

Different on the Inside

By Susan Golubock, Founder, Making Sense of Autism

To look at us
You and I appear very much the same.
Yet I have learned that we experience life,
And therefore, view our experiences,
Very differently.
I have learned that I just don't think like you,
No matter how hard I try,
And believe me I have.

My nervous system seems to be
Configured differently.
I've learned to do what you do,
At least the mechanics of it,
But I don't understand
Why you do it.
I've memorized the words you use
And can repeat them fluently.
Figuring out what you mean
And why you say them
Is the hard part.

I process words literally, concretely, and naively,
Which often leaves me baffled and confused.
I thought that by pretending to be you,
I would someday understand you.
But I don't.
Any more than you understand me.

There are times when I join in
and genuinely enjoy interacting with you
but I rarely feel that I belong.
I can focus on you
or I can focus on me
but understanding the complexity of relationships
is very much beyond me.
There are times when I can connect
with my feelings, or yours
but never both at the same time
And some emotions not at all.



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There are times when I really think
I understand you
then you change, and I don't.

Even though I have stopped trying to "be" like you
I haven't stopped trying to understand you.
It would mean a lot to me
If you would try,
Just for a little while,
To understand what it must be like to be me.

Remember those awkward social moments
As an adolescent or pre-adolescent
When you were trying to "fit in",
But didn't really know what was "in"
Or what was expected?
You stood there in conspicuous silence,
Rehearsing everything you wanted to say,
Waiting for a chance to speak,
Then blurting out some untimely statement
Or more than you really intended
Not knowing when or how to stop.
Imagine having those "moments" occur regularly
With family, friends, and strangers alike.
Your best defense is to
To memorize the required "small talk",
Keep your mouth shut,
And let others talk about themselves.
Meanwhile you struggle to filter out
The background noise they so easily seem to ignore,
Processing maybe 50% of what they say.
Then there is the feeling of panic
When the dreaded unexpected question appears
Requiring you to suddenly shift from processing to production
Without the time you need to do it.
It makes you wonder,
With interactions so difficult,
Why so many people consider socializing
To be so much "fun".

Remember the time when you were startled
By a car horn? Or fire alarm?
Or a touch on the shoulder that you didn't expect?
Think about what it felt like.



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Your heart raced.
Your senses were being assaulted.
Your mind was suddenly jolted out of focus
For a brief second or millisecond
Until you realized what had happened
And could calm back down again.

Imagine instead the panic escalating as you
Struggle desperately to register what happened,
Causing you to feel violated, angry, and disorientated.
THEN imagine being asked to function in this state
For the next number of minutes or even hour
That it takes for your system to pull itself back together again.

Imagine what it is like to be startled
By everyday experiences,
Like the sound of a cup touching a saucer
Or someone suddenly making a gesture with their hand in your direction.
Think what it is like to have your nervous system put on edge
By the sound of someone chewing
Or the thought that someone just might come close enough
To brush up against you in a crowded room.
Your environment becomes a mine field.
The bathroom, car and bedroom are your foxholes.

I seek ways to block the barrage
By hyper focusing my attention
On some single object or task,
Just as I might do with a good book,
To “tune out” a world
That provides one with so little peace.

Remember those occasions
When you couldn't retrieve the names
Of people or places or things
You know that you should know?
Imagine that happening 3-5 times a day.
Not being able to make those connections,
Or any connections,
Without setting memory triggers
And practicing words that you want to say in advance.
All this just to remember what you need to do or say
With people you work with every day.



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Have you ever looked for something
That you expected to be there,
And it wasn't,
Just when you needed it most?
Do you remember that moment of panic
And how you froze with indecision
As to what to do next?
Living life "spontaneously"
Would be like this for me
A continuous series
Of panics and indecision.

Despite my many years of experience,
My brain still yearns for consistency,
Yet finds none.
"New" responses require a lot more time
Than the milliseconds it requires for you
To review all the possibilities,
So, my brain either "freezes"
Or falls back on "old" responses.
Either way I'm "stuck".
Later I can think it through
And "pre-plan" for the next time,
Only next time it is likely to be "new" again.

Among the words
That I most dread to hear,
Yet hear so often,
Are "Lighten up!
Don't be so Intense."
"Don't take life so seriously."
In essence you are telling me
To stop functioning
Because that is what would happen.

Remember how hard you worked
To learn a sport? Or play an instrument?
Or drive a car?
Remember how the task initially seemed so overwhelming?
You might have thought you would
Never reach the ease that comes with mastery.
Imagine succeeding
But never being free of the need
To think your way through each task.



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Not being able to listen or talk
And put a pot of water on to boil at the same time
Because each requires your exclusive mental focus to perform,
Each and every time.

Remember those times when you had more to deal with
Than you thought that you could handle
And you were ready to blow up in frustration
Or collapse in utter fatigue?
Perhaps you closed yourself off from others,
“Vegged out” in front of the TV
Re-organized your closet,
Or found some sensory pleasure in which to engage.
People seem to understand this need
In themselves and others,
On occasion.
For me this need occurs throughout the day,
Every day.
When I appear “zoned out”
“In a world of my own”
Or “obsessively organizing”,
I’m just trying to conserve energy
Or forage through the thicket of input
That overwhelms me.
I can’t wait to get home to collapse,
And I can’t proceed without planning.

To calm my overstressed nervous system
I have had to learn “alternative” strategies
Such as leaning, propping,
Rubbing, squeezing or stretching;
Whatever I can get away with
That gives me the body movement
And deep pressure input
I need so desperately throughout the day.
I leave the rocking and stimming,
Which are more “natural” ways of coping
For when I am alone.
I have learned that “my way” is “unacceptable”.
Thus, even my coping behaviors have become
Just one more thing for me to “hide”.

Most people hold on during a crisis and
Relax when it is over.



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I hold on and hold on
But am unable to “let go”.
Instead, when the crisis is over
I collapse
Because modulation is something
My nervous system has never learned to do.
It must be hard to understand.
I appear, because I hide things so well,
Like someone who can handle so much.
Yet, inside I experience a roller coaster
That is either up or down
Rarely if ever experiencing solid ground.

If you stop to think about it
You do know what it feels like to be me,
Briefly, in a less exaggerated way,
Just as I experience
Briefly, on my more integrated days
What I imagine it must be like to be you.

As you grow
Practiced tasks get easier,
Allowing you to add complexity and variety to your life.
When growth is hindered,
Practiced tasks only get memorized,
Not generalized.
Each situation must be struggled through
As if it were new.
Complexity only overwhelms.
There is no energy left for variety,
Yet what is expected of you and I
Remains the same.

Think back to a time
When you were experiencing an event or period
That was particularly difficult
And someone said to you,
“Oh yeah, I’ve had that happen to me” or
“That happens to everyone at some time or the other”.
I’ve been told that the intent of these comments
Is to encourage you
To do what you had to do to “get past it”,
To avoid making a “big deal out of it”.
To me those words are particularly painful.



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The way my nervous system operates
Is an “event” that happens every day
Not a situation or feeling that will “pass” with time.
It is what I must deal with.
I accept myself for who I am
And I do what I must do.
Yet sometimes,
Being me does feel like a big deal
And some encouragement would be nice.
When I talk about what is particularly hard or frustrating for me
I’m not pitying myself nor the life I’ve been given to live.
I’m not suggesting that your difficulties are any more or less than mine.
I’m not looking to blame someone
Or be excused from what I know are my responsibilities.
It would mean a lot to me though
If someone would recognize
Just how much effort I put into
Meeting the expectations in life
That you and I share
With unequal resources to pull from.

I am not looking for recognition for what I have accomplished,
Because I am not driven by accomplishments.
Most of the time it only serves to remind me of
What I have had to compromise within myself
To “achieve” these accomplishments.
I want recognition for myself as a person.
Recognition for how hard I work,
Because of and despite my differences,
To function in a world
That does not readily accept those differences.
THAT would make me feel good
About how far I have come
And encourage me to keep on trying.

Is being me a tragedy?
Far from it!
In fact, if given the freedom to live and do
The best I know how,
At the pace and in the way I know works for me,
I would quite enjoy myself and my life.
Alone time is something I very much cherish.
It’s people time that challenges my nervous system



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And if I let it,
My self-esteem.
In some ways
My differences have enabled me
To develop “talents”
That I might not have without them.
By using intellect rather than emotions
I have earned the respect of co-workers
As a mediator during stressful events.
My ability to “hyper focus”
Once I start on a task
Means that others can always count on
A job that will be done well
Down to the littlest detail.
Processing new
And especially abstract information
Is often tedious for me.
I need to see and experience things
Before I really comprehend them.
But once I do
I can use what I have learned
In highly creative and holistic ways.
I enjoy having and using these talents
Just as you do yours.

I am fortunate that I have found a profession
In which my “talents” are appreciated
And my “differentness” accepted.
I know others who are less fortunate.
They are never given the chance to show their “talents”
Because their “differentness” is considered a “disability”.
It seems odd that we value so much
The beauty of diversity in nature
Yet seem afraid to share and appreciate
The differences among and between ourselves.

I’m not asking that life’s expectations
Be changed for me.
I seek only acceptance for the ways I choose to meet them.
Remember what gives joy to you
Is often extremely uncomfortable for me.
The way that you would do something
Is often NOT the way that would
Enable me to best succeed



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Or more importantly find pleasure or self-satisfaction
In what I might accomplish.
I don't experience loneliness
Or have the same needs and wants that you do,
So, don't pity me for not having what I don't miss or want.
I recognize that your life,
With all its complexities,
Has its own set of difficulties.
Your definition of accomplishments
And what you find encouraging
Go beyond the simplicity
Which defines me.
I'm only asking for the same rights
and freedoms you seek for yourself:
To be accepted for who you are,
To be the best person that you can be.
Don't assume that I want or think or experience
The world the way that you do.
As nice as you may think it is to be you,
I only want to be me.



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AUTHOR'S NOTE: There was plenty of evidence from my earliest days to suggest that I was on the autism spectrum. For over 50 years I kept my silence and spent a great deal of energy trying to hide my differences...to "be" like everyone else. Most would say that I was successful. I have a career, two master's degrees, and 30+-year marriage. I am only now finding the emotions and sense of self that I had to give up to accomplish this. With it I am discovering just how much I have missed and do not know about living, because I spent so much of my life just trying to survive. Despite everything that I did (auditory training, vision training, sensory processing therapy, vitamins, diets, etc.) to be like everyone else, I did not "cure" myself. I only learned to compensate by "pretending" to be what I was not. Despite persistent sleep and gastrointestinal problems, and now "tics" (which may be secondary to the encephalitis I had as a pre-teen), I am much happier now than I have ever been. I am grateful for the acceptance and support of my husband as well as my old and newly discovered friends.