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# When Hopes and Great Expectations Have Gone with the Wind!!!!!!!Living with an Autistic Child, is it a Tragedy or a Blessing? None Can Tell but the Expert

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**Abstract**

"Whenever there is a help, there is a hope"; having a child with Autism Spectrum Disorder (ASD) is not the end of the world, with the necessary help autistic caregivers can face their problems in taking care of their children and efficiently deal with them. By knowing that these special children are not odd but different and by recognizing their potentials and savant abilities, professionals and caregivers can help them in creating their own future. Lastly but by no means least, it is worthy to remember that many of the autistic caregivers have turned their tragedy into a blessing by believing in their own capabilities of changing not only the life of their children but also the whole world for them.

**Keywords:** Autism spectrum disorder (ASD); Autistic caregivers; Autistic caregivers meet the professionals' day; Autistic caregivers' support groups.

## Introduction

Ohhhhh dear; why are you doing that???!!!!! Stop beating your head….Stop shaking your arms….Stop spinning, you made me dizzy……..Do you listen to me??? Do you understand what I am saying??? Look at me, please look at me, look at me in the eyes…… Ohhhhh my God…..How can I make him understand me???.....How can I make him feel how much I love him???.....How can I help him??? With these desperate words, the mother of one of my newly diagnosed autistic patients tried to explain her daily suffering seeing her child acting in a way she can neither understand nor tolerate.

Parents before the birth of any of their children live for months dreaming of having a beautiful healthy child and when that child is born they celebrate his or her birth joyfully with great expectations about his or her future. If the child suffers from one of the neurodevelopmental disorders especially Autism Spectrum Disorder (ASD), they watch their hopes and great expectations gone with the wind day after day; they may live in shock and or denial for months and when they finally admit that there is something seriously wrong with their child; they may spend months searching for ways to help him. In their long journey to find what is best for their child; they might become anxious or depressed if they do not find the necessary autistic caregivers' professional and social support.

### What does the term "neurodevelopmental disorders" mean?

The neurodevelopmental disorders (NDD) are a group of conditions with an onset in the developmental period. Such disorders typically manifest early in development and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. The range of developmental deficits varies from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence. The NDD frequently co-occur; e.g. individuals with ASD often have intellectual disability and many children with attention deficit hyperactivity disorder (ADHD) also have a specific learning disorder [1].

### What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, non-verbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition, diagnosis of ASD requires the presence of restricted, repetitive patterns of behavior, interests, or activities. Within the diagnosis of ASD, individual clinical characteristics are noted through the use of specifiers (with or without associated intellectual disability, with or without accompanying structural language impairment, associated with a known medical, genetic, or environmental condition, or associated with another mental or behavioral disorder [1].

### Why is ASD unique?

ASD is a highly variable neurodevelopmental disorder [2] that first appears during infancy or childhood, and generally follows a steady course without remission [3]. Children with autism may be severely impaired in some respects but normal or even superior in others [4]. Overt symptoms gradually begin after the age of six months, become established by age two or three years [5] and tend to continue through adulthood, although often in more subtle form [6].

### Pediatricians and ASD

Pediatricians play an important role in early recognition of ASD, because they usually are the first point of contact for parents. Parents

are nowadays much more aware of the early signs of these disorders because of frequent coverage in the media; if their child demonstrates any of the published signs, they will most likely raise their concerns to their child's pediatrician [7]. An autistic culture has developed, with some individuals seeking a cure and others believing that autism should be accepted as a difference and not treated as a disorder [8].

A pediatrician commonly performs a preliminary investigation by taking developmental history and physically examining the child. If warranted, diagnosis and evaluations are conducted observing and assessing cognitive, communication, family, and other factors using standardized tools, and taking into account any associated medical conditions [9]. Assessment of behavior and cognitive skills is essential both to aid diagnosis and to help recommend educational interventions [10]. A differential diagnosis for ASD might consider isolated intellectual disability, hearing impairment, and specific language impairment [9].

## Goals of treatment of ASD

Because there is no definitive cure for ASD, it is always vital to remember that the main goals when treating autistic children are to lessen associated deficits and family distress, and to increase quality of life and functional independence [11].

## Therapeutic modalities for ASD

There are many therapeutic modalities for autistic children but no single treatment is best and treatment is typically tailored to each child's and caregivers' needs [11]. Families and the educational system are the main resources for treatment [12].

Psychosocial interventions may have some positive evidence, suggesting that some form of treatment is preferable to no treatment [13]. Intensive, sustained special education programs and behavior therapy early in life can help children to acquire self-care, social, and job skills [11] and often improve functioning and decrease symptom severity and maladaptive behaviors [14]. Available approaches include educational intervention with intensive applied behavior analysis (ABA), developmental models, structured teaching, speech and language therapy, social skills therapy, and occupational therapy [11].

Many medications are used to treat ASD symptoms that interfere with integrating a child into home or school when behavioral treatment fails [6], [15]. These medications include psychoactive drugs or anticonvulsants, with the most common drug classes being antidepressants, stimulants, and antipsychotics [16] but such medications may have adverse effects [11] and no known medication relieves autism's core symptoms of social and communication impairments [17]. Animal studies have reversed or reduced some symptoms related to autism by replacing or modulating gene function [18], [19] suggesting the possibility of targeting therapies to specific rare mutations known to cause autism [20], [21]. Although many alternative therapies and interventions are available; few are supported by scientific studies. These alternative therapies include gluten and casein free diet, heavy metals chelation therapy, and hyperbaric oxygen [22-24]. Some alternative treatments may place the child at risk; autistic boys have significantly thinner bones if on casein-free diets [25], botched chelation therapy killed a five-year-old child with autism [26].

## Autistic caregivers

Autistic children, whether accepted as different or treated as having a neurodevelopmental disorder, their caregivers are continuously under extreme stress. On one hand, they are tortured because of seeing their children living such a denied childhood and on the other, facing silent or expressed accusations from others as being responsible for the condition of their children [27]. Accordingly, having a child with an ASD has been proven to exert a substantial pressure with dramatic effects on a family. Parents and siblings of children with ASD experience more stress and depression than those of children who are typically developing or even those who have other disabilities [28-33]. The role of Pediatricians; in educating and supporting autistic caregivers to empower them in helping their children and alleviating their own stress because of their parenthood worries and community accusations and stigma, is crucial [27].

## Autistic caregivers' meet the professionals' day

Because of the vital role that autistic caregivers play in the lives of their children, Child Psychiatry Clinic, Children's Hospital, Ain Shams University has conducted its first Meet the Professionals' Day (MPD) for them on March, 2015. It has been designed to evaluate their knowledge, Concerns, and needs from the clinic, community, and future autism scientific research. Analysis of the data Zaky et al. (2015) [27] collected on that day showed that it was very useful and fruitful in breaking the ice between the professionals and autistic caregivers paving the way for them to know each other in a comfortable setting outside the clinic and its restricted time and routine limitations. On the other hand, MPD showed how important it was to assess the knowledge of autistic caregivers about a disorder depriving their kids from enjoying their childhood. Such assessment helped us as professionals to arrange for educational programs that meet their needs, dealing with their concerns, and empower them to help their children in a more efficient way. MPD was also very effective in taking a closer look at those who are obliged to live autism every single day of their lives and in answering all the questions they have in their minds, let them express their fears, and face their concerns about the future of their children.

Establishment of autistic parental support groups seems very worthy to let them share their feelings, fears, concerns, and experiences in taking care of their children with each other and with members of the professional teams and society. On the other hand, creating public awareness about the problems and difficulties the autistic children and their caregivers face will improve their capabilities of dealing with such problems and difficulties and successfully overcome them that will certainly improve the quality of their lives [27].

## To summarize

"Whenever there is a help, there is a hope"; having a child with ASD is not the end of the world, with the necessary help autistic caregivers can face their problems in taking care of their children and efficiently deal with them. By knowing that these special children are not odd but different and by recognizing their potentials and savant abilities, professionals and caregivers can help them in creating their own future. Lastly but by no means least, it is worthy to remember that many of the autistic caregivers have turned their tragedy into a blessing by believing in their own capabilities of changing not only the life of their children but also the whole world for them.

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