

**Re: Autism & Cognitive
Challenges. More than just
a Carer: A career that
makes a difference**

By Dr. Wendy Lawson

My carer, my lifeline

**It isn't much fun, having a stranger wipe
your bum.**

**Wanting to go out but not able to give a
shout.**

**These are such minor issues, I hear
someone say.**

These & other issues, I face every day.

**I need support, I have no doubt. My
family do their best. But YOU can offer
respite & give us each some well
earned rest.**

My carer, my lifeline

YOU can make a difference. YOUR presence offers hope.

YOU can make us laugh again. You can help us cope.

Without YOUR care & steady support, I might not have a chance.

But, because of YOU my future looks bright,

I can go on, with goals in sight.

YOU offer a way to lighten my day & enable a future in no other way.

What To Expect From This Talk

- **A brief definition of 'caring' & a 'carer career' with regard to Autism Spectrum**
- **4 key principles: what it takes to make a difference,**
 - **Personality (being personable)**
 - **Acceptance (Rights; respect)**
 - **Using Interest (Choice)**
 - **Building Understanding (In(ter)dependence)**
- **The Future**

Caring

- **To show interest, concern & consideration for another.**
- **To actively commit to another's wellbeing.**
- **To put to one side the needs of ones self in order to respond to the needs of another.**
- **To demonstrate value & respect towards another in need.**

Carer, Career?

- **A career as a carer is not an option for some.**
- **Others feel they don't have any other options.**
- **Whilst others see caring for someone as a privilege.**
- **Some take this even further and develop their career as a 'caring professional'.**

To make a difference?

- You have to be a special type of person to be a caring professional.
- This career requires training, courage and stickability
- It helps to have a sense of humour and be able to let the day 'go' when you are off duty.
- Keeping work and personal life separate is a priority.
- Taking time out for 'you' is a must.

Acceptance

- For any family or individual to accept that they need support isn't easy.
- How would you like to have many of your daily needs delivered by a stranger?
- Could you ask even your best friend to wipe your bum or feed you your dinner?
- Accepting you need help & accept it being done for or to you, could chip away at your pride & independence.

Acceptance

- All support must be offered and delivered with dignity.
- This isn't easy when so many situations are undignified!
- We all start out with accepting this is the case but each of us has a right to value our need for support and to accept this as our right.
- Believing this to be our 'Right' however can impact upon our care, & our carer.

What carers in AS need to know

- In AS learning differently than typicals = need acceptance of that difference & particular support that accommodates our different LS.
- Correct assessment of AS individual needs, is essential
- Building success needs to allow for our autistic diff – ability
- This means appreciating our human right to exist as ourselves.

Sensory Environment

- **If an individual has sensory issues (hypo or hyper) we are not 'available' to learn.**
- **Sensory assessments are imperative**
- **Addressing sensory needs (physical, social or emotional) is essential; ignoring these or hoping they will 'disappear' with time is not an option.**
- **Every individual deserves a sensory environment that does not cause them pain or discomfort.**

Families, supportive services

- **No-one is an Island: Parent support groups.....**
- **Connected to supportive services (health, education, leisure, local council)**
- **Educational settings (early intervention, school, college & beyond). Employment settings & society (carers & families need to communicate effectively).**

Families, supportive services

- **Means: involving AS individual's themselves. Non-typical support (i.e., beyond the typical)**
- **Catering for non-typical language = Using alternative ways to allow for communication**
- **IT; digital cameras; mobile phones, signing, Picture Exchange Program (PECS).....**

Caring for the carer (YOU)

- **Stay up to date with current research & don't think you already know all there is to know.**
- **Have regular breaks and share with a confidant or have professional supervision in the area of your work.**
- **If you need help don't be slow in coming forward.**
- **YOU can make a big difference to the kind of life a family or individual experiences!**

Obsession (Special Interest) in AS

Willey, (2001) “At the base, I have to wonder, are we so very different from marathon athletes, corporate presidents, bird watchers, or new parents counting every breath their newborn takes? It seems lots of people, NT or otherwise, have an obsession of sorts. In my mind, that reality rests as a good one, for obsessions, in and out of themselves are not bad habits.

Obsession (Special Interest) in AS

There is much good about them. Obsessions take focus and tenacious study. They are the stuff greatness needs. I have to believe the best of the remarkable – the artists, musicians, philosophers, scientists, writers, researchers and athletes—had to obsess on their chosen fields or they would never have become great. In some respects, then, it must be said that obsessions do not have to be considered handicaps. (p. 122)

ACCEPTANCE (Rights)

- Being accepted for who I am is the very best thing and sends me a message that I am valued.
- Part of that acceptance is understanding that I have interests that take over my attention.
- Using those interests constructively keeps me motivated and gives me a starting place to learn how to share with others in our every day lives.

Recognising strengths

- Profiling and observation; great ways to recognise strengths.
- Often strengths come from interests. Interests don't have to be a distraction. They might be an asset.
- Highlighting my difficulties & all I cannot do might not be constructive.
- I don't need others to focus on these, as much as I need them to focus upon my strengths.

Valuing my disability/diffability

- **Appreciate strengths and use them to assist me in learning about life.**
- **e.g. Some individuals are good with maps. Mapping can help us plan, de-stress & predict.**
- **Some are good with numbers; counting, ordering, calendars, dates and figures; these might help build a structure that we can hang our day on.**

Developing confidence

- **If we feel confident and valued we are less likely to need to be stubborn, difficult and unfriendly.**
- **I only learn to respect if I am first respected. Treat us the way you would want others to treat you.**
- **But, remember our diff-ability.. we may not learn as you do, but we will learn.**

You can make a difference

- AS & Cognitive Challenges pose huge problems within a society that only accepts you if you fit into the same size as everyone else. We do not fit that profile.
- Therefore, we need dedicated carers who will think 'outside the square' and support our different way of learning.
- You can make a positive difference.

The Future

Life on earth is but a moment caught within
the crease of time,

The seasons come and go again,
You have your life, and I have mine.
The seed that's planted within the ground
Cannot choose what to become.
A potato, an apple or a rose for some.
However, for it to be the very best,
It needs rich soil, not poor.
The sun and the rains must come,
To open that seeds door.

The Future

**I may be born to nourish others,
I may delight the senses.
I may grow tall,
I may grow small,
I may stay stunted beneath wire fences.**

**My future may not depend on my stock,
So much as it does upon sources.
Sources of warmth, sources of care
I depend on the nurture to be for me
there.**

The Future

**Then I can blossom and sing with the
birds,**

Then I can grow my potential.

**So plant me in goodness and all that is
fine,**

Please keep the intruders away.

**Give me a chance to develop, in time,
To become who I am, in life's future, one
day!**

Resources

Web pages: www.mugsy.org/wendy

– www.autismandcomputing.com

- www.autistics.org
- Getting The Truth Out
- <http://www.youtube.com/watch?v=JnylM1hl2jc> (In my language)
- www.youtube.com (Posautive)
- Wendy's BOOKS & other resources:
- Jessica Kingsley Pubs.
(www.jkp.com)