

Praise for Charlotte Amelia Poe's work

Winner, Spectrum Art Prize, 2018

'Raw and remarkable.'

—*The Guardian*

'Shows us both the desperate and bleak angle to autism,
as well as the beautiful side.'

—Professor Simon Baron-Cohen

'A passionate, hugely articulate argument for the
acceptance of difference. Every teacher, every parent,
every person should read this book.'

—Meg Rosoff, author of *How I Live Now*

'Charlotte has the rare ability to take you on the most
incredible journey from the depths of despair to
laughing out loud.'

—Mary Simpson, Chief Executive, Spectrum

'Charlotte's unique and powerful account is of immense
personal and political value. Experience and expertise come
together with shocking generosity.'

This is a guide for our times.'

—Sacha Craddock, art critic, writer and curator

HOW
to BE
AUTISTIC

CHARLOTTE
AMELIA
POE

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For M,
Because you were there at the lowest points,
you deserve this high point.

Okay?

xx

For E, E, R & R,
I hope you never, for a single second, doubt that
I have loved you every day of your lives.

xx

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*I must now unmake,
And rebuild.*

how to be autistic

you will be told you are a troublemaker, that the thing you can't put into words yet that divorces you from everyone else is responsible for the way the other kids pick on you and you really must try harder to fit in. you will realise quickly that you cannot trust anybody, not really, because they will ask you to do things that break you, that will haunt you for years. you will meet people who you will revisit in nightmares and go to places that will hide behind your closed eyelids as you toss and turn at night. you will learn to be afraid. you will learn how to be afraid and still breathe. you will learn fear as survival.

nobody will ever tell you what is wrong with you, just that you are wrong, and that what you do and say is wrong. you will look at the world and you will see everybody else and find yourself lacking, and not know why. you will cling to the edges of tables and shift in your seat as you try not to pass out as another wave of panic crashes through you. you will vomit on your shoes.

you will not be allowed to go home.

you will learn that retreat is safer than attack. that home is safer than outside. that people are cruel for the sake of being cruel and the scars of their words will etch into your brain. you will scratch at your skin and pick at the scabs and mark yourself in the most base animal way of blood and torn flesh. you will make deals with the devil.

you will cry hot tears and smudge your eyeliner. you will wash the streaks off with cold water and be sent back to class. your legs will fold and you will forget how to stand. you will believe them when they tell you that you are doing this on purpose. you will learn to hate yourself the same way they hate you.

you will take tablets designed to sedate and you will still not BE sedate. you will fondle the silver of the blister packs and thank every god you can think of for these small blue marvels that allow you a space to think and be without the constant gnaw of anxiety. you will leave the house and the world won't end. you will learn that these tablets are the only thing that can save you.

you will learn that the people designed to help you don't care whether you live or die. you will learn that being suicidal means a four week wait for an appointment. you will learn about forged care plans and missing medical records. you will listen as medical health professionals lie through their teeth about you. you will wonder why nobody ever took a step back and actually looked at you.

you will stop looking in the mirror. you will feed the hatred and disgust and loathing that grows black and malignant inside of you. you will line up for the firing line and stand, back straight, facing the muzzles of guns because you believe you deserve it. you will think you are a burden. you will be told over and over by charities that say they want to help that you are better off dead. you will hear about the murders of other people like you and hear the sympathy poured out to the murderers. you will learn that your life has less value than normal people.

but—

you will live in spite of it all. you will read and write and draw and paint and create and sing and dance and laugh and love. you will be magnificent. you will feel the catch in your breathing as you walk towards the best day of your life and you will keep walking. you will hold close to you the people who didn't abandon you. you will never, ever be able to give enough thanks to the heroes who ran up the phone bill, who made appointments, who begged and pleaded on your behalf. you will look into your mother's eyes and know that she loves you without conditions. you will live to see your sister's children grow from helpless to incredible. you will sleep with your cat's fur brushing the end of your nose and smile to yourself as she purrs. you will push yourself further than you thought you could survive, and you will survive.

you will survive.

you will survive.

see, here's the secret. to break concrete with your bare hands, you have to train for years, breaking your fingers and healing those fractures until your bones are stronger than your obstacle. every time you've cried, every time someone else's words have broken you, every time you've wished you were dead but survived the night, you have broken and healed the micro-fractures of your soul. you are carbon, turning slowly to diamond. and every single time you were knocked down, you stood back up.

carl sagan once said that we are all made of star stuff. that when the universe first exploded out on itself it created the atoms that eventually became us. so, when your breathing hitches, remember that you are swallowing ancient planets, that every single second since the birth of our reality has been leading up to this moment. so, you're allowed to be afraid.

there's no bravery without fear, no courage without that awful lump at the back of your throat and the turning of your stomach.

you will survive.

because it's been thirteen point seven seven two billion years since you were created, and you are fucking cosmic. you have shone in night skies before day and night existed. you are a fluke, a chance, something so utterly unlikely that the odds are incalculable. and yet there you stand. a miracle.

they'll never understand, the ordinary folk. because they take what they see for granted, and it's not their fault, it's just all they've ever known. you have had to fight for your existence every step of the way. so you know, you know the cost of survival.

and i know, and you can trust me on this, that you are going to claw your way through this life and one day, a long time from now, greet death with a smirk and a firm handshake, utterly unafraid, because fear is something you know, but, like a wolf showing its fangs, your fear makes you powerful.

and i think, maybe, that's why they were afraid of you. because they knew your potential. they knew that you were more. that in the light of the moon you were beautiful. so they tried to hide it from you. tried to beat it out of you.

they failed.

you will survive.

Foreword

19 January 2019

Autistic people really don't like change. I think that's a fair, if broad, statement to make. And yet so much has changed for me in such a short amount of time that I am beginning to question it. I think maybe it could do with some tweaking. Perhaps autistic people don't like change when it is thrust upon them against their will.

When I made my video, 'How To Be Autistic', I made it on a whim, sent it off, and genuinely forgot about it. A year later, it changed my life. And then, I wrote this book. It would be easy to say this is a happily-ever-after story, but I don't want to be disingenuous. Do I still struggle with the same problems I describe at the start of the book? Yes, I still struggle hugely with going out, and I'm still socially isolated. The dark days when the depression causes a near physical ache still happen, more frequently than I'd like. That doesn't just stop because you've been on Sky News, unfortunately. But—I've been given the opportunity to do and experience amazing things. I've felt bolder within myself. I saw Hozier in London, at the venue KOKO, sitting up on the balcony,

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listening to him sing my favourite song, 'Arsonist's Lullabye'. It was magical, and terrifying, and I don't think I could have done that without the knowledge that I am worth something, that people have judged me and found me not lacking, but inspiring. I went to America! My god, I went to America! I got on my first ever aeroplane and flew above the clouds and landed in New York and hated pretty much every second of it because I'm pretty sure travel is autistic hell—jetlag, food problems, people everywhere, waiting around, new places, new faces, being away from my mum—but I did it. I met Captain America himself at ACE comic con in Chicago (it was only a short hop away and coincided) and even though I look half-dead in the photo and can remember none of the experience, I did it.

Truth is, there are a lot of 'I did it' moments, but they get drowned out by the 'I didn't do it' moments. Humans are bias machines, and we are especially influenced by negatives. We want to believe the worst about ourselves and will pick those scraps up throughout the day and piece them together until we have something that we can look at and say, 'look, aren't I terrible', even if everyone else says otherwise. Maybe that's just me.

To be honest, this whole thing feels like a scam. I keep waiting for the email that says, hang on a minute, you're not a real writer! You don't deserve that art prize! You didn't even finish high school! How dare you! I feel like I've tricked everyone into believing I'm worthy somehow, when really, I don't have a clue. I'm not a grown-up—get someone who knows what they're doing! I follow other autistic people online and they seem to write and indeed suffer, more beautifully, more eloquently, advocate more strongly, and I just sit there, thinking, I don't know what you want me to say.

Foreword

Then, last night, as I was thinking about how I should write this introduction, it hit me.

When I wrote this book in the fevered rush, on the high of winning and full of hope, yet to come down from it, I knew what I wanted to say, because it was what I'd wanted to say for years. It poured out of me, this burst of words, anger, sadness, hope, joy, trauma. And now, as I reread it, I realise I don't need to compare myself to other people, to how other people perform their autism. If this book helps one person, then it will have been enough. If it inspires one person, it will have been enough.

I hope you're going to wonder why I wasn't diagnosed earlier. It would be easy to dismiss it as 'just how it was back then', but that isn't true. While more people are being diagnosed nowadays, anyone who does not fit stereotypical patterns of autism (male, white, young, straight, cisgender, antagonistic, otherwise mentally healthy, for example) will be passed over. As mental health funding is cut, we face real challenges in getting diagnosed. I talk about my own diagnosis later on, so I won't dwell on it here, but please, if you do feel you or someone you know is autistic, chase that diagnosis and don't give up until you have it. Don't give up after you have it either. Autism, unfortunately, is a life of never giving up. My mum never gave up on me. She could have. Reading this, you would forgive her for doing so. But she never did.

She told me I could be anything. I always wanted to be a writer.

Hey, look, mum, I made it.

I do

22 December 2016

It's 5am on the morning of my little sister's wedding and I've been awake for fifteen hours. I'm tired enough to drop, but sleep evades me. Instead I'm browsing the internet, talking to someone on Twitter, and, oh, I'm all dressed up in a gold velvet-look dress, with curled hair and painstakingly applied makeup.

I'm not going to the wedding—I've told my sister that. She's known for weeks. I don't leave the house, it's just not an option. In the back of my mind I'm thinking maybe I could Photoshop myself into some of the wedding photos, and the thought makes me want to cry.

I'm not going to go. I can't. Even though it's as low key as a wedding can be, at Norwich Castle with maybe a dozen guests, every bit of me resists.

Except.

There's this tiny part of me, often buried, that screams that I need to go. That I need to see my sister get married. The same part of me that nearly cried when I saw her try on her wedding dress for the first time.

I do

I look at the webcam photos I've taken of myself. I check the battery and lens of my camera. She wanted me to be the wedding photographer—I was going to be. Until my anxiety decided I couldn't be. My uncle's going to do it instead. He knows what buttons to press.

And I take a diazepam tablet.

Within half an hour I'm wide awake. That's what diazepam does to me—it's called a paradoxical drug effect and it's common in autistic people. It's the same reason coffee makes me drowsy.

The diazepam also calms my mind enough to allow me to think. It's nearly 7am by now and I know my mum will be awake. I send her a message. It's simple, but terrifying for me: *I'm going to Rosie's wedding.*

I try to choke down some food, but the anxiety is clenching my guts and the last thing I want is to throw up or cause a scene. Instead, I wait until I can talk to my mum.

She's pleased—but busy. The wedding is at 10am and Norwich is an hour away. She has to get over to Rosie's to help get Rosie and the kids ready.

I'm back to waiting, and the gremlins are creeping in again.

But I'm going to do this. I have to.

I go over to Rosie's with my dad, and though I don't know it at the time, my mum tells me later that Rosie is thrilled to see me there. Ethan, my nephew, looks dapper in a bowler hat and suit—he's the ring bearer. Ella, my niece, looks gorgeous in a red dress. She's the solitary bridesmaid. The bouquets are handmade with love and care. I grip my camera tighter and take in the scene. This is really happening.

I get in the car, sandwiched between Ethan and Ella in the backseat and I distract myself by chattering nonsense to the

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pair of them. It's normally a long drive, but today it doesn't feel like it at all. Before I know it, we're parking up near the castle.

When we get out of the car, we discover that Rosie's veil is sitting on the kitchen counter at home, so my brother, Joe, makes a mad dash across Norwich to buy another one. It's a gentle kind of hectic and the wind is heavy and chilly. My sister chose to have a December wedding because she adores Christmas. There will be a Christmas tree at the reception.

We're allowed inside and the waiting begins again in earnest. Anyone with anxiety will tell you that waiting is the worst part of anything. I fill the time by taking candid photos of everyone. Rosie looks beautiful, utterly radiant and everyone else looks so smart. I'm wearing a leather jacket.

Finally, it's time to go in. As I'm the official wedding photographer (my uncle had been fully briefed on the use of the camera, but the role is now mine again) I get to position myself by the window out of the way and watch as everyone gets ready. Nat, Rosie's fiancé, a gentle giant of a man, who rides a motorcycle and is covered in tattoos, and is a thoroughly decent bloke, stands at the front of the room waiting.

And then the music starts up, and my sister walks in, arm in arm with my dad. I start snapping photos, the beep of my camera going off with each one.

The ceremony isn't like what you see on television—it's more intimate, it's weighted and sincere. Rings are exchanged and vows are made and after the kiss I snap a photo of Rosie hugging her new husband, her hand resting on the back of his neck, displaying her new ring, her new commitment. It's my favourite photo of the day.

The official business of signing documents begins and

I do

for whatever reason you're not allowed to photograph that. But they provide dummy documents for the newlyweds to pretend to sign, so I snap more photos. Light filters through the window and makes everything seem ethereal. I just know that these photos are going to be beautiful.

Finally, we file outside and I take photos of the two families that have become one. I'm exhausted, and it shows later in the photos of me, but I'm not Photoshopped in, I'm actually there.

I don't go to the reception. Instead, I go home to sleep.

But my mum tells me that me being there, at the wedding, meant so much to my sister.

And it meant so much to me too.

And looking back, I think that was the first time I beat this thing, the first time I really pushed myself. I got to see my sister get married and I wouldn't change those memories for the world. Anxiety is a huge part of my autism, but for the first time it wasn't in control.

I was.