

Living Loving and Longing in a Family with Autism

Talk given for the *Luke Priddis Foundation*, October, 2010

My background:

I was a respite carer of a boy with severe autism when I was in my early 30's. Our family cared for this boy, (let's call him John) one weekend a month for about 2 years until he became too much of a danger to our small children. In that time, we became involved with his family as a regular form of social support during the week and each weekend. John came to our family birthday parties, with his younger brother. We even went on holidays together once!

So I would say I have a teaspoon of understanding of some of the ocean of experience each of you have. I could send John home and catch up on sleep. When he was violent or had a meltdown, we could tell ourselves that it was just for a few days and his family had to do this all the time. They had sorted out the tactile issues, the food issues, the clothing issues. And they had all the responsibility and costs for his education and care. John needed to be placed in care once he reached his teens. That is a sad reality for many families, and, of course, there are new treatments now which do make a difference for many.

As part of my counselling business, I have been working as a counsellor with families with children on the Autism Spectrum for several years. I have met some of these children, or their siblings, or their mum, or their mum and dad. Sometimes I help siblings work through their feelings, other times I help mums sort out their whole life. And I also work with couples because with all the stress and busyness they have lost something they think is important: each other! All of these clients have taught me so much, as did John and his courageous, loving family. I thank them and hope to learn so much more in my work.

I was also a high school teacher and taught some students who were diagnosed with Aspergers, and I worked in Special Education for 2 years. As well, I have worked as a casual in schools for children with additional needs. So I have had an interest in children with additional needs for a while. Would you believe when I first went to university at 18, my goal was to train as a teacher and then to work with children with Autism!

That has not happened, but here I am, and I am open and willing to learn from you tonight, even as I hope some of my talk tonight will give you some ways to make sure you care for yourself in all this.

I want to remind you that what you are doing is significant, is worthwhile, is hard as hard as hard, and yet you are doing it. That is remarkable, and I never want to forget that. I don't want you to lose sight of that, because if you do, you may fall into the quicksand of depression and hopelessness.....or run away into drugs or alcohol or work..... It's hard, and you're doing it! Stick that message on the fridge if you need to.

So why do you need to care for yourself?

In this talk, I will be focussing on parents and their needs. But I want to acknowledge that many grandparents are hugely involved, and there may be others here. So these principles apply to all those in a caring role. Research has shown that parents of a child with ASD experience higher levels of stress compared with parents of children with other developmental disabilities (Pottie and Ingram)

Think of the Oxygen Mask in a plane...you first. If you've blacked out, you can't help your child, so you have to put yours on first....not logical, but actually the best way to go.

You need to care for yourself, because your job of caring for a child with Autism is one of the toughest gigs a parent can be given. Let's look at what stresses are on you.

Based on what other parents in families where there is ASD have said,

There can be stresses in the following areas:

- Feelings of needing to know so much about ASD and what it means for your child, or for you
- Uncertainty or a sense of having very little control over the future for your child
- The difficult behaviours, melt-downs and anxiety of the child with ASD
- The complexity and frustration of the system of care for your child
- Daily challenges of life with a child with ASD: things are often slower and less predictable
- A sense of isolation or loneliness because socialising can be more difficult and result in loss of friends
- Financial pressures because you may have lost income, and the cost of treatment can be enormous
- Exhaustion from the appointments, lack of sleep and balancing the needs of all the family
- Feeling judged, blamed or misunderstood by others: in public, in your extended family, with friends
- Dealing with ill-informed but well-meaning advice from others
- You may lack intimacy and time out with your partner
- Feeling overwhelmed by what you have to fit in your day
- Feeling like you have lost yourself in all of this

- Feeling a cocktail of draining emotions such as anger, grief, helplessness, guilt or fear

SO, with all these extra stresses it can be tempting to think there can't possibly be time to care for you. But caring for you will positively impact on your ability to care, as well as make your life more enjoyable because you are coping better with the stresses of your role. Later we will be looking at the positives you may have developed through having a child with ASD, because this is so important in acknowledging your growth and learning, and the gift that your child is in your life.

So...

How do you minimise Stress in your life as a carer of a child with ASD?

Most parents who have written about this agree there are 3 basic things that you need to do to minimise the stress of being a carer in a family where there is ASD:

1. Get organised

2. Look after yourself

3. Get help

Tonight I am focussing on the second one, *Looking after yourself*. But first I want to say this about getting organised: I am not very good at getting organised! So I have needed to look after myself and ask for help in getting organised. But I have learnt if I am not organised, things take longer to do, I am more stressed, things get lost a long time before they are found, and I give myself a hard time for being so dithering. You might be good at it, so you don't need my lame attempts at suggestions. Perhaps you have some ideas?

And about the third one: *Get help*? I see that as part of *Caring for yourself*, and so I will talk a bit about that. Some people find getting help, asking for help, or accepting help harder than others. But you probably need to get a "degree" in **Getting Help** if you have a family member with ASD! But more of that later.

Looking after yourself

Remember: WE ALL RESPOND TO STRESS DIFFERENTLY,

so be patient with others.....what works for you might not work for them.....

- a. *Learn to think of the glass as half full (Positive self talk, coaching yourself, positive thinking and praise lead to better mood and increased ability to cope, better sleep and health) This needs practice.*
- b. *Relaxation exercises, meditation, slow breathing (increases getting in touch with what you feel, and with your body; brings down breathing rate, lowers stress.*
- c. *Seek out support groups/ counselling (Support, encouragement, information, sorting out feelings, priorities, grief; reduces isolation, names of the "good guys" eg recommended specialists in your area)*
- d. *Ask for help when you need it. Financial, personal, social, respite, counselling... Persist. You deserve all the help you can get.*
- e. *Communicate effectively with those you love. (Bottling it up leads to explosions) Don't know how to express yourself well? Seems not to be working? Ask for help.*
- f. *Welcome all your feelings: none of them are wrong, or bad. It's ok to grieve what might have been... (better that than to withdraw, attack others in anger, or get sick because you have locked them up inside)*
- g. *Look after your marriage. When relationships work, you feel more happy and more capable, safe and secure. It can protect you from some of the stresses of caring. Your children benefit because they pick up the vibe....They sense you are more relaxed, joint parenting works better and you have more energy.*
- h. *Single? Cultivate some friendships that meet your need. People who listen without judgement or advice-giving, who accept your situation and respect and honour you are great. A sense of humour in them helps too.*
- i. *Self-soothing is really important: find ways to calm yourself, without abusing alcohol or drugs. Nature can be soothing, prayer, or crosswords, Sudoku, cross-stitch or repetitive card games like solitaire.*
- j. *Find social support and friendships that work for you. Sometimes other parents in the same boat*
- k. *Trouble getting to sleep? Avoid the computer for at least an hour before getting ready for bed. Avoid caffeine after 4pm. Some parents find a relaxation tape helps them unwind, or a warm bath.*

I. 10-15 minutes time-slots to care for yourself: (Which of these might work for you?)

- *Read a magazine*
- *Take a long shower (you might even have time to wash your hair!)*
- *Take a Walk*
- *Listen to a relaxation tape*
- *Slow stretches*
- *Cuppa in bed*
- *Sing along to your favourite CD*
- *Write a thank you card to yourself*
- *Draw your feelings*
- *Talk to God if that works for you. Tell him if you are angry at Him: He will already know anyway, and is big enough to take it!*
- *Write down your family's best points*

What strategies have been shown to be least helpful when parenting a child with ASD?

Research shows that reacting to the diagnosis in certain ways over time will make it harder to cope. The following long-term responses decrease your coping:

Withdrawal

Helplessness

Escape

Worrying

Blaming

Avoiding feeling /expressing grief

If you or your partner are responding this way what can you do?

Talk about your feelings and gently invite them to share theirs. Give them time, as men in particular often need more time to come to terms with the diagnosis. Acknowledge each other's contributions and roles.

Recognise that this issue may not respond to a problem-solving approach, which is often how men cope with issues. Some of these issues cannot be fixed: a child with ASD may not reach the goals you work for. And this means letting go of hopes and dreams all over again. Grief comes and goes, as painful as it is. It will come, and then if you feel it, it will move through you so you can get going again.

What are the Positives of parenting a child with ASD?

Based on the IAN Research Report Sept 2009, parents with children on the Spectrum reported that they see the following positive outcomes from their situation:

- Their child is a source of joy
- A sense of accomplishment in having done the best for their child
- A sense that their marriage or family had been strengthened by what they had gone through together as a result of the child's diagnosis
- A new sense of purpose in life
- A sense of personal growth (because they had become more compassionate, less selfish, more tolerant)
- Increased spirituality
- A new perspective on what is important in life.

I have added a few more based on what parents have told me:

- Discovery of inner strength they didn't know they had
- Development of skills in the political and social justice community
- Formation of a new identity, together with new dreams, values, hopes and expectations

Stories from studies.....

Some parents told us they had come through the distress and grief of the initial diagnosis to adjust, celebrate their child, and thrive. One father told us his marriage had been brought back from the brink of a breakup because of his son's diagnosis. "Before our son was born my wife and I were on the fast track to divorce: constantly arguing about money and nitpicky stuff. After he was diagnosed, all of our money went into treating him so there was no longer any money to fight about. Our marriage is stronger now because we spend our energy getting him better and being good parents for him and his sister. He has taught us a lot about what is important in life: to be happy, just to be able to live a simple life and survive from one week to the next."

Similarly a mother said, "Most of the time we felt like no one else understood what we were going through. We felt like all we had to depend on was each other. It made us even closer because we made our marriage top priority. We knew it wouldn't do our son any good to lose the security of both parents. We decided not to let ASD be all our family was about."

A special note to Dads

You are needed! Your child needs you and your partner needs you. You may not be able to fix Autism, but you can make a huge difference to your family's life by stepping up and facing the challenges the diagnosis has brought. It's ok to be sad or mad, so long as you are in there lovingly.

Learning about your child's specific needs and feelings will enrich your relationship with him/her. And the other kids will need you more than ever. Stand tall, dig deep. You are not a money-making robot: you are a dad, a partner, a person.....

A special note to Grandparents

Your role can make all the difference, to your child, and to your grandchildren. Research shows your role can make all the difference.

Pacing yourself, setting boundaries and being non-judgemental are the 3 keys to your role. The blessings can be immense as you take on a new challenge later in life, leaving your later years focussed on what is truly important, what really matters....

A special note to Mothers

You, especially need to learn to care for yourself. What's the worst thing that can happen if you stop? Mostly I find the worst thing that parents are afraid of is our deeper feelings. That's ok. Feel them and they will pass. You will be happy again.

Share the load! Invite your man in to become an expert on your child. Let him know which of his magnificent qualities you and your family need most. Get help if the relationship is struggling...yes! It's usually the woman who brings the man. That's ok!

And remember, if your marriage does not come first, your child will come last.....