

Help for NT spouses whose partner has Asperger's/high functioning autism

SALVE for NT Spouses: Support * Assistance * Listening to and believing * Validation * Education



Where do we go for help? Is there any help for spouses of individuals with Asperger's/Autism Disorder?

These questions are asked by neurotypical (NT) ¹ spouses all over the world. Their reported loneliness and despair is the same regardless of nationality, gender, education, social status etc. Traditional counselling has failed due to the unique nature of largely unrecognized, unacknowledged difficulties associated with marriage to someone on the autism spectrum.

Because of the deficits included in AS/ASD/Hfa ² the person with the disability are usually unaware that their behaviors can be detrimental to the loved ones. Nevertheless the NT spouses are burdened as the result of their AS partners autistic behavior, which typically includes: Rages, rigid routines, denial of other people's experienced reality, impaired communication skills, isolation, lacking in social intelligence and tact, mental and emotional abuse, lack of mutual respect and responsibility, depression, etc.

It is particularly distressing for NT spouses that other people don't understand. Adults with AS/Hfa ² are usually good at camouflaging their disability outside the home as a self-protection; their pervasive neurobiological developmental disorder is therefore largely invisible to the outside world. As a result, NT spouses experience being 'trapped' in a harmful state of isolation and constant stress ³.

What is the best help for spouses of a person with AS/high functioning autism?

Aspergerpartner.com asked the founder and Director of the non-profit organization FAAAS, Inc ⁴, Karen E. Rodman. For twenty years, FAAAS Inc. has been supporting and educating spouses and families of adults with Asperger's/ASD ² about this complex neurobiological disorder, and thus has gained a unique expertise about a severe condition which society, including medicine, is still largely ignoring.

FAAAS is considered to have today's greatest insight into everyday abnormal realities for NT spouses and children.

FAAAS: "When you have a wound on your skin, you put on salve as protection or to promote healing. When you suffer from Ongoing Traumatic Relationship Syndrome and Cassandra Phenomenon, OTRS /CP ⁵, caused by the abnormal impacts of a partner's usually unrecognized Autism Spectrum Disorder, you also need 'SALVE'."

SALVE is the term FAAAS' founder coined as the only possible solution for NT spouses who are daily exposed to the mental and emotional impacts caused by their autistic partner's developmental disorder.

She explains:

SALVE for NTs is:

What is OTRS/CP?

Ongoing Traumatic Relationship Syndrome (OTRS) is a trauma-based syndrome, which affects spouses, children and siblings of individuals who have social disorders such as Asperger's Syndrome (AS) and high functioning autism (Hfa). OTRS is not a mental illness. OTRS is a normal stress reaction to ongoing abnormal interactions within an intimate relationship and family life.

Cassandra Phenomenon (CP)

is a metaphor for the emotional and physical suffering to spouses and children of adult individuals with AS and high functioning autism, because spouses and children are typically disbelieved as they attempt to share the cause of their sufferings with others.

Read more here: <http://faas.org/otrscp/>

Support..... for NTs by other NTs. Support can come from people who are familiar with OTRS/CP and others who are NTs themselves.

Assistance.....dealing with AS spouses/children. Assistance can come from neurotypical professionals or by counseling solely for the NT, or from other NTs who know about and ideally have experienced OTRS/CP. In the future, assistance would be in the form of resources for the family and spouses regarding legal, health, counseling needs of the entire family unit.

Listening to and believing.....by the medical, psychological, judicial, religious and political communities. Listening to/believing the NT spouses' experiences behind the four walls of their home.

Validation.....of what the NT spouses and partners have experienced, by sharing similar experiences, problems and impacts with others who have experienced the same.

Education.....about what OTRS/CP and AS/ASD really are and the impact on NTs. Education of NTs, and of health professionals, caregivers, counsellors, judiciary and political community.

FAAAS: "SALVE is simple and obvious. It is clear that each NT spouse will need his or her own type of SALVE. It will vary from person to person, which is why it is so generic. At the moment, SALVE will need to come from other NTs, as there are few professionals who understand AS/ASD and AS behavior, fewer still that will be able to understand and accept OTRS/CP, which is the fallout from AS/ASD behavior and action behind closed doors."

Results

- ✚ SALVE is what happens when another NT spouse is listening to you, believing you, sharing her/his own experience with you.
- ✚ SALVE is what happens when you confidentially share your experience and despair with other NT partners in a support group or conversation forum exclusively for genuine NT partners. SALVE can occur on the phone, through emails, in coffee shops, small groups.
- ✚ SALVE is what happens when another NT spouse is validating you, validating your experience of life with an AS/Hfa partner who by definition has a pervasive empathy disorder, social disorder, communication disorder, relationship disorder, autistic rages, in addition to numerous other severe consequences of his/her invisible neurobiological disorder.

SALVE for NT's can **not** come from someone on the autism spectrum or from organizations controlled by individuals on the autism spectrum. SALVE must come from persons with a normally and mature developed Theory of Mind.

What will be the effect of SALVE?

The practical changes as a result of SALVE will vary from person to person. Being exposed to SALVE over a period of time,

- ✚ the NT spouse can regain a normal perception of reality and may be able to distance herself/himself from the AS/Hfa partner's wounding and stressing behavior.
- ✚ the NT spouse may be able to set boundaries to protect her/his mental, emotional and physical well-being.

- ✦ the NT spouse may gain courage to speak about the partner's autism disorder and disabilities and thus relieve herself/himself from the burden of covering up for the partner's gaffes when out in society.

Most important, the NT spouse may be able to make optimal choices under the given circumstances. Whether it is to leave the marriage/relationship, or disconnect within the framework of the relationship is up to the individual NT spouse. As a result of SALVE the NT spouse may make an informed choice about whether to stay in the relationship.

It is important to emphasize that an NT-AS relationship cannot be 'fixed'. Neither SALVE nor anything else can 'fix' an NT-AS relationship. The autistic partner's disorder is incurable and pervasive. SALVE results in a *relief* for the NT spouse and is therefore also of benefit to the AS partner. Within the relationship the NT spouse and children will still be troubled by the deficits of the AS partner's invisible developmental disorder.

ASD deficits affect all aspects of marriage and life, for the autistic person and for her/his spouse and children. SALVE will help the well-being of the NT, and the children, and of course the autistic partner. Autism communities should be the first to advocate for SALVE for NT spouses, whose well-being is vital for the support and care they provide for their AS loved ones.

Are there alternatives to SALVE?

According to FAAAS, in order to achieve relief for the NT spouse there is currently no alternative to SALVE. Nonetheless, questionable alternatives *are offered* by the counselling industry such as couple therapy, alternative counselling and books with long to-do lists, which impose heavy responsibility for the AS partner's behavior on the NT spouse. However, none of the alternatives work in the long run. No therapy, couple counselling, pill, diet or to-do-list can unwire an autistic brain and thereby delete the autistic impacts in an NT-AS relationship.

For the neurotypical partner there is no alternative to SALVE, which is merely:

Supporting, **A**ssisting, **L**istening, **V**alidating and **E**ducating the family about a neurobiological developmental disorder and its impact upon the family unit.

From NT Spouse's who have received SALVE:

"I was astonished to finally read articles that have accurately described my experience of emotional trauma in my marriage. It has been liberating and a great relief."

"Ongoing Traumatic Relationship Syndrome, that's what I have. It has a name! OMG thank you, I'm not alone! Now I know it's not my fault."

"This makes me feel sane again. My reactive behaviors were really fear, loneliness, unheard, unloved, depressed, emotional torture from the behavior of a spouse with a disorder that no one outside the home could see."

"For so long, I have felt alone and confused, thank god for truthful information."

For me it's about knowing "I'm not mad, it's not me, it's his Asperger's, I didn't cause it, I can't fix it, it's dangerous for me to try and engage with him on anything other than an information passing level, I'm a human being and worthy of respect, my emotional and social needs are the deepest needs of humanity, those which sustain and hold successful caring societies together."

"You saved my sanity".

Lorna Wing, a pioneer in the field of understanding autism spectrum disorder, made it clear: There are basically only two options for the NT spouse of a person with asperger /high functioning autism. Either accept the AS/Hfa partner as he/she is; or terminate the relationship. Consequently, she warned against those,

who would advocate various cures, just as she warned against professionals who believe they can make an autistic person act less autistic.⁶

Similarly **Uta Frith**, another pioneer in the field of autism research, warns against ‘the charlatans’, who claim they can treat autism.⁷

FAAAS agrees on the basis of the organizations long-standing, non-profit work supporting spouses of a person with Asperger’s/high functioning autism:

“Sometimes NT spouses have tried various unhelpful therapies before they contact FAAAS. It is not only about wasted money. Some NT spouses are even worse off after seeing counsellors who are not familiar with OTRS/CP, who offer conventional therapies that are damaging to the NT spouse, even blaming the NT spouse for the autism related problems in the relationship.”

SALVE is now gradually being mentioned by various support group initiatives and organizations around the world. These groups are beginning to see the importance of the support, validation and listening to the NT spouses that FAAAS has been advocating for, for twenty years.

Can a professional counsellor also offer Support, Validation, and SALVE to NT spouses?

Karen E. Rodman, FAAAS: “Yes, provided the counsellor has a deep insight into OTRS/CP, including the long-term effects of living in an intimate relationship with an adult Asperger /high functioning autistic. For the moment only a few professionals understand ASD and AS behavior ‘behind closed doors.’ Until then, **SALVE** will predominantly need to come from other NTs. They are the experts. No one else has greater insight in the tabooed reality of living with an unrecognized Asperger/High functioning autistic than other NTs.”



Notes and references:

- 1) **Neurotypical** or NT means neurologically typical. The term means that the persons referred to do **not** have any developmental disabilities. In contrast to neurotypicals (NTs) are individuals on the autism spectrum, including individuals with Asperger’s syndrome and high functioning autism who per definition do not achieve normal developmental milestones as a consequence of their neurobiological disorder.
- 2) **AS/ASD/Hfa** all refer to **Autism Spectrum Disorder (ASD)**. **AS** usually refers to Asperger’s Syndrome or Asperger’s Autism, which is a part of the autism spectrum. **Hfa** refers to **High Functioning Autism**. **Hfa** and **AS** (aspergers) are typically used for autism with normal IQ. **ASD** is an incurable pervasive neurobiological developmental disorder and listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).
- 3) Research into the well-being of NT spouses: http://www.theneurotypical.com/summary_of_findings.html
- 4) FAAAS, Inc. , Families of Adults Affected by Asperger’s Syndrome, read more: <http://faaas.org/>
- 5) OTRS/CP, Ongoing Traumatic Relationship Syndrome and Cassandra Phenomenon, read more: <http://faaas.org/otrscp/>
- 6) Lorna Wing, The Autistic Spectrum: a Guide for Parents and Professionals, 1996
- 7) Uta Frith, Autism: A Very Short Introduction, 2008

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