

Challenges in Parenting Special Needs Children

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My Children

- Jason – 25 years old
- Ryan – 22 years old, Perthes Disease from 3 years old, ongoing hip issues, soon to have a hip replacement
- Olivia – 11 years old, Autism, Anxiety, Severe Motor Tics
- Cassie – 8 years old, Mild Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Foetal Growth Retardation Syndrome



Challenges

- Grief
- Accepting a “New Reality”
- Financial Concerns
- Managing Sibling Issues
- Stress on Marriages
- Education Concerns
- Expectations of Others
- Strategies to Limit impact on Families

Grief

Stages of Grief – At the birth and / or diagnosis of a child with a disability, parents will often experience grief. These stages may not happen in this order and different stages may re-appear as the child ages.

Denial – This is not really happening, The doctor is wrong, She will grow out of it. I didn't sign up to have a child with a disability.

Anger – This isn't fair, This isn't what I wanted, Resentment towards families with non-disabled children. Blaming ourselves or others – If only I had eaten better during pregnancy, It is all my husbands fault, The teachers poor teaching ability is why my child doesn't talk at school. If only I had done something about this earlier.

Bargaining - Asking a higher power for help or trying to compromise a situation to "lessen the blow." If I pray really hard, my daughter's autism will disappear. If I pay the best doctors my son's hips will improve. If I am a better parent, this will all disappear. This typically results in a short-term solution to a long-term issue.

Depression / Sadness - Feelings of loneliness, panic or guilt; feelings of devastation and sadness. Parents may feel like they're the only parent or family going through this and that no one really understands what it is like. Talking to people about what you are going through is so hard and embarrassing? When you do try to talk to friends or family, they really just don't seem to understand the situation or truly understand how painful it is to see your child struggle. A true sense of loss of all the hopes and aspirations for your child.

Acceptance - Including growth, optimism and letting go of limiting beliefs of what is and is not possible. You come to a place where your child's disability is accepted and his or her differences celebrated with the understanding that her (and your) journey is not a straight line, and that she can and will be successful in so many ways. You let go of comparing your child to other kids and take a good, hard look at all the wonderful things she has to offer and her accomplishments that make her the special person that she is. You know that you are her best advocate and have the clearest insight into her abilities.

My Personal Grief

- Olivia has the most limiting challenges of all my children.
- Olivia received an Autism diagnosis shortly after the death of both my parents.
- My feelings of grief for Olivia's loss of a "normal" life greater than grief for my parents' deaths.
- Important to acknowledge the grieving process and talk to people in a similar situation.
- Grief is a normal and natural part of having a child with a disability
- It does improve!

New Reality

- Part of the Acceptance process is getting used to a new reality.
- Acknowledging that your family is normal, just a different kind of normal.

DIFFERENT

NOT LESS

Don't waste time being

normal ['nɔ:m(ə)]

adjective

1 conforming to a standard; usual, typical, or expected

**just be your own
wonderful self**

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Financial Concerns

- Cost of medical care, therapies, treatments, medications, transport
- Waiting lists for free services
- Inadequate government funding for services for children with disabilities
- Parent/s inability to work due to care requirements of children
- Remedies – No easy solution
- Talk with parents in similar situations, share ideas and resources
- Don't be too proud to ask for assistance

Ongoing Stress – Glass Half Full

- A psychologist walked around a room while teaching stress management to an audience. As she raised a glass of water, everyone expected they'd be asked the "half empty or half full" question. Instead, with a smile on her face, she inquired: "How heavy is this glass of water?"
- Answers called out ranged from 8 oz. to 20 oz.
- She replied, "The absolute weight doesn't matter. It depends on how long I hold it. If I hold it for a minute, it's not a problem. If I hold it for an hour, I'll have an ache in my arm. If I hold it for a day, my arm will feel numb and paralyzed. In each case, the weight of the glass doesn't change, but the longer I hold it, the heavier it becomes." She continued, "The stresses and worries in life are like that glass of water. Think about them for a while and nothing happens. Think about them a bit longer and they begin to hurt. And if you think about them all day long, you will feel paralyzed – incapable of doing anything."

Glass Half full cont.

- In a similar way the “weight” of caring for a special needs child can be compared to holding that glass for a long time.
- This ongoing stress can cause problems within families, marriage issues, sibling concerns, carers that are worn out.
- The more people who can help “hold the glass” the lighter it will feel, but don’t place too high expectations on siblings as they are children also.
- Parents need to find a way to “put down the glass” occasionally, by finding respite, help, talking with like minded people.

Relieving Stresses

- Respite via a care agency, family, friends, time along at home
- Meditation, mindfulness, living for the moment
- Talk with like minded people
- Join a support group or start a support group
- Remember how far you have come

Whenever you
find yourself
doubting how
far you can go,
just remember
how far you
have come.

Remember
everything you
have faced, all
the battles you
have won, and
all the fears
you have
overcome.

– Unknown

Reliving stresses

- I “put the glass down” by walking my dogs on the beach



Marriage Difficulties for Special Needs Families

- Higher divorce rate for families with disabled children
- Why?
- Alienation – The demands of having a new baby can be hard on a marriage, but the babies parental demands will diminish over time for a typical child; Not always the case for a child with a disability. One of the two partners may grow resentful and feel left out of any attention. Sometimes parents are forced to work shifts around a child, making time together almost impossible to find.
- Money – or rather a lack of it.

Marriage Difficulties for Special Needs Families (cont)

- ***Loss of love rather than deepening of love.*** We expect to grow closer as we age and have that common bond experience of life together. Sadly when you add in a special needs child couples can change in attitude, needs, wants, dreams and goals. Sometimes one of the parents wanes in the love they feel for their partner. This can be due to one parents alienation of the other while caring for the child, and staying focused on the child so much they forget themselves or their partner. Constant fighting over care for the child, lack of help, and not enough money can cause parents to simply loose sight of the very things that brought them together to start with.

Marriage Difficulties for Special Needs Families (cont)

- ***One of the parents “does a runner”***. This is a parent who simply cannot cope with the job of raising a special needs child, and leaves the family home. While this is not the norm in most special need homes, it can and does happen.
- **Possible Solutions**
 - Communications - Talk, talk and talk some more!
 - “Date Nights” When couples first meet they regularly go out together to enjoy experiences. This can be hard to achieve in a special needs family, but it is vital for the parents to experience some “time-out” together. Can be hard to find a suitable carer for a disabled child but date nights can be achieved at home. Try not to talk about children during date night, instead talk about the things you enjoy together as a couple.

Education Issues

- Educating a child can be hard;
- BUT, Educating a special needs child can be far harder.

- Finding a suitable school
- Providing education on Life Skills
- Educating the Educators about your child's individual needs
- Dealing with bullies

I don't think
the ~~worst~~ thing
that could
happen to ~~me~~
is raising a
child with ~~special~~
~~needs~~. I think
the worst thing
is to raise a
~~child~~ who is
cruel to those
with ~~special~~ ~~needs~~.

Expectations of Others

- Other people may stare, be rude, exclude and discriminate against you, your child and your family.
- In a perfect world, this would not happen.
- Building resilience in a special needs family is vital.
- Choose to be around people who accept your situation unconditionally.
- Personally, I have lost contact with friends and family because of autism, BUT, the friendships I have made because of autism are far more valuable friendships.

Conclusion

- Many, many challenges in parenting children with special needs.
- Carers need to look after themselves and each other.
- Talk with others in a similar situation.
- Join a support group, start a support group

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