Reactions to Diagnosis

For some families the journey to diagnosis is like a roller-coaster, with emotional ups and downs along the way. Some parents are autistic themselves, some receive an autism spectrum diagnosis alongside their child, whilst others are not on the autism spectrum. Each of these scenarios can take a different pathway, with a child being diagnosed as a toddler all the way through to not receiving a diagnosis until mid-teens or even adulthood.

The huge variation in time to diagnosis occurs due to a number of different factors:

- The way autism presents in that child or young person
- The way the child communicates
- Accessibility and affordability of autism assessment locally
- Family knowledge, understanding and awareness of autism

There is no right or wrong way to react to the journey of an autism spectrum diagnosis. Some families celebrate receiving an autism spectrum diagnosis, as they now feel more confident moving forward to support their child.

Other families, or individual family members, may struggle to accept an autism spectrum diagnosis and this can be different for each individual in the family. Some reactions are based in cultural concepts of difference and disability.
Reducing stress...

The diagnostic process is perceived as less stressful when families feel heard and collaborated with. The more professionals that a family needs to consult, the more stressful the experience is for them. In addition, the more practical and helpful the information a family receives about what the diagnosis means for them and their child, the lower the stress levels become. This means that accessing up to date, accurate information about autism and developing a clear, shared understanding of how autism presents in their child and what the impacts of that are, can significantly decrease parental stress. Another way to decrease stress through developing a grounded understanding of autism is to attend workshops or other autism focused events.

Impacts of family reactions...

How a family reacts to their newly diagnosed autistic child or young person, can have a significant impact on the wellbeing and self-esteem of that child or young person. This doesn’t mean that the family has to put their own emotions and feelings aside, rather that when talking to or about the child or young person, that it is helpful to use positive and supportive language. It is okay for families to be frustrated or sad or even angry about the diagnosis journey at times. After all, most parents experience these emotions during their parenting journey.

Reactions from the extended family and community may be more or less supportive than the family and newly diagnosed autistic child or young person expect. This in itself can lead to a whole range of emotions. For some families, there may be a period of grieving, balanced with relief as they come to terms with what having an autism spectrum diagnosis means, but that now they know why their child presents differently to their peers. It can be very helpful for families to meet, not only other families with autistic children, but also autistic adults.

Getting to know autistic adults can provide families with a genuine understanding of the huge variety of adult life outcomes experienced by people on the autism spectrum in reality. Meeting and sharing experiences with other families with children on the autism spectrum can provide a way to create genuine connections and problem solve using the group’s collective experiences, skills and knowledge.
Grief and stress can come and go, with some people only experiencing moments of these in response to particular issues or events, such as being on a wait-list for a service or seeing their autistic child experience sensory overload in the community. For other people, grief can be longer term and can be compounded by stress. It is important to remember that all parents experience stress and that grief is a normal response to situations of change and/or loss. Parental stress plays a significant part in predicting quality of life for the whole family, when one or more of the family members is autistic.

What can help?

Putting in place strategies to manage your own wellbeing will help to move forward. However, some people may need to have more formal supports in place to manage their feelings and stresses.

Informal supports for parents and other family members to manage their stress in relation to having a newly diagnosed autistic family member are:

- Learning from other families about what strategies minimised their stress
- Increasing your social network to include people who are accepting and supportive, such as autistic adults, local autism support groups for parents and families
- Learning and using a range of effective problem solving strategies.

Effective formal supports and strategies:

- Attending courses and workshops to develop an understanding of autism
- Seeking counselling or psychologist support

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