

**Autism and Asperger's Conditions**  
**A practical guide for nurses**

**Note**

*Healthcare practice and knowledge are constantly changing and developing as new research and treatments, changes in procedures, drugs and equipment become available.*

*The author and publishers have, as far as is possible, taken care to confirm that the information complies with the latest standards of practice and legislation.*

# **Autism and Asperger's Conditions**

## **A practical guide for nurses**

*by*

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# Introduction

*'So, what exactly is this 'disease' called Asperger's syndrome?'*

Let me explain. At the Royal College of Nursing's Annual Congress at Harrogate in 2005 there was a resolution debate around learning disability services. During a two minute verbal contribution to the debate a nurse mentioned that his then 12-year-old son had Asperger's syndrome and that there was a possibility that he, too, might also have the condition. His self-diagnosis was based upon a reflective reading of the first two chapters of *Autism and Creativity* by Michael Fitzgerald (2004). The more this nurse read of Fitzgerald's book, the more certain aspects of his own life story finally started to make sense. He had reached the 'eureka' moment of understanding who he was.

During a coffee break later that day the nurse was approached by a nursing colleague who asked him, in all seriousness and with an apparent lack of knowledge regarding Asperger's and similar conditions on the autism spectrum, what this 'disease' called Asperger's was. To say the nurse was stunned is an understatement. He mumbled something vague and unhelpful about Asperger's syndrome being a form of autism before self-consciously disappearing into the crowd. He had hoped that someone would ask him intelligent questions about the syndrome and his experience of it or to use his knowledge, which he had gained not only from completing a master's degree in the subject, but also from working with service users in a professional capacity and from being his son's 'informal carer', but no one did. So much for 'coming out' and his five minutes of fame. The Congress resolution debate and his contribution to it were, however, reported briefly in the *Nursing Times* (2005). The nurse who spoke during that Congress debate was me, and the 'self-diagnosis' was later confirmed after a period of assessments.

The question still stands, despite the initial phrasing of it being somewhat inelegant and betraying a serious lack of knowledge on the part of the nurse asking it. I spent the following year repeatedly asking myself and others what an appropriate response to this question should be. Clearly, a few information 'sound bites' would not suffice even to cover the essential basics of what autism and Asperger's syndrome are, let alone anything approaching an in-depth discussion surrounding its causes, presentation, assessment, effects and interventions. Numerous discussions were held with a wide number of interested people including parents of people with Asperger's syndrome and autism, fellow nurses,

social workers and teachers. The suggestion of a book about Asperger's syndrome and autism aimed specifically at nurses was raised as a possible solution to the question. As the year progressed the idea of writing such a book took root and grew. So this is where we are now: a book about Asperger's syndrome and autism aimed specifically at nurses.

## **Purpose**

What, then, is the purpose of this book? Is there not already enough written material about autism and Asperger's syndrome? Why the need for more?

Agreed, there are whole libraries of books, journal articles and internet formats on autism and Asperger's, with more being added almost weekly. However, the conversation that I had with my nursing colleague at Harrogate and subsequent conversations have convinced me that this information, although both available and plentiful, is not getting through.

As nurses we do not appear to be as informed and aware as perhaps we should be about Asperger's syndrome and autism. This lack of awareness is evident each time I take my son, who is now 17 years old and who has Asperger's syndrome, to our local A & E department. Both myself and my son are met by silence when I ask the nurses how much they know about Asperger's syndrome and autism. 'Well, I did once watch the movie *Rain Man* with Dustin Hoffman. Wasn't that about autism?' seems to be the stock answer and also seems to be the limit of many nurses' knowledge about these two conditions. Such lack of knowledge is further hampered by the use of a biological, medical and disease model to understand autism and Asperger's syndrome; hence the idea of Asperger's being a disease, which actually it is not. In his Masters of Education dissertation, a shortened version of which can be found in Barber (2001), Barber investigated the need for an accredited course in autism spectrum conditions (ASCs) specifically for nurses and makes the point that registered nurses are generally poorly served by existing opportunities for in-depth training in the field. In this study many parents expressed the belief that nursing interventions aimed at either themselves or their ASC children would have been better if the nurse had had some knowledge and understanding of ASC issues. This finding was supported by those with ASC who were questioned as part of Barber's dissertation. Those with ASC suggested a need for specific courses for all nurses who come into contact with this group of people.

Barber echoed a number of writers who suggest that those with an ASC are as much prone to physical health problems and illnesses as are the general



population, and in the areas of mental health and learning disabilities, possibly more so. Clarke (1996) suggests that anxiety, depression, bipolar mood disorders, schizophrenia and related forms of psychosis are heightened in those with autism. Midence and O'Neill (1999) highlighted the need for all healthcare professionals, especially doctors, to have a vastly improved awareness and understanding of developmental problems such as autism and Asperger's syndrome. Green-Allison (1999), the founder of the National Autistic Society (NAS), supported by Peeters and Jordon (1999) agreed that a core autism-specific training system is needed.

In order even to get to first base in terms of understanding autism and Asperger's syndrome, rigid, narrow and regimented biological and medical thinking needs to be ditched in favour of holistic and social models. Asperger's and autism are complex conditions and knowledge about them is evolving as people's understanding of their causes and presentation and therapeutic interventions for them changes and improves over time.

Barber (2001) suggested that, since adults and children with ASC require access to a whole range of healthcare services, better educated nurses should lead to enhanced service provision and may also lead to enhanced recruitment and retention of key qualified healthcare professionals. Such recruitment and retention is essential and access can only be achieved if these healthcare professionals are empowered by more knowledge about the health needs of this patient group.

There also appears to be an assumption that Asperger's syndrome and autism are childhood conditions and once people reach adulthood the conditions will either improve drastically or even disappear. Such thinking appears to be reinforced by the vast number of published articles about children with Asperger's and autism but the relatively few about adults. On that assumption, as the parent of a child with Asperger's syndrome, I can, in a year's time when he reaches 18, look forward to my son suddenly 'getting better'. This is highly unlikely – autism and Asperger's is for life; I should know, having recently been diagnosed with high functioning autism/Asperger's syndrome myself.

So, what then is the purpose of this book? The short answer is to raise awareness, understanding and the profile of Asperger's syndrome and autism – and not just among nurses. The questionnaires distributed by Barber (2001) on the autism training and learning needs of registered nurses were also completed by the doctors in a local GP practice. The findings indicated a similar lack of knowledge and need for training among the GPs surveyed. However, since only three GPs completed the questionnaire, it is not possible to generalise the findings, although they do point to the need for cross-professional awareness of ASC.

However, it is not the intention of this book to be merely an academic exercise in raising consciousness and awareness. There are already books and journal articles available on many aspects of Asperger's syndrome and autism, the most important and accessible being Wing (1999), Jackson (2002) and Morgan (1996), others, including Fitzgerald (2004) and Hobson (1993), and, looking at ASC from a parents' perspective, Maurice (1993). It is hoped and intended that the information contained in this book will contribute not only to nurses' understanding but also to their nursing practice when working with and for those with Asperger's syndrome and autism and their families and significant others.

It is also hoped that some nurses, and possibly even some of our medical colleagues, may become sufficiently interested in Asperger's syndrome and autism to study these conditions in greater depth (see the Resources section at the end of the book for information on books and courses available). It is even hoped that some may consider becoming involved in a more overt political arena.

What is meant by this? For far too long mainstream service provision for those with Asperger's syndrome and autism and their families have been hampered by a lack of knowledge, understanding and funding, and this group has lost out as a result. Mainstream service provisions have often lagged behind initiatives proposed and actioned by those with autism and ASCs and their families. The NAS is a case in point. The NAS is a voluntary sector organisation set up by the parent of a person with autism to meet the needs of other such parents and people on the autism spectrum. In an ideal world such a service need should have been recognised and acted upon by care professionals and care agencies such as the NHS long before parents recognised the need, thus pre-empting any call for action by parents, family members and those with autism or ASC. This has arguably not been the case and autism services are not alone. Many other health conditions have been recognised and provided for by voluntary sector organisations before mainstream services recognised them.

In the case of autism this may have been as a result, either directly or indirectly, of 'victim blaming', i.e., the so-called 'refrigerator mother' theory of causation much favoured in the late 1960s (Bettleheim 1967). Indeed, Caiseal Mor, an Australian who has autism, was subject to excruciating physical, sexual, psychological and emotional abuse throughout his early years during the 1960s because it was claimed that autism could be 'cured' through the application of such measures (Mor 2007). Whilst such archaic thinking may have been consigned to the scrap heap of history, discrimination against those with autism and ASC has, unfortunately, not. This discrimination will be further discussed later. It is the duty and responsibility of all health, and, indeed, social care and

education professionals to recognise and challenge the causes and effects of such discrimination on those with ASC. Health and social care staff have a duty to stand with those with autism and ASC even including facilitating them to participate in 'political' activity such as the so-called 'mad pride' events if that is what they want. On a more everyday level, health and social care staff have a duty to ensure that services and information which those with autism and ASC and their families and 'informal carers' need are available and accessible. They should also make sure that the days when those with autism and their families have to fight for appropriate information and services, and for basic respect and dignity are consigned to the past. In order to fulfil this duty, staff have a responsibility to be aware of and understand what autism and ASC are and what they are not. This is the purpose of this book: to help raise and improve such awareness and understanding; to provide nurses, doctors and other health and social care staff with the necessary information to enable them to 'be with' those with autism and their families and, through this, to raise awareness to improve service provision and nurses' interactions with those with ASC.

## **Aims and objectives**

As has already been noted, the intended aim of this book is to improve nurses' professional interactions with those with autism and ASC through improved awareness, knowledge and understanding of:

- What autism and ASCs are and are not.
- Diagnostic issues.
- The history of autism.
- The possible causes of autism and ASCs.
- Issues affecting children, adolescents and adults with autism and ASCs and their families.
- Nursing interventions for children, adolescents, adults, and informal carers.

In order to achieve these aims the reader will be able to:

- Define both autism and Asperger's syndrome and discuss the various definitions available.
- Assess the value and appropriateness of the various diagnostic tools available.
- Place autism and Asperger's syndrome within a historical context.

- Understand and discuss the possible causes of autism and Asperger's syndrome.
- Understand and discuss the effects of autism and Asperger's syndrome from early childhood through to adulthood.
- Understand and discuss the effects of autism and Asperger's syndrome to the wider family.
- Apply the above understanding in the professional work environment.

Whilst the above aims and objectives are not exclusive, the intention is for the reader's awareness and understanding of autism and Asperger's syndrome to be challenged and changed. It is intended that this will lead to an improved way of working with this group of people.

## **Chapter overview**

This book covers all the major stages of the life of a person with autism or an ASC from early childhood diagnosis through to adulthood.

*Chapter 2* investigates what autism, Asperger's syndrome and other forms of ASC actually are and are not. There is a lot of confusion regarding the meanings of the different terms, a confusion not helped by looking at these conditions from a rather reductionist 'medical model'. It could be that an unconscious adherence to such a model led to the phrasing of the question: 'What is this disease called Asperger's syndrome?'. Therefore this chapter focuses on the main signs of autism and Asperger's syndrome and how, through the variety of assessment tools available, these signs lead to a diagnosis.

*Chapter 3* considers the history of autism and Asperger's syndrome within social, medical and religious contexts.

*Chapter 4* focuses on some of the causes of autism, Asperger's syndrome and other ASCs. There has recently been controversial and often heated discussion about the role that the MMR (measles mumps and rubella) vaccine has played, and the relationship between mother and child as a possible cause of autism and Asperger's syndrome. This debate, along with an investigation into genetic and other environmental causes of autism, will be highlighted.

*Chapter 5* focuses on diagnostic issues in both childhood and adulthood. Diagnostic differences between autism and Asperger's syndrome are highlighted as are the differences and appropriateness of the various diagnostic tools applied to children and adults. *Chapter 6* focuses on an adult's journey towards, through and beyond diagnosis.

The next three chapters (*Chapters 7, 8 and 9*) explore the differences in presentation and lived experience of autism and Asperger's syndrome from early childhood through to adulthood. The focus of many books and articles tends to be on young children, with the implication that these are childhood conditions which magically disappear once the person hits adulthood. However, over the past few years there have been an increasing number of publications that deal with the adolescent with autism and Asperger's syndrome in relation to sexuality, relationships and social skills (Jackson 2002, Willey 2003, Wrobal 2003, Harpur et al 2006, Painter 2006, Larkey 2007, Yoshida 2007). There still, however, appears to be little that focuses on adults with these conditions. Morgan (1996) is one of the few exceptions to this. *Chapter 8* also revisits diagnostic issues as applied to adults, and investigates the phenomenon of 'self-diagnosis' of autism and Asperger's syndrome and self-disclosure and the risk of being 'outed', which many people with autism and Asperger's syndrome face. Alongside this, mental health issues and adults with ASC, which, up until now, have been unfairly neglected will be highlighted.

*Chapter 10* focuses on the links between mental health issues and autism and Asperger's syndrome. A recent survey carried out by the National Autistic Society regarding the experiences of adults with ASC and the services available to them (NAS 2008) indicates that one in three also experiences mental health issues, mainly depression, as a result of social isolation. Possible treatments and solutions to mental health problems (Dubin 2009) are highlighted. *Chapter 11* discusses autism and the criminal justice system and the implications of this for those who work within the system.

The next six chapters (*Chapters 12–17*) investigate nursing interventions from a number of perspectives. The first of these is historical and focuses on nursing and, where relevant, medical and social interventions practised in the past (ranging from downright weird through useful to brilliant), the present, and a bit of 'crystal ball' gazing, for the future.

*Chapters 13 and 14* discuss person-centred planning and personalisation as applied to those with autism, and *Chapter 15* focuses on the sensory issues which are believed to influence many if not most aspects of autism.

Nursing interventions for 'independent adults' with ASC form the focus of *Chapter 16*. Whilst many adults with ASC are able to find and keep meaningful and paid employment, live independently on their own, have a meaningful social life, connect with others and even marry and have children, many do not and will need support to achieve 'reasonable' independence. Even those who are able to live independently may need a range of nursing interventions to maintain

that independence. These interventions include the skilful and sensitive use of diagnostic assessments for adults who consider themselves or are considered by others to be on the autistic spectrum, support for those who as yet have not had a formal diagnosis, support for those who wish to disclose their autism status to significant others such as employers and colleagues, and support for adults with ASC when they need to access healthcare services.

The final chapter in this section (*Chapter 17*) focuses on the largely neglected area of the nursing, health and social care needs of informal carers of those who have autism and Asperger's syndrome, be they parents, siblings, partners, children or friends. It is arguably and sadly often forgotten that informal carers will also have needs, needs that often go unmet with sometimes tragic consequences for the family and wider society. The role of the nurse and other healthcare professionals in meeting these needs is highlighted.

*Chapter 18* focuses on the various welfare benefits that are available to those on the autism spectrum and their families.

*Chapters 19 and 20* discuss specific legislation. *Chapter 19* discusses the Autism Act 2009 in terms of what it says, what it doesn't say and its implications for service provision, and *Chapter 20*, whilst not referring to those with ASC, discusses the implications of the Mental Capacity Act 2008.

*Chapter 21* provides a very brief summary and draws together emerging strings of thought such as the use of labelling and language as power constructs which may lead to inadequate and inappropriate services being offered to those with autism or Asperger's syndrome.

A selection of resources including books, journals, multi-media and courses is provided at the end of the book.

## **Conclusion**

I hope that your curiosity and interest in autism, Asperger's syndrome and ASC has been aroused and that, rather than being put off the subject, you are beginning to question the idea of autism and Asperger's syndrome as diseases or are dissuaded from using an illness or disease model of thinking. Autism and Asperger's syndrome are not diseases but rather a different way of life, of thinking, and of receiving and processing sensory information, a different way of viewing, understanding and interacting with the world and other people.

Both anecdotal and research evidence suggests that nurses' knowledge of autism and Asperger's syndrome is not what it perhaps could and possibly should be. The purpose of this book, therefore, as has already been stated, is to help fill this gap in

nurses' knowledge and understanding and through this to change attitudes towards and ways of working with those with autism and Asperger's syndrome. Through this change it is hoped to improve the delivery of health and nursing services and to change negative experiences on the part of both those on the autistic spectrum and those who provide health, medical and nursing services.

### Key points

- The purpose of this book is to raise awareness and understanding of people with an autism condition among nurses and other healthcare professionals.
- This book came about as a response to just such a lack of understanding expressed by a nurse.
- Autism and Asperger's Conditions: A practical guide for nurses covers a wide range of issues relating to the care and support of those with an autism spectrum condition from a variety of perspectives.

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