This fact sheet aims to describe some of the reactions and emotions that parents experience after a diagnosis of autism in their family, as well as those that are experienced as children develop. Strategies and suggestions associated with coping are also described.

Reactions to diagnosis

All parents react to a diagnosis of autism in different and highly personal ways. For some parents, a diagnosis of autism comes as a shock, as they hear for the first time that their child is developing differently to others and is likely to always be different in some ways. For other parents, a diagnosis of autism comes as a relief and an explanation after many years of doubt, questioning, self-blame and guilt regarding their child’s differences and difficulties. For many others, there is sadness and worry as their fears are confirmed.

Parents also adapt to a diagnosis of autism in different ways. For many parents, a diagnosis provides access to services along with a better understanding of their child’s behaviour. It is important to note, however, that some parents continue to feel anger and frustration along with feelings of sadness as they understand the long term impact of autism on their child and family.

Grief and loss

When the term ‘grief’ is mentioned, people often think about the emotions that surround the death of a loved one. However, grief reactions can occur whenever people experience other types of loss, such as the breakdown of a relationship. It is also very common for parents to experience grief when their child is diagnosed with a disability such as autism spectrum disorder. While the child with autism is obviously still alive, parents may grieve the loss of the ‘hoped for’ child.

Traditional models of grief, such as the well known Kubler-Ross stages of grief theory (denial, anger, bargaining, depression & acceptance) and theories around ‘grief work’ are based on theories about people with terminal illness and those who have lost loved ones. These traditional models expect that the people experiencing grief will move through stages to a point of acceptance. Some researchers have suggested that these models are not always well defined and that there may not be evidence to support the theories. Others argue that the notion of stages of grief puts pressure on the bereaved to move through the stages in a certain timeframe and to reach a stage of ‘acceptance’ with no more feelings of grief.

At times, these models have been suggested as ways to understand the grief experienced by parents of children with disabilities. It is the experience of many parents, however, that they do not move through time bound and prescriptive stages of grief and that for most parents, ‘acceptance’ does not really describe the mixture of emotions they continue to experience. For many parents, the grief they experience is better described by the term ‘chronic sorrow’.

‘Chronic sorrow’ is a way of understanding the complex emotions experienced by parents who have a child diagnosed with a disability and was first described in the 1960s by Olshansky. ‘Chronic sorrow’ does not mean that the parent is constantly experiencing grief related feelings; rather, the term describes the way sadness and other grief related feelings can occur at any time, even though the parent is able to function normally and experience happiness at other times. Importantly, Olshansky and other researchers emphasise that these reactions are a normal response to a very challenging situation. There is no emphasis on ‘acceptance’ of the diagnosis and no suggestion that experiencing episodes of grief years or even decades after a diagnosis is anything but an expected outcome of a situation that does not resolve.
It is important to note that the feelings of sadness can lessen with time but that grief can be triggered by both internal and external factors. For families of children with disabilities, these triggers are often related to developmental milestones, such as starting school, when parents can revisit the same sadness and grief related feelings that occurred when their child was first diagnosed. These milestones bring into focus the difference between the imagined or ‘hoped for’ child and the reality of the child with a significant disability.

While the information described above might be confronting for some, it is important to recognise the ongoing implications of a diagnosis of autism spectrum disorder. Many parents are resilient and rightly continue to hold high hopes for their child. The idea of ‘accepting’ a diagnosis in order to move on with their lives is no longer seen as the only way to parent a child with a disability; nor should parents who periodically experience grief in the form anger or sadness in relation to their child’s diagnosis be seen as ‘in denial’ or yet to ‘accept’ the diagnosis. Periodic grief is a normal reaction to a difficult situation.

Stress

In addition to feelings of grief, it is well documented that parents of children with autism experience significant stress and that this stress is greater than that experienced by parents of children without disabilities and parents of children with disabilities other than autism. The sources of this stress have been attributed to a number of factors including greater caregiving challenges, child characteristics and child behaviour, which can lead to feelings of restriction and family isolation. Some authors suggest that stress may be related to grief as parents mourn the loss of what they assumed to be a typically developing child. Parents of children with autism also report stress associated with negotiating the maze of services they need to support their child and their family.

What can help?

Parenting a child with autism can be challenging and stressful and parents are likely to feel periods of sadness and grief. Fortunately research suggests that there are a number of things that are likely to be helpful for many parents:

- Positive coping (as opposed to avoidance or denial) has been found to be associated with lower stress and better coping for parents of children with autism. Positive coping strategies include:
  - seeking information about autism and your child
  - pursuing respite opportunities where appropriate
  - maintaining your own interests
- Talking with someone – this might be with a trusted friend or family member or through a support group.
- Developing social supports – parents with social supports report better interactions and lower stress. Social supports might come from spouses, extended family and friends as well as support groups and other networks, including online communities.
- Community supports such as respite, recreation activities and education programs can help families with feelings of grief and stress.

Summary

All parents will react to a diagnosis of autism in individual ways but it is important to recognise that many parents will continue to experience feelings of grief from time to time. It is normal for parents to experience periods of sadness, anger and frustration, interspersed with periods of normal functioning and happiness. Support groups and other social supports, along with positive coping strategies, such as seeking information and maintaining interests in the community, are helpful to many parents experiencing feelings of grief and stress.
The Positive Partnerships initiative is funded by the Australian Government Department of Education through the Helping Children with Autism Package. The views expressed in this publication do not necessarily represent the views of the Australian Government or the Australian Government Department of Education.

References


