

Annotated Bibliography
Helping Couples Manage Asperger's Syndrome

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Introduction

As late as the 1990s, Asperger's Syndrome (AS) was considered to be a relatively new field of study. It is named for Hans Asperger, a Viennese paediatrician of the earlier twentieth century, who noted particular similar patterns of behaviour in some of the children who came to his clinic, and recorded his findings (Asperger, 1944). AS is not an illness, but might be better described as a neurological condition in which the brain has been "wired" a little differently to that of someone without AS, who, in turn, is often referred to as a "neurotypical" or NT individual. AS has previously been considered a high functioning form of autism, with the acknowledgement that its presence can vary in both severity and manifestation of symptoms, and some aver that it should be classed in a category all of its own. It was not until 1994 that Asperger's Syndrome (also sometimes referred as Asperger Syndrome) was officially recognized by the American Psychiatric Association (APA), under the umbrella of Pervasive Developmental Disorder (PDD). The most recent release of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), published by the APA in 2013, has acknowledged that AS can be diagnosed as a disorder separate from autism.

Regarding the disorder itself, there are some common elements which can aid in its identification: The most common and severe of all is difficulty in social interactions and relationships, understanding social cues, misunderstanding of even simple communication (such as taking words very literally) and difficulty making friends. In addition to this, people with AS usually have a need to adhere to a strict routine, where unannounced change can cause huge stress and distress to the individual concerned. They often also have an extreme sensitivity to certain sounds, light, textures, smells and tastes. At the same time, they may be particularly gifted in a certain area, and often have a liking for collecting certain things to the point of appearing obsessive. They may have a habit of "tuning out" into a mental fantasy world to escape the reality of a situation they find difficult to cope with at a given moment.

Depending on the severity of the condition, some people with AS may learn to cope and adjust to their social world without ever being diagnosed, while others can be taught to manage. In either case, the presence of AS can cause great strain in marital and other adult relationships, particularly if the condition is undiagnosed, or if one partner doesn't have AS or is unfamiliar with it. Because the thinking processes can be quite different in the minds of a couple impacted by AS, conflict can become a major issue.

There is a wide range of resources in which children with AS are the focus of AS literature and research, but much less that is relevant to the practical life of adults who are already in a long-term relationship. As Lozzi-Toscano (2004) says, "... all of these studies address the biomedical model of assessment with Asperger's and not the practical, clinical, and familial aspect of the syndrome. Researchers have focused most of their attention in finding out the biological and neurological roots of the syndrome and hardly address the "real-life" experience of living with the disorder." The purpose of this bibliography is to suggest some resources for counsellors and couples being impacted by AS that can provide insight and offer strategies and suggestions through which a couple can learn to cope more effectively with the neurological differences present in their relationship.

Initial searches on both the Massey library search as well as the standard Google site, for "Asperger" AND "adult" AND "relationship" yielded a number of academic articles which were mostly about brain function or were child-related. Adding the word "counselling" and trying a few other combinations yielded some more useful results. Overall, though, by far, the greatest number of relevant results yielded from both online searching and the physical library Dunedin were

autobiographies of people who either have AS or have been impacted by a family member having it. This would indicate that there is still quite a need for academic resources to be published about the topic of long-term relationships and AS. Hopefully some more of these will emerge in the years to come.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

Aston, M. C. (2003). *Aspergers in love : Couple relationships and family affairs*. London: Jessica Kingsley. Retrieved from:
<http://eds.b.ebscohost.com.ezproxy.massey.ac.nz/eds/ebookviewer/ebook/bmxlYmtfXzEwNTOyNl9fQU41?sid=a9c9a1e6-d28a-4394-9102-51b8662d7b99@sessionmgr110&vid=28&format=EB&rid=10>

FORM NO: 1 of 10**Keywords:** Asperger, couples, family, counselling**Relevance rating: 100%****Annotation:**

Maxine Aston is a counsellor qualified in Psychology who specializes in Asperger's Syndrome. She published this book in order to provide a comparison of the differences between someone who has Asperger's Syndrome and their partner who does not, and how those differences can then affect their relationships. Her findings were obtained from researching the relationships of forty-one adults with AS and thirty-five partners of the former. Interviews, questionnaires and case studies were utilized to obtain her information.

Aston covers the usual range of AS symptoms such as routine, social interaction and sensitivity to various senses, but she takes her study further in that she addresses more disturbing topics such as verbal and domestic abuse, and their prevalence in relationships where AS is present. She also includes a chapter about the area of counselling people with AS, acknowledging that many who seek counselling come away dissatisfied with the outcome, mostly due to a lack of awareness and understanding of AS on the part of the counsellor. This reinforces the idea that a counsellor needs to have a good background knowledge of understanding the perspective of someone either with AS or living with someone who has it, to establish an effective therapeutic relationship, as described in Annotation 9.

The book is an extremely relevant source of helpful material for anyone who is in a long-term adult relationship with someone who has AS, or who may find themselves counselling someone in that situation.

While the book contains much very helpful information, it is important to note that many of the difficulties described in the anecdotal examples given may also occur in relationships where AS is not present.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

Aston, M. C. (2003). Asperger syndrome in the counselling room. *Cpj: Counselling & Psychotherapy Journal*, 14(5), 10-12. Retrieved from http://www.maxineaston.co.uk/published/AS_in_the_Counselling_Room.pdf

FORM NO: 2 of 10**Keywords:** Asperger, counselling, counsellor, communicating**Relevance rating: 100%****Annotation:**

In this article, Aston explains how a couple may present when approaching a counsellor for the first time. She points out some typical body language, such as an AS man avoiding eye contact, followed by a typical verbal exchange which exposes the very different viewpoints that each person may have of the relationship. From the beginning of the article she stresses that a relationship between a couple impacted by AS is highly likely to face problems in interaction and understanding, which outsiders may not even be able to see.

Aston goes on to caution counsellors about counselling couples with AS if the counsellor is not familiar or experienced with the condition, and suggests some approaches the counsellor can take initially to move the couple towards a path which will assist them in understanding the situation and eventually being able to make an informed decision about whether they can somehow learn to manage the relationship or whether they decide it is not going to improve. She mentions counselling situations where the non-AS, or NT, person has felt frustrated, disbelieved and targeted due to the counsellor not understanding the dynamics of an AS relationship.

Like many other writers on the subject, Aston emphasizes that a person with AS may be so rigidly set in their thinking, responses and routines, and often quite unaware of the effect their actions (or lack of actions) are having on their partner, that any "change" to bring about improvement may fall largely upon the shoulders of the NT partner, in order to accommodate the condition which the AS person is not capable of changing, since they are "wired" into it.

The article is not long, but it succinctly makes the reader aware of the potential frustration an uninformed counsellor can bring to an already difficult situation along with the potential avenue to be of valuable assistance to such a couple.

Aston has written many other documents about Asperger Syndrome, and this one may be a good starting point for a counsellor who suspects they have encountered a relationship of this nature in their counselling room.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

Attwood, T. (2007). *The complete guide to Asperger's Syndrome*. London, England: Jessica Kingsley Publishers.

FORM NO: 3 of 10**Keywords:**

Asperger, psychology, textbook, expert

Relevance rating: 98%**Annotation:**

Tony Attwood is a highly qualified clinical psychologist who currently operates out of his home in Brisbane, Australia. He has become renowned for his knowledge of Asperger's Syndrome and has written several publications on it, along with contributing forewords to a number of other authors who have written about the subject. *The Complete Guide to Asperger's Syndrome* is a textbook written from a professional standpoint to both professionals and laypeople to assist in their search for answers about AS. It contains information about the terminology used in this and other disorders, which are sometimes mistakenly diagnosed instead of AS, as well as providing a wealth of information about the typical struggles that people with AS, or those living with someone who has AS, go through from childhood to maturity, school years and adulthood.

Chapter 13 of the text particularly focuses on long-term adult relationships. Attwood offers explanations and insights about the kind of people with AS are drawn to, and goes on to describe the typical problems such couples might face. There are suggestions for strategies to help the couple manage the relationship.

While the book in its entirety is a rich resource in terms of providing knowledge of AS, the section on adult long-term relationships is rather brief. This particular section could have been expanded with more typical scenarios described and more strategies offered to couples when facing daily conflicts and differences. Attwood has a web site with other publications included, but many of these relate to children with AS.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

Bradshaw, S. (2013). *Asperger's Syndrome – that explains everything: Strategies for education, life and just about everything else*. London, England: Jessica Kingsley Publishers.

FORM NO: 4 of 10**Keywords:** Asperger, family, relationships, adjustments**Relevance rating: 85%****Annotation:**

Stephen Bradshaw has produced a comprehensive text addressing the topic of Asperger's Syndrome, and it is probably one of the most recent in the field. The book contains subsections of nearly every area relating to life and AS, from childhood through to adulthood, professional explanations of the symptoms of AS, its historical recognition, strategies for education and counselling, and anecdotal inclusion of parental experiences. It also includes an extensive bibliography, a glossary and index, with links to relevant web sites as well.

The book is a little different to others, regarding long-term relationships, in that it focuses more on the perspective of what an AS person may experience when first encountering the area of sexual knowledge and romantic relationships, but this is useful in that he points out the pitfalls such people may fall into, due to their tendency to take information very literally and not understand or be able to "read" the person they are approaching for intimacy or romance. There are some valuable inclusions of experiences had by counsellors when talking to a young person with AS which have resulted in misunderstandings by the client with potentially disturbing results. Bradshaw relates how these counselling "gaffes" honed the skills of the counsellors concerned, by helping them become more careful how they communicated with people with AS.

Because of the wealth of information contained in the book, it could be considered as a useful handbook when used in conjunction with the other resources suggested in this bibliography.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

Edmonds, G. & Beardon, L. (Eds.). (2008). *Asperger Syndrome & social relationships*. London, UK: Jessica Kingsley Publishers.

FORM NO: 5 of 10**Keywords:** Asperger, adults, social, thinking**Relevance rating: 85%****Annotation:**

In this edited book, fourteen individuals, both male and female, who have Asperger's Syndrome share their experience in life particularly with regard to social awareness and relationships. The editors have contributed comments here and there, some on a cautioning note to the reader, reminding the latter that the perspective offered may be quite different to how a person without AS might think about it.

Each contributor approaches the subject of social life from a slightly different perspective, from making friends, to online social environments, to how to be understood by those who don't have AS.

While the book does not specifically address long-term romantic relationships, the contributions are written by adults who describe their thinking processes and expectations from the adult AS point of view, and in some cases they describe how their thought processes impacted romantic endeavours and experiences in their lives.

One of the typical idiosyncrasies often found in people with AS also becomes apparent in the book; for many people with AS, effective and reciprocal verbal communication may be difficult, but the written word appears to come a lot more easily, to the point of pedantic detail, which may become somewhat tedious for the reader!

Because the book presents an example of a group of similarly-wired AS people who think on a slightly different wavelength to those without AS, it may provide insight in understanding how to counsel such a person; the routines, trusts and literal interpretations can explain to an NT person the actions and reactions of someone with AS.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

FAAAS, Inc. (2010). Ongoing Traumatic Relationship Syndrome/Cassandra Phenomenon (OTRS/CP) FAAAS, Inc.: *Families of Adults Affected by Asperger's Syndrome*. Retrieved from <http://faaas.org/otrscp/>

FORM NO: 6 of 10**Keywords:** Asperger, Cassandra, relationships, trauma**Relevance rating: 95%****Annotation:**

More recently, symptoms have been noted in some neurotypical (NT) people (those who do *not* have AS), who have been living long-term with an AS partner, that show evidence of ongoing trauma and suffering on the part of the NT person. FAAAS, Inc. initially attributed the name "Mirror Syndrome" to this condition but later revised it to "Cassandra Syndrome", with it still later being revised to "Cassandra Affective Deprivation Disorder" (CADD). The name was derived from the mythical figure Cassandra, in Greek mythology, who was given the gift of foreseeing the future, but which gift was accompanied by the curse of no one believing her when she told them what was going to happen – even though she proved to be correct. The NT partner of the AS person can find themselves in a similar position – trying to explain to others how the AS person is in the home and being met with incredulity on the part of those who do not live with the person.

Because of the nature of AS, and the fact that some AS people can adapt to certain environments, it can be difficult for the NT partner to find someone who will believe them when they explain that there is a darker side to the AS person. When they try to discuss it with others, they may be met with disbelief, contempt, ridicule and can eventually experience ongoing feelings of invalidation, depression, feelings of being abused and isolation. If a counsellor does not know about AS or this aspect of its effect on another person in the home, they can unwittingly be an exacerbator of the NT person becoming more isolated and more traumatised. In this article, FAAAS, Inc. explains the finer points of Cassandra Syndrome, pointing out that it is the result of ongoing, *unrelenting* trauma. The article states that such individuals eventually feel "isolated, no one validates us, we lose friends and family, and we feel like 'hostages' in our own homes" (FAAAS, Inc., 2010).

FAAAS, Inc. strongly recommended that Cassandra Syndrome be incorporated into DSM-5, which was released in 2013 and is currently being refined, but they were met with some resistance and it is unclear at this point in time whether it has actually been included. There do not yet appear to be any peer-reviewed studies on the phenomenon.

However, that does not mean it simply does not exist. So, it may be important that potential counsellors are aware of the possibility that they may encounter a non-AS partner suffering from such a condition in the course of a counselling and be ready to support and assist the non-AS person as well as the AS person.

The webpage actually contains three documents about Cassandra Syndrome, with the first two contributed by FAAAS, Inc. itself and the third being an excerpt from another author who has noted the same condition when counselling. The first one is recommended as a good overview.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

McCabe, P., McCabe, E. & McCabe, J. (2003). *Living and loving with Asperger Syndrome: Family viewpoints*. London, England: Jessica Kingsley Publishers.

FORM NO: 7 of 10**Keywords:** Asperger, family, relationships, adjustments**Relevance rating: 95%****Annotation:**

Living and Loving with Asperger Syndrome: Family Viewpoints is unique in that it has been written by each member of an entire family: the father, Patrick, who has Asperger's Syndrome, Estelle, his wife, and Jared, their son, who was seventeen years old at the time of writing. The entire family has a deep interest in writing, with Patrick having published articles for years as well as a lengthy university level thesis and Estelle worked as an editor part-time from home. Jared, too, has embarked on a career in writing.

The family wrote this book to help other families understand the dynamics of Asperger's families, how it can impact families, and how families can learn to work with it successfully. They describe the struggles and frustrations they went through for years, before Patrick was finally diagnosed with AS. Ironically, it was the son, Jared, who as a teenager, pointed out to his mother that his father did not seem quite "normal". It was this observation that prompted the couple to get answers. Once the diagnosis was obtained, like many other families in similar positions, they learned what they could about the disorder and learned how to understand and accommodate Patrick's processing differences, particularly his rigidity with regard to routine, and the social challenges from both his point of view of needing "space" and his wife's point of view of having to cope with what others considered "rudeness".

The inclusion of Jared's experience as a child of a father with AS adds a valuable dimension to this account. He relates, for example, how difficult it was to explain to his peers that if he was only five minutes late home, it would be enough to cause great anxiety to his father and result in him being grounded, regardless of how reasonable and true his explanation for the minor lateness was.

While this book has not been endorsed by some of the well-known experts in the same way many other autobiographies have been, it provides a rich background of anecdotal experience consistent with many of the common symptoms that people with AS typically have. This being the case, it may prove to be worthwhile as a resource for a potential counsellor to understand how overall family dynamics and child-raising can be affected by AS.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

Morgan, J. A. (2012). Premise: Marriages/relationships between non-Asperger partners and Asperger partners are extremely difficult. *FAAAS, Inc.: Families of Adults Affected by Asperger's Syndrome*. (January, 2012). Retrieved from <http://faaas.org/2012/01/premise-marriagesrelationships-between-non-asperger-partners-and-asperger-partners-are-extremely-difficult/>

FORM NO: 8 of 10**Keywords:** Asperger, relationships, marriage, families**Relevance rating: 100%****Annotation:**

In this online article, Morgan refers to published research that has shown what kinds of skills and strategies contribute to a successful marriage, pointing out that even for a non-AS person marriage can be a challenge, then goes on to explain that when AS is present in either or both partners, the challenge becomes even more difficult. For each skill or aspect of the relationship mentioned, he explains how the same aspect is often perceived and acted on quite differently by a partner who has Asperger's Syndrome. The article highlights the need for each partner to learn how to understand each other's thinking, if possible, in order to put the success principles into practice.

Like other authors, Morgan mentions the paucity of helpful information from the academic community in these matters, when he says, "What is particularly disturbing is that in the 16 or so years that Autism spectrum has been identified there has been very little acknowledgement by the medical and psychiatric/psychological community that those with AS do desire to have relationships and that many of them marry. The difficulties of AS with social interaction compound the difficulties in the relationship; especially when there is a non-AS partner."

The article paints a rather dire picture for marriages where AS is present, emphasising the likelihood that to be successful will take ongoing years of hard work, and in some cases the difficulties may never be overcome. However, it contains an excellent list of principles and suggestions through which some couples and counsellors may have a better understanding of the typical issues faced, and therefore ways in which some of those issues can potentially be addressed.

Morgan refers to actual couples, with anecdotal examples of their experiences in marriage. It is clear that he has developed a good understanding of the nature of AS, particularly in regard to social interaction and empathy difficulties, and the pedantic kinds of conflict many couples find themselves in. The article provides a means of comparison between relationships with and without AS and may be useful for that reason.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

Ramsay, J., Brodtkin, E. S., Cohen, M. R., Listerud, J., Rostain, A. L., & Ekman, E. (2005). 'Better strangers': Using the relationship in psychotherapy for adult patients with Asperger Syndrome. *Psychotherapy: Theory, Research, Practice, Training*, 42(4), 483-493. doi:10.1037/0033-3204.42.4.483. Retrieved from <http://eds.b.ebscohost.com.ezproxy.massey.ac.nz/eds/detail/detail?sid=a9c9a1e6-d28a-4394-9102-51b8662d7b99%40sessionmgr110&vid=12&hid=106&bdata=JnNpdGU9ZWRzLWxpdmUmc2NvcGU9c2l0ZQ%3d%3d#db=pdh&AN=2006-03309-007>

FORM NO: 9 of 10**Keywords:** Asperger, counselling, therapeutic, relationship**Relevance rating: 95%****Annotation:**

One of the terms used in counselling is “therapeutic alliance” or, as in this article, “therapeutic relationship”. This refers to the establishment of a good working relationship, or a bond, between a counsellor and his or her client, where empathy, trust and a sense of well-being occur that promote an effective and rewarding counselling environment where progress can be made in terms of transparency and goals (McLeod, 2013).

The authors of this article explain that therapeutic relationship is of great importance when counselling a person with Asperger's Syndrome, and yet by the very nature of AS, establishing that relationship can be unexpectedly challenging, because the very way in which the AS person may interpret what is said may result in a misunderstanding. So it is important that a counsellor approaches such a session with a clear understanding of how typical AS people function; in other words, the counsellor should already have a good knowledge of Asperger's Syndrome.

Suggestions are made about how to initially approach the person with AS in order to relieve any initial anxiety they may have. They also point out potential pitfalls that may occur in conversation.

While the article is not directly about helping couples manage their issues, it is certainly important in raising a counsellor's awareness of the differences in thought processes they may encounter. This awareness may help a counsellor establish a background understanding of the communication challenges he or she may face when counselling a couple where AS is present. However, the authors also caution that, “We should state at the outset that psychosocial treatment paradigms for adult AS are just now emerging and are based wholly on anecdotal evidence, as there are no extant studies of clinical effectiveness.” This, again, highlights the fact that the area of AS is still a relatively new area of study and plentiful evidence of research-based solutions to the problems faced by those impacted by AS may be yet to come.

ANNOTATION**TOPIC: Helping Couples Manage Asperger's Syndrome****Reference:**

Simone, R. (2010). *Asperger's on the job*. Texas, USA: Future Horizons Inc.

FORM NO: 10 of 10**Keywords:** Asperger, employment, relationships, adult**Relevance rating: 80%****Annotation:**

One might wonder why this particular book has been included in this bibliography. The reason is that in the workplace adults are usually interacting with adults, with social relationships to navigate on a daily basis for several hours at a time, just as they are in the home, if the AS person lives with an adult partner or other adult person. So the same kinds of difficulties may be encountered to some degree in the workplace as they are in the home.

This book pinpoints some of the difficulties employees with AS may experience, and offers insight to both them and their employer in learning to maximize the benefit of the working relationship. In some instances, focusing on the gifts of the person with AS and what they have to offer the workplace could be equally beneficial when applied to a home situation. For example, many AS people just like to get on with things without too much discussion about it. Simone suggests ways the employer can work with this to his or her advantage. In the home, if a non-AS partner recognized the gift and desire of their partner to complete a job to the point of perfectionism, they may be able to then understand their partner's "single-mindedness" and encourage it in a positive direction without feeling ignored, disrespected or frustrated.

The foreword of the book was written by Dr. Temple Grandin, another recognized early authority on the subject of autism and Asperger's Syndrome. Dr. Grandin is currently a Professor at Colorado State University.

Conclusion

Peer-reviewed results of academic research, focussing on what has been shown to help couples manage an adult relationship where AS is present, has proven to be rather scarce at the current time. Many of the authors of the autobiographies referred to mentioned their frustration at the lack of informed, official and useful information available to them as they sought both a diagnosis as well as answers to the problems they were facing in their relationships. There is an increasing number of academic research articles about AS being published, but as mentioned earlier, nearly all of these address the medical side of AS, such as brain activity. In addition, the majority of the research has been carried out in relation to children, with much of that research also pertaining to childhood education.

As parents sought diagnoses and answers to the problems their children were having, many also found there was a dearth of information available, with academic and peer-reviewed literature being almost absent as late as the year 2000. Some parents published autobiographies in order to share their struggles and findings with other families who were also having trouble finding “expert” information. Indeed, one parent writes, “One of the things that irked me was the rush of clinicians who had read a little about the disorder, treated one or two patients, and then hit the lecture tour as ‘experts’. Sometimes, it was obvious that the parents in the room knew more about Asperger Syndrome than the speaker.” (Fling, 2000). Most parents and couples explained that the reason they published their life experiences of living with Asperger’s was to help fill this gap; to make available some practical suggestions for other families, based on their own experiences.

For a potential counsellor to be successful in treating couples who are impacted by AS, or at least, to be somewhat helpful, it is clear that such a counsellor needs to do his or her homework in regard to learning as much as possible about Asperger’s Syndrome, and its related disorders and effects on others. In addition to the annotated items, the reference list below and list of web sites provide other helpful literature which may assist in giving the reader a well-rounded knowledge of the issues couples coping with AS may face. Slowly, more literature is becoming available, some published by world-renowned experts, which may also be of valuable assistance for someone wanting to find out more about AS.

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<http://www.autismspeaks.org/what-autism/asperger-syndrome>

Temple Grandin

<http://www.templegrandin.com/>

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