



'This Is How It Is' is published by Community Arts Partnership in 2016 on behalf of the Spectrum Women's Autism Group (swag). The copyright of poems in this anthology lies with the individual owners. The cover artwork is the copyright of Karen Tigue.

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As part of Community Arts Partnership, Literature and Verbal Arts outreach programme I was asked to facilitate poetry workshops for the Spectrum Women's Autism Group, the first women's support group for autism in Ireland.

Initially, like most people with autism, the women had difficulty communicating with others. The workshops, however, provided them with an artistic platform to express themselves, and aspects of the challenges of their daily lives, through poetic language.

This was extremely significant as they felt for the first time that they had a 'voice' that others could identify with. In particular, they hope that their voice, via their poems, will reach out to others who are currently struggling with everyday life with autism. Their poems have the capacity to both change and challenge perceptions within the wider community, while educating and promoting a deeper understanding of autism.

Their collection of poems will take you on a journey of everyday life and the complications associated with autism. Some of the poems are humorous, some are harrowing, but all have been written from the heart with a searing honesty. They give a glimpse of life rarely seen by others, to challenge your perceptions. Enjoy.

Martelle Mc Partland

Foreword

Spectrum Women's Autism group (SWAG) is a group run by and for women on the autism spectrum. We were the first group for autistic women in Ireland. The main aim of the group is to provide peer support for women on the spectrum. This condition can lead to us being socially isolated, but we aim to break this through meeting people who understand what we are going through on a level that most people can never hope to understand. This is the first time that we have opened up and written about our experiences of this condition. This was facilitated by the support of Martelle McPartland, funded by the Community Arts Partnership, who has given us a voice, which many of us lacked before. We had never written poetry before.

We would like to thank the Spectrum Diagnostic and Therapy Centre, Dungannon, for the use of the room and in particular we would thank to thank Jo Douglas, Consultant Psychologist, for her support in setting up and providing ongoing support to the group.

Debbie Bond SWAG Chair

Poetry

Would my brain stop writing poems
I really need to sleep
They come to me at four am
And when I'm driving down the street
A line in a song
A word someone says
It triggers off
A stream of thought
That ends up in a poem
I used to think
I couldn't write
But I can't seem to stop
It seems like a tap
Has been turned on that
I can't turn off

by Debbie Bond

Star

Am I from this planet? Or another? I'm not like others,

But I'm made from the same The material of stars.

Mutism

Asked a question. Search for an answer, But the phrase book Has none. I need one quick Or they'll think I'm stupid. If you want help You should talk. The words jumble In my head Pressing my skull. I try to speak, To shout, to scream, But no sound comes out Just a metallic taste. I want to run, Or the ground to Swallow me whole, But instead I remain Frozen in fear.

Friends

You want to make friends, So join a club, a society Or take a class So I did this,

And now I have GCSE psychology, Can do Tiffany glass, Make patchwork quilts And cushions.

I know how to do Salsa dancing, Kick boxing And yoga.

And much, much more, But at the end, I had no more friends, And instead all I felt was Alone in a crowd,

Normal

At home I'm normal
Outside I'm not.
They've tried to teach
Me the rules
To manage in the world,
But they don't always work.

I'm not into make-up Hairstyles or boys. I want to read books And play with toys. I want to use tools Instead of curling tongs. I'm not like the other girls.

Most people don't want To discuss string theory Or space. They want to talk about things Like sports and soaps. Things of no interest to me.

So I get lost in conversations, Feel on the periphery of the world, Out on the edge looking in.

Sugar and Spice

I'm such a girlie girl
Sugar and spice and all things nice
That's what I'm made off
But I can be such a Tomboy
I like trains more than any boy I know

But I going to be a ballerina And 'jetee' 'weeeee' straight into The arms of my handsome prince I love my wee doll Pipin I'm practising to be a mummy someday, I'm so sweet and gentle

I like to play skipping, hop scotch, Rounders and netball. I adore flowery dresses, My hair in pig tails, Patent shoes, My legs in silky white tights Just to complete the cute look.

But sometimes
I get so confused
And frightened
And I cry.
For they tell me

I'm a boy!

by Adrianne Elson

Seasonal Affective Disorder Sad

I was born in the dark part of the year, When I'm unsure how to survive, I long for the returning sun.

Words

They want me write in my own words
But my words are not my own
They are snippets and phrases
Stolen from others, TV, books and songs.
Added to my phrase book
Like a foreigner in my own country.
Stored for when they're needed
If they really want my own
Shall I do like Doctor Seuss
And create them.

Stanlow Oil Refinery

Railway sidings 1996

A wild mint plant grows As nature's victory against Mankind's work.

The multi-coloured rainbow Chemical stream runs by.

Steam pipes whoosh and hiss As synthetic clouds rise.

Stones abound around the mints roots Acrid, air stinging the eyes.

Shunting railway tankers Ring and rumble, rest in sidings.

Lorries roar by Splashing through filthy puddles.

A thick haze hangs in the air. A sense of danger, everything so serious. Everything could go bang at any minute.

But still the little mint plant Grows like a battlefield poppy. Natures answer to it all.

by Adrianne Elson

Do I Fit?

I don't fit in

I can't join the Farmer's Union As I'm a vegan.

I can't join the Scripture Union As I'm the wrong religion.

I can't join the Sports teams As I can't play the games.

I can't join the Artists As I can't paint.

I can't join the Popular girls As I don't bitch and drink.

I can't join the Geeks and nerds As I'm the wrong gender.

I fit in with Those who don't.

Boyfriend

You're twenty five, You've not had a boyfriend? Are you a lesbian? Or have you been abused? You're safe. You can tell us the truth.

I tried to tell the truth But they did not believe. I'm not a lesbian. I haven't been abused.

Instead I don't know How to know If a boy fancies me, Or if I fancy him What to do.

No one taught me The rules of this engagement. So how was I to know What to do

Connections

I draw lines to Connect dots That aren't meant To be connected.

I see, hear And experience Things that pass Others by.

Most people are Too consumed in Social etiquette to Notice things around.

I read and learn, Absorb new information. I take theories And I question them.

I pull it all apart, Challenge what is believed, In order to try To make sense of my world

Tunguska

4πr²,
It's in the air,
It's not a bird.
Tunguska in Russia

Was it an alien? Was it an asteroid? Was it Tesla flexing His manic rage?

Where is the crater? One tree in the Middle left standing 1000 km of flattened trees.

If a tree falls and no one sees Did it fall? Not this one. Bright as a second Sun

3 seconds to run.

by Jonathan Donnelly

Empathy

I feel everything I experience everyone's emotions I can't watch sad programmes without crying The suffering on the news is too much, I am crushed by their emotions But I often can't express it. I can't translate the sensations in my body, To a word that you will understand. My facial expression may not match What is going on inside. If I see you distressed and don't react, It's not because I'm cold but Because I don't know what to do, And even if I do I may not be able to, As your emotions overwhelm me, Or it requires physical contact Which I'm unable to manage. This leads people to believe That I lack empathy When instead I have too much.

Failed Attempt Age 14

Waking up crusty mouthed, Sick splattered body,
Broken head pounding, Hands shaking,
Sweat dripping,
Twisting and turning in a bed,

In a room with a note should Not be the worst shame ever. But it can be, For I wrote that note Never intending to see The start of the next day.

But I saw that day Because I failed, I couldn't find a way.

To live amongst The noise and chatter, Voice's judgements, False perceptions of myself

Footsteps down a damp tunnel follow me in the dark to sleep.

Is Death a Rush?

Is death a rush?
Endorphins,
An overload of dopamine?
Illusion of calm
Fades into acceptance
The high too high to resist
A bungee cord with doctors pulling
Light fades in and out
The voice of distance shouts
A living dead quantum state.

Anon

Detaching

Life hurt too much I wanted to die. I tried but I failed So I tried again, And again.

I wanted to escape The pain that crushed My whole body And fogged my brain.

It stole my happiness, My love for all things. I tried to cry But no tears came out.

My emotions trapped, Unable to express them Or find the words To communicate The feelings, That gnawed at my body Eating me from inside

Locked Down

Locked psychiatric unit

Hell had double locked doors. A ten foot high fence, with barb wire at the top

Hell had banging doors.
People screaming, shouting
and kicking all night long.

Hell had no food. Gave no comfort, love or safety.

Hell was terrifying. Gave no sleep, for the fear of attack.

Hell left me broken. Left me scared of people, even those trying to help.

Hell left me traumatised. Left me scared of the world and wanting to be dead.

Hell should have helped; Instead made things worse, much worse than before.

Hell's memories were buried, but Memories have come back to haunt me still.

It was a place I never should have been.

Melt

Things in my head Makes me wish I were dead I don't want to see I don't want to be me I'm awake half the night And nothing is right

I don't want to complain
Because (they'll) say I'm insane
If my troubles I say
They will put me away
And my children will hate me
So just medicate me
And tell me too mindfully
Meditate cognitive cogitate yeah.
We'll mindfully meditate this.

Anon

In dreams the mind goes for solace and punishment, sleepless nights of reflection lest we find the mirror.
The deceit. The hurt at holding in the truth, from a child hands a crushed flower in the dirt, forced the hand around the nettle.

In the Wrong Body

In shadows lurk hooded figures Like young grim reapers Throats clear Instilling once again that fear

In public bars tobacco cracked laughs
Punctuate the air with embarrassed sniffs and laughter

Lonely villages Mean fevered streets A cocktail Of happiness, truth, guilt and shame

In the family home, the mask, the lie In the workplace, the act, the play To make it through the day

The looks, the jealousy, at those you wish you were But can never be

by Adrianne Elson

Psychiatric Hospital

The noises hurt my head The TV, people shouting, alarms That continued all night long. Too many smells Of food, cleaning products, Other's perfume and deodorants. My head felt like it was going to explode. The bright lights burnt my eyes, I wanted to hide from them, Or turn them off. But I couldn't. They are on all night long Disturbing my sleep. The nurses didn't understand The doctors didn't get me I couldn't communicate. The people coming and going constantly Never stopping Never giving peace The constant change The constant moves I needed a settled space A place on my own, Where I could recuperate Away from people, To just be alone.

You're Fine

You go to large meetings. You wear nice clothes. You've lost weight. You look well.

But all they see

Is the mask, The costume, The act, The script.

They don't see

Me being sick in the night,
Not sleeping for fear,
Pacing the floor,
The uncontrollable shaking.
Unable to eat
Or think
Or do anything at all.
The battle each morning
To get out of bed.
The constant fight with
The voice in my head.

They don't see

The scars covered up, The wounds buried deep, That drive the battle on.

Trapped

I'm trapped
In these four walls,
Too scared to leave
For no reason at all,
But I can't cope
With being stuck inside.
The conflicting panic
Of being closed in,
But also of being outside,
Leaves me drowning in fear.

by Debbie Bond

Movement

I need to walk, To run, To move.

I need the Repetitive action To feel calm.

I can't sit still All day or else I'll be climbing The walls.

Anxiety

Anxiety an old failure friend, A shadow, my shadow, No matter if sunny and bright Or the depths of The darkest night.

Never far away, Always ready to spring into flight, It helps sometimes But it can conquer the best Of my dreams in their fledgling state,

Unbidden, unwelcome, It creeps into my room at night, Steals under the covers holding tight, It whispers everything is wrong And nothing will ever be right.

To say I wake and worry at 3 am alone and Estranged from myself would be an oversight. A daily battle, could this ever end, Of heart pumping breathlessness, Brain racing, thinking thoughts with dizzying speed.

Here I am at my most vulnerable, Sometimes in silence, other times, The thoughts form into words, Slip from my mouth uncensored, Unedited naked to your judgements.

But truth is in those razor sharp moments. Well the shameful truth is I have no control, Only knowledge that I'm responsible For what I say, no matter what.

Meltdown

The little things Everyday things cause The pressure to rise The computer not working The phone joining in Burning food Or finding it off. Two TVs with the same Programme on, Echoing and Trying to push The information into My head twice, But all I get Is a jumbled noise. The pen doesn't work, And I can't find another. The cats meowing And fighting. I can't get the Theories into my head. Nothing significant, Just little things, The pressure just builds, And builds, and builds. Until it explodes. The trigger being Nothing big, But the final straw That pushed it over. Exploding not at the cause But just whoever is near.

Sleep

Dear brain, Could you please stop. It's two am. I don't care if Penguins have knees.

I can't find the Optimum number Of frogs for An equation with No integer solution.

I don't need to Find the meaning Of life, the universe And Everything Everyone knows The answer's 42.

I don't need to go over Everything that I did Today, last week, Last month, Last year, In my life.

What I really need Is to sleep.

Breaking the News

There came a time, a day, a place, When I had to sit him down To tell him the worst news He had ever heard, I've ever said.

In the moment of hearing
He crumpled and fell
Like the final curtain,
Scrunched into a ball,
Then rigid and straight,
Falling, flaying through emotions
He had never felt before.

He echoed back my news, Your other mums dead my love. Such a simple sentence, Yet complicated Beyond all reason.

He echoed it back to me, 10 times per minute, Recording and listening To the playback, Over and over for days, Awaiting the funeral, Trying to absorb the meaning.

I wonder if I'm enough,
To see my own child
Through these very moments,
Never mind the years of
All that was to come.

The Longest Walk

To the end of the street 68 metres, X amount of strides, X amount of half strides.

As custom would have, It's all that's needed, To honour our dead.

Clear day autumn, still, warm, Smart suit, polished shoes, Mourners come to the door, Tight smiles, strangeness in their eyes.

Coffin as heavy as the box was hard.
Cold body, stiff and still.
Leading the way, chain gang walk.
No slave sang a song of hope for freedom,
For there was none left within
The bearers shackled by
Grief, custom and convention.

Homophobic Obituaries

Wife?

Wife doesn't designate legality or intimacy But tells of the relationship from one to the other.

Widower?

Widower tells of what is and what's lost, an event, But misses out what's happened, the whys, Who's left, but not who's gone.

Orphan?

Orphan is a half-truth but half is not enough, To understand the human story Behind obituaries in newspapers.

Son?

Son is a relationship, a relationship of heart, He wasn't named, he was forgotten, A slip of the mind quite on purpose. I know, I've seen this many times before.

You

I hid you I covered you up I had no words To explain you.

When I got the words And I felt you Taking control. I told others of you And they said I should have Said earlier But how could I Without the words To explain you.

Now you have
Damaged my body
Infected my brain
Become my way
Of coping
When nothing else works

I want rid of you But I don't know how As you constantly Remind me of your presence.

Anon

Autism

You're not autistic You can't be

You're female You're too intelligent You make eye contact You hug your mum You can talk You have empathy You're too sociable You have friends You can drive You seem so normal

Careful What Ya Tell Girls

Butt of the rifle
Snug to my shoulder
Gender roles
Designed to keep me in chains
Cracks the air
'Girls can't shoot guns'
Had I ever heard that before?

I glance at my dad Who smiles and nods at me Smiles at the soldier in the booth But it was a strange smile One not meant.

I break
Load
Close
Nestle
Breathe deeply
Breathe held
The familiar calm and steady descends

I rest
Aim
Fire
A line
In sight
A bead
I fire.

Break remove Load close Breath held Fire. One more familiar run at routine Like most routines auto calm

When he hands me my three bullseye targets, Dad's challenge 'good for a girl?'
'No, it's good for anyone'
Apology accepted

by LGC

Shot Gun Miss

I'm quiet waiting my turn Broken gun over my arm.

Waiting, waiting, waiting
A misplaced all-consuming bang
Before the clang and clatter
And silence
Stillness
No one talks
Crows now departed

In that silence,
In that stillness
I beg my eyes to look at my feet
I was never her aim,
But had she missed?

Glasgow Tenement

Children laughing running feet
Mixed with clanging pans of food.
The coldness of damp
Screams and shouts of neighbours woes.
Pay day rank whiskey smells of conflict
From three floors up
The panic of electric meters
And scrabbles for change,
And should I be excited or afraid
Or just keep running in circles.

by LGC

Mondays

Potatoes and mince.
Remnants of grey Mondays
A day that bled the colours away
A day of murder

Each crunch of sinew, Flashes a picture of the animal that was I retch again, Vanishing images in my head.

I pick through the gristle, sinew or rotting muscle, It's gonna be another long, long night

Rattlesnake Bite - My Nearly Lost Fight

I could almost pretend
He was biting into an apple
If it wasn't for the ooze of red
Pouring from his mouth
Dripping, staining
The front of his shirt.

Ringing terror filled Screams of chaos

He tried to pull away
But teeth still looked shut
Like a lion tearing
From an animal flank.

People looked on, Perhaps they weren't seeing,

I couldn't pull her off him My hand on his shoulder Then round his chest The strangest hug I ever gave.

When he went To bite again

I was afraid, Before I punched I was afraid I wouldn't stop. Locked in violence Locked in action An ancient dance My head sings Ancient songs.

He took me into A praying mantis grasp Attack, counter, defence Happened, lightning fast.

I felt the warmth
Of the night
The stars in the sky
The buzz of a neon club light
A reflection of a puddle
The gathering crowd
My hammering heart
Blood rush
In my ears
Like a sea shell sound.

I felt the strength
In my legs
The fade in my arms
His hands round
The back of my head
Creak of my leather jacket
Convinces me
He's getting closer.

Gaping mouth Blood soaked chin Did he just snarl? Half a head taller
Stronger than I
My head his aim
I fear his rattlesnake bite strikes
Her fear was for them
She had AIDS
It was public now

Would I die? How long had it been? Was the virus still live?

My mind calculated Times and angles Of cause and effect Action and reaction But caring little For consequences.

I found a solution
In the soft skin,
His Adam's apple
Just one palm heeled blow
Would stop this

Save my life
But end his
In the split second
Between thought
And reaction
Lay all my future.

Could I take a life?
To save my own
Combined force
Of thought and action
Like chemical fusion
Or nuclear reaction.

Single focus purpose Was becoming

I was so serious and sober

It felt like all my life Was down to the next second The next action

What really frightened me Was that I knew When push came to shove As often as it did

I really can
I always could
I never wanted to know
When all else fails
I really would.

Potatoes

Fresh from the ground. Covered in mud. Washing them, Struggling to get clean.

Mud going everywhere. Running down my sleeve, Covering the sink, It's spreading.

The sink is brown, The vegetable brush too. The brown muddy water Flows as a stream.

Not going down the drain, But running down The worktop, the cupboard, And flooding the floor.

Standing in the puddle. The water freezing Hands and now feet. As the battle is lost.

But the battle continues As need to get clean Dinner can't contain mud Which is all there is.

The mud has gone everywhere, Over me, the sink The whole kitchen. I can't get clean!

Addiction and Those That Live in Recovery

I watch the living hug, embracing each other like survivors of a hard won battle, if they are lucky a daily reprieve is the best case scenario. To life or a destructive force within that often turns out to be greater than them. That choice is always on the cards, in the balance of a day lived. After 5, 20 or 25 years a slip can turn to a fall and with God or luck or divine intervention they might make step one again, but only might. What if today was the last day they ever lived clean for the rest of their lives no matter how short that would be, when may that day lurk around? What obstacle, what success or failure they just can't navigate anymore? Yes, I said success or failure because we often don't recognise or count our successes as being the tipping point to death, not until experience tells us so. A mind focused on destruction, their own destruction and destroy they do or they must. Repeating the same mistake, expecting different results is short, succinct, logical and true. I get to witness how it plays out in people lives in complicated, convoluted, concentrated.

Today my friend ran their car into a wall at 70 miles an hour; yesterday he was at work, went home to his wife and kids and bounced his toddler on his knee. But today he woke with no desire to find the end of the day, he didn't want to return to the living hell of using, the shame in using but after two decades he still wanted his pain to end. Did you really think it ended when the drugs and drink were put down? That they were the problems, are you really surprised it's just the start of the pain and the problems and the trying to figure it out. Know your enemy! At least he went out clean, but he went out, at least he went out clean but out nevertheless. Some chose the shame but get taken out anyway.

At their funerals I normally sit defeated, alone not wanting to leave the 4% but hostage to my own fears anyway. The why and what ifs are often demonic and unsalvageable in what else could they have done. But funerals are not all about me they're really about grieving families and children lost in their eyes and coded eulogies saying, but not saying addict! Forced play stupid smiles they don't understand why and often there is no single why to be given. We only ever get 24 hours reprieve if we are lucky and 96% are not that lucky. Now you work out how many 100,000 that is per year as I work out how many funerals that is this year for me.

Acne

Tree tea put on spots
To try to clear
The teenage acne
No treatments seem to work
Some even seem to make it worse
Some caused rashes or burnt skin
The desperate hunt for a solution
To remove the embarrassing spots
That plagued my face
And affected my confidence
Why did I have them so much

Suffocating

Air freshener Strong perfume Deodorant Fabric softener Polish Paint Fish Flowers Coffee brewing Cooking Bread baking.

Too many smells Too strong, I need to escape

Long Drives

Crowded car, Stuck in traffic, Getting crushed, Too warm, Felling sick. But gran Had the solution The mint imperials From her bag. The mint to Settle stomachs sick The old remedies Always worked She thought But the remedy Was not found

Gran

You were always there
On the phone,
To call round to your house.
It was a safe place,
A refuge from the world.
You always cared
Looked after me when sick
Wrapped in a blanket
You stroked my head
But now you are gone.
We are saying goodbye.
But I don't want to
Not yet

Best Friend

You were my best friend. You helped with my study. You were there for me. You understood me In a way that no one did. You helped me a lot To get through tough times. I could talk to you When I had no voice You didn't need words You just knew. I gave you your medication. I hugged you till the end. You fought to keep going. But in the end Your body gave up Now you are gone In a box in the ground. I miss you so much And I always will. I grieved for you so much. Some people said too much Because to them You were just a cat.

Dyson

Straight though the blue Ahead 1 A.U.
Heat upon heat.
Furnace of creation
Sucks in mass
Blow out dust
In star we trust
Is mankind's future
A licence to Dyson?
Or radio stretched long,
When all is done.

Anon

Living with Autism

Living seems an intricate dance Of intertwined bodies and intertwined minds. Smiles and glances, gesture and gazes. But watching and learning is never enough When a frown or a raised eye brow Changes the whole situation and you're lost For new appropriate steps, As you clumsily plod on anyway, When it's obviously a whole new song Everyone has adjusted to, but you. You may not realise for a day, a week, A month, dare I tell you years. But memory returns a situation and Then you realise what was impossible to see, What everyone clearly saw at the time, And it shouldn't matter that it's from a long time ago But somehow today it does. Red faced, heart pounding, anguish That slowly silences over time. No wonder so many of us sit this one out. But you, at least you could chose, just for a day, To do our dance at least for a while. That dance would change the world, For a few or the many, The hidden and the seen.

Beach Baby 1

Beach buggy
Toddling in sand.
Beach baby
Holding my hand.
Tiny footprints
Counting sandy piggy toes.
Salty lips and finger tips.
Safe beside me.
How fast life goes.

by Karen Tighe

2

His soft baby skin.
So delicate to touch
Mine is so rough
I'm sand - shoving this buggy.
Tough.
I took on too much.

by Karen Tighe

Walking in Glenariff

Packed lunches, Sandwich mushy, Tastes funny.

Too salty, Texture wrong, Should be firm.

Gone warm, Not how it should be.

Nature Pool

Seaweed stench and Dead prawns piling. Sea Point Place, Where we paddled Poison pollution empties The harbour of life Old Molly Malone's mussels And cockles No longer Alive. Alive. Oh.

by Karen Tighe

Sense

Bangor Rock Lady Pink and sweet On my salty lips Sticky toffee Apple fingers Cotton candy On a stick And vinegar vapours On salted steaming chips.

by Karen Tighe

Tribe

I felt alone in this world, That I was the only one Who experienced life this way. I searched for an answer, Went up many blind allies. But life led me to the answer. Through this I have found Others like me.

I have found my tribe.

Tired

Having walked far Up hills and down To reach the end.



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