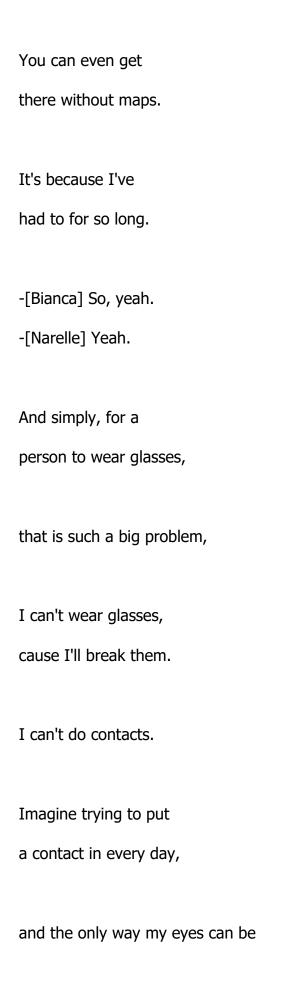
and have other skills,

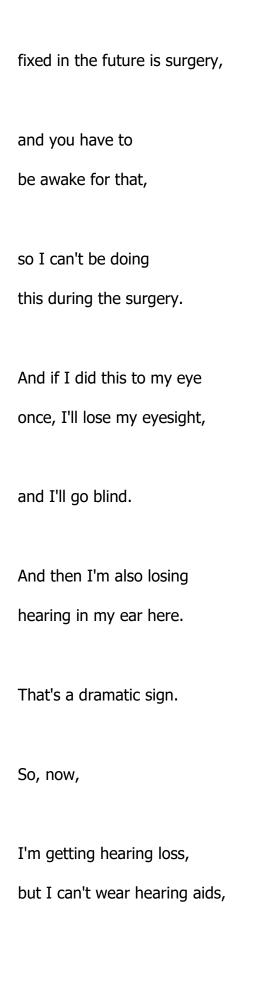
because I couldn't have a phone in the palm of my hand.

My carer goes,

B, you're amazing.

You remember everything.





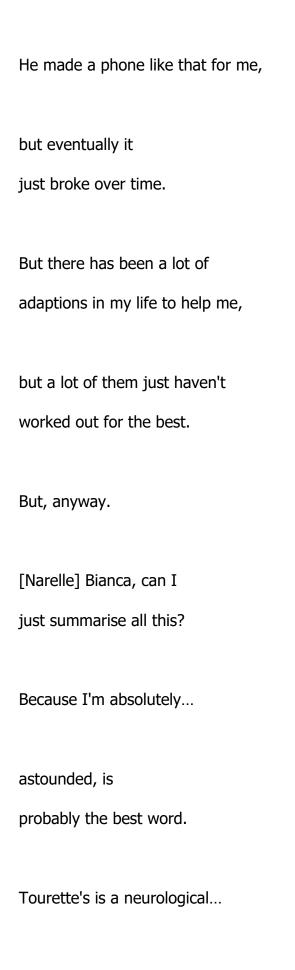
because I just push them out of my ears. So I don't want to be blind and deaf in the future, just because of my disability, we can't have the right surgeries, or be able to do things to help me. [Narelle] And add to that, if the videos don't have captions, and you're deaf, and you can't see properly, what are you to do? [Bianca] Yeah, my disability

stops me from wearing glass, and have hearing help. If I'm blind, I'll come and hang out with you, Narelle. We can just talk and hangout. [Narelle] Sounds great. [Bianca] We'll have no eyes together. [Narelle] Yeah. And do you know the thing, I never, I'm gobsmacked, Bianca, cause I didn't... because I don't know about Tourette's,

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I didn't realise that, yeah,
they are massive issues,
not being able to wear
glasses, contacts, hearing aids,
[Bianca] This is
what I'm trying...
[Narelle] Yeah.
It'll even be down to things
like, you can only use a phone,
but you can't use
computers, and it's...
you know, your
communication is, you know,
the digital communication world
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is not going to be fully open to you.

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[Bianca] For such a
long time, I kept breaking,
before I could have a phone,
befpre I invented my phone pillow,
I had to have communication because I
was living in my house on my own.
and I didn't have
any communication.
So we bought like
15,000 house phones,
and I broke them all.
And a man in Sydney made me,
you know the intercoms
to let in, like a hotel?
Oh, let me in.
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Go on.

[Bianca] Can I just say one more thing and you can wrap it up?

Another thing that people don't realise for me to live in a home,

so I've broken bones,

I break chip rock.

I break so much.

I've broken kitchens.

So, my whole house has been modified for my needs.

So I've got hard wooden walls, plastic windows.

So that's what I'm saying.

And I have to have certain furniture that works,

like there's so many problems in my life that I have to face,

and get around each day.

To simply to live in a normal house, I could never do that.

[Narelle] So to sum all this up,

Tourette's is a neurological condition that is genetic,

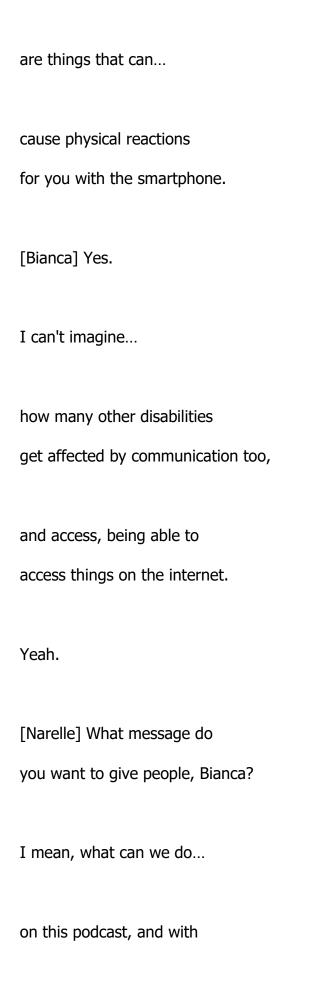
and you're not sure which.

It's either an overproduction of dopamine or seronine ...

which causes tics.

They're uncontrollable tics,
and it can be anything from
swearing to sudden movements,
to breaking things.
And the effects for you is down
the street with communication,
the, the way people
think about you.
And then, the next step is also you
cannot use a computer or keyboard,
mouse.
You cannot use any of that.
You've had years where
you couldn't even use a phone.

And so, upir dogota;. the ability to... be like myself or anyone else that uses... ...phones for everything that we do, like for me, it's voice over, and all the tools that I use. That's even limited, and you now are dependent on a smartphone. And you've invented a pillow to keep the smartphone safe. But even with a smartphone, there is issues there, because there



the tools that we've got,

to help get the message out?

[Bianca] It'd be great if the NDIS listened to start off with,

because then that can create society understanding.

But I feel like...

all we need to keep everyone with disabilities getting together,

advocating, discussing, doing podcasts like this, because...

the day that everything changes to help people with disabilities,

there'll be more money coming into the economy.

There'll be more people coming out. So, I just feel like everyone just has to start... ...working together as a whole to get there. Hopefully the government will look at Tourette's... as something that's needing funding, which is very much needed. And then all I ever need, everyone, any disability, any mental disorder,

compassion and kindness is always key, you know?

If you see when someone's struggling on the street, help them.

You know, do that. Are you okay?

Would you like me to help your bags, put your bags in the car for you?

If the world was more understanding like that,

and everyone comes together and helps each other,

I think it'd be a

different world.

But I don't know

how we get there,

but we can only do it one foot at a time, I believe,

[Narelle] Oh, my

God, you're so right.

I so agree with you. And,

yeah, Bianca, thank you so much.

Bianca, how can people keep in contact with you,

and follow you?

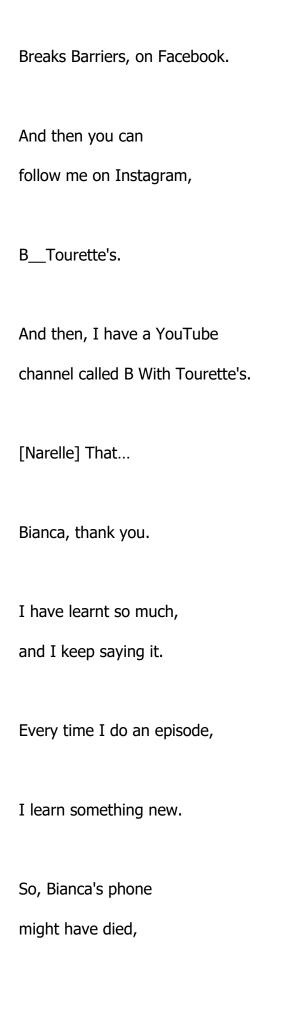
Because I think your

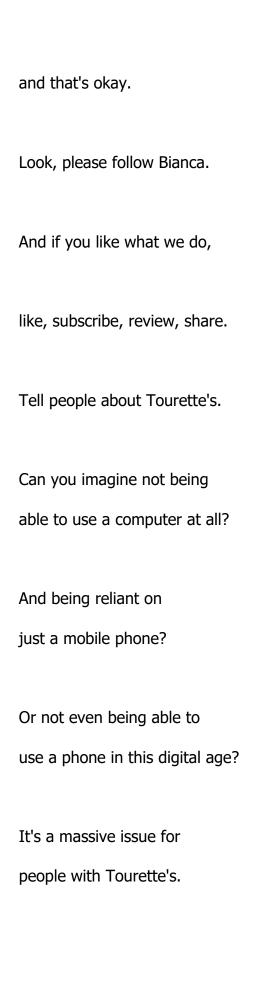
message is just so important.

[Bianca] If you'd like to

follow me on Facebook,

my Facebook, Facebook group, B





And I like what Bianca
said, empathy and kindness
It's going to make
a better world.
We'll see you next time.

[music playing]