

Treatments and therapies for autism

Thinking Autism Guide for Parents

2nd Edition



LOTTERY FUNDED



Introduction

Autism and Autism Spectrum Disorder (ASD) are general terms for a group of developmental disorders that involve impaired communication and interaction with others, repetitive behaviours and restricted interests and activities. Research may soon change this, but for the moment only surface symptoms constitute an autism diagnosis. Those symptoms, their severity, and their underlying causes can differ from individual to individual. While there is no single intervention that works for everyone, just as there is no single cause of autism, treatments and therapies which target specific problems can often help reduce or even eliminate symptoms and difficulties that are associated with autism.

Current and growing research is overturning the assumption that symptoms of autism are inborn and remain static and lifelong. Typically-developing children can lose previously gained skills and milestones of normal development and regress into autism, and some children on the autism spectrum present with decreasing symptoms over time. A substantial minority of ASD children also reach documented 'optimal outcomes' and subsequent loss of diagnosis. Research has shown that even those children who reach 'optimal outcomes' can still struggle with remaining issues such as social anxiety or cognitive impairments, illustrating that the primary goal of professionals and parents should always be to improve health, overall functioning, level of independence and quality of life of the individual, regardless of the label.

Produced in order to provide parents and carers with an overview of some interventions for autism available in the UK, this booklet focuses on therapies and treatments that can be home-based and in which parents can play an active role. The words treatment and therapy have similar meanings. They both imply management and care that can ameliorate debilitating symptoms and improve quality of life. As such, treatment and therapy must be individualised in order to have the best chance of success. An individualised plan means choosing among the best options for every person, targeting their specific symptoms and difficulties. We hope that this booklet offers some understanding of the choices available.

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Behavioural and Developmental Interventions for autism

Behavioural therapies are designed to reduce problem behaviours and teach appropriate behaviours and skills. Developmental and relationship-based interventions, in contrast, are not designed to directly target behaviours but instead aim to improve a child's* ability and interest in social interactions and communication. This is achieved by using the child's own interests and actions as a starting point to building and improving parent-child relationship and teaching skills.

When choosing the right intervention(s) for your own child, start from their unique needs and personalities. Family situation, including availability of help and support from family members, friends and volunteers should also be taken into consideration. It is always recommended that parents research each option in depth (detailed information on some interventions is available on thinkingautism.org.uk), and by talking to professionals and especially to other parents in similar situations. Seeing these various interventions and programmes in action by visiting families already running them, or centres or home providers will also help you make the decision that is best for your child and your family.

** The words child and children are used in this document a great deal; however, our charity knows that people of all ages can learn and develop in all ways. Please know that all treatments and therapies can be helpful to many individuals, regardless of age.*

Applied Behaviour Analysis (ABA)

ABA is a learning programme aimed at improving areas such as speech and language, communication, academic learning, problem behaviours, and general life skills.

A qualified consultant defines areas in which a particular child has deficiencies and develops a plan on how to work on these. **The programme breaks skills into small tasks, which are taught through repetition by therapists working with the child on a one to one basis.** When the child does the task successfully, s/he is rewarded.

A variety of play-based activities can make an ABA session fun for children. Undesirable or harmful behaviours, like aggression or self-harm, are discouraged or ignored. As the child learns the skill and it becomes automatic, tangible rewards are faded away and replaced by social reinforcements, like praise. Data is taken throughout the session for all tasks, so that progress can be tracked and modifications made. The programme can run in tandem with targets set by other professionals, such as occupational or speech and language therapists

Traditional Lovaas approach, Verbal Behaviour and Pivotal Response Therapy are types of ABA. A successful programme is likely to use



a combination of aims and methods from all types, depending on the needs and character of the child.

A traditional ABA approach recommends 20-40 hours per week of therapy, as well as therapist workshops and meetings with consultants. This can be time consuming and expensive, however, even a smaller number of hours per week can often result in improved skills and behaviours.

A consultant should hold a BCBA qualification awarded by the US-based Behavior Analyst Certification Board. The UK Society for Behaviour Analysis is the UK regulatory industry body uk-sba.org.

Several local authorities in the UK will now fund ABA. There are also some special schools that offer ABA as part of the curriculum. Most of them take pupils placed by local authorities, and some have a limited number of fee-paying places.

● **More information, including the evidence base for ABA, can be found in Thinking Autism ABA info-sheet in resources section of the website thinkingautism.org.uk**

DIR®/Floortime™

DIR/Floortime was created by Dr Stanley Greenspan and Dr Serena Weider. Parents and caregivers are coached to provide the intervention from a DIR practitioner. The DIR practitioner meets with the family once a month, or more frequently if preferred.

DIR stands for Developmental, Individual Differences, Relationship-Based:

Developmental: Parents are coached in understanding their child's level of self-regulation and emotional functioning, and how to support them to develop the next capacity. These nine developmental capacities are important for healthy emotional, social and intellectual growth:

1. To be calm and interested in their surroundings;
2. To engage emotionally with others;
3. To initiate and respond in two-way purposeful communication;
4. To communicate in a complex way;
5. To think imaginatively;
6. To think logically and develop 'theory of mind';
7. To see the many reasons for things;
8. To be able to think in shades of grey;
9. To be able to self-reflect.

Individual Differences: In autism, sensory, motor, psychological and biomedical differences are the norm. These profoundly affect each individual's experience within their bodies and in their world. The parent and the DIR practitioner work together with the broader network of professionals to remove challenges, foster development and support the child/adult with autism in reaching their potential.

Relationship-Based: The emotionally charged,

loving interactions between the child/adult and their caregivers are at the core of the model.

Floortime play integrates the D, I and R, so that the child/adult with autism can evolve towards independent thinking, sustaining warm, loving relationships and having fun!

● **Further information can be found on icdl.com or stanleygreenspan.com**

Intensive Interaction

Intensive Interaction is a naturalistic, nurturing, learner-centred, play-based therapy that aims to increase learning and development more typically via quality relationships and play.

It focuses on addressing some of the key difficulties and impairments present in autism by working on and developing social interaction, relationships, flexibility, and reducing stress and anxiety. I.I. supports the child/adult via ever more meaningful interactions, "conversations", games and relationships. It does this in a respectful, joyous, dynamic and playful way, continuously adapting to the individual learner and his/her interests. I.I. sessions are meant to be highly enjoyable for both parties involved!

I.I. is highly individualised and involves sensitively tuning in to learners to ensure that the parent/therapist works at their level. Mainly taking the lead from the learner means that the activity, "conversation" or game is highly motivating, the pace and tempo are just right since they are learner-led, and the content is

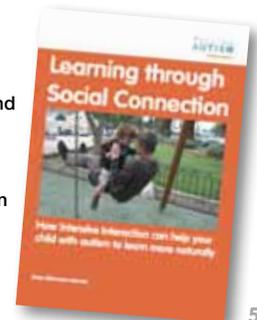
understandable as, again, it is chosen by the person with autism.

All human beings require a sufficient quantity and quality of social interactions. Sadly this is sometimes difficult for individuals on the autistic spectrum. I.I. is a way of socially including a person with autism whilst simultaneously teaching him/her how to be more social and making these social interactions increasingly easier to access. It is based on research on how these communication skills are developed naturally.

By making social interaction easier, I.I. makes subsequent learning easier as the child/adult learns to relax, trust and truly enjoy the company of others; to increase their ability to read and use body language, facial expressions, eye contacts, and intonation; and to become more flexible and to explore and trust the world around them.

To access I.I. there is a Facebook group for parents, one-day as well as advanced courses run at various locations around the UK, and various books and DVDs. I.I. consultants can be called to your home to work with you and your child with autism and many schools and professionals around the UK and in other countries offer Intensive Interaction.

● **More information, including the evidence base for I.I., can be found in the Thinking Autism guidebook, available in the resources section on thinkingautism.org.uk**





Relationship Developmental Intervention®

RDI aims to empower parents by helping them to better understand how autism impacts their child and how they can 'guide' their child to overcome obstacles associated with autism. RDI is based on research both in general child development and autism, and works on building the child's capabilities in social interaction, overcoming 'black and white' rigid thinking and gaining own emotional recognition and self-control.

Parents work with a RDI Certified Consultant to help their child master the developmental milestones autism has restricted, such as

seeking parent guidance; flexible thinking; social referencing; developing memory abilities that enhance learning individually and collaboratively; making decisions, problem solving in the moment and through reflection; and developing and maintaining friendships and relationships.

A RDI programme focuses on quality carer / child interactions that are tailored to the child's unique development with the aim of moving the child forward developmentally, socially and emotionally. The carer uses everyday activities such as housework or play to target RDI goals. Filmed interactions allow the consultant to provide feedback to the family. Families use the RDI Platform, which is a secure database, to share these filmed interactions privately with their consultant and to access other important components of the programme. Eventually, the consultant wants to teach and hand over the 'RDI guiding principles' to the family and fade the role of the professional service. RDI Consultants train through RDIConnect and recertify yearly.

- For further information rdiconnect.com.
Information on Education, Health and Care (personal care plan) funding: brightfuturesschool.co.uk/resources/



The Son-Rise Program® (SRP)

SRP began in the 1970's in America when one family, seeking help for their son, created a child-centred social therapy programme, now known as Son-Rise.

SRP focuses primarily on social interaction through play. The activities of play are child-led in the early development phases. As the connections between child and therapist develop, SRP becomes a more adult directed programme where play is more structured to help the child to learn.

SRP focuses on four key areas of social development: Eye Contact and Non-Verbal Communication, Communication, Interactive Attention Span, Flexibility. Progress is plotted on the SRP Developmental Model.

SRP is home-based, with a dedicated, distraction-free playroom, possibly a bedroom, which helps to create a favourable learning environment for the child. Interaction is on a one-to-one basis, with the adult using the three 'E's' (energy, enthusiasm, excitement) to engage the child.

Parents are usually the leaders of their own programmes. They receive their training through UK-based SRP training events, or by attending the Autism Treatment Center of America. A UK-based SRP teacher can also be

sourced who will demonstrate techniques and provide training and feedback. There are also independent practitioners who have previously been part of SRP that can provide similar services.

The size and scale of each programme can be adapted to meet the child's and family's needs. Programmes can be full or part time. SRP requires a team of therapists. The team can include family members but many teams use volunteers sourced locally from universities and colleges. The most expensive resource is time. Some programmes can run for over five years. Financial contributions can sometimes be obtained from Local Authorities to help fund programmes.

- More information and useful links:
Son-Rise Programme: autismtreatmentcenter.org;
Play Therapy Based Programmes: autismseminars.org, autismathome.co.uk.





Sensory and Motor/Physical Interventions for autism

Motor and physical interventions are therapies which make use of, or which aim to improve, motor functioning—control, coordination and movement of the body. Sensory interventions are treatments and therapies that make use of, or aim to improve functioning and balance of one or more of the senses.

Most children and adults with autism have movement and coordination difficulties and/or sensory processing problems. Frequently, the severity of the motor-sensory complications directly relates to the severity of autism. In addition vestibular (balance) and proprioception (sense of position of own body and movement) problems are often present.

Addressing these dysfunctions can help in a variety of ways, from improving gross and fine motor skills to tackling sensory sensitivities thus reducing discomfort, stress and anxiety. As the person is less overwhelmed, awareness, focus, executive functioning and social skills can improve.

Sensory and motor interventions can be delivered by health care

professionals (such as occupational therapists, behavioural optometrists, or physiotherapists), parents and carers, and by people on the spectrum themselves. We have provided a non-exhaustive list of therapies and activities that are available in the UK, several of which are covered in greater detail.

Combined-Multi Component Therapies

There are a number of interventions that use a wide range of motor and sensory techniques, including:

- Occupational Therapy
- Sensory Integrative Therapy
- Retained Reflexes Therapy
- The Low Arousal Approach
- Equipment-specific approaches such as Therapy Ball Chairs
- Multi-Sensory Environments such as Snoezelen
- Restricted Environmental Stimulation Therapy

Physical Activities There are many interventions based around physical activities undertaken by the person on the autism spectrum, including:

- Martial arts-based activities such as tai chi, taekwondo or karate
- Mind-body interventions such as yoga, meditation

- and slow breathing
- Sports-based activities such as running, jogging, rebound therapy (trampolining)
- Creative therapies such as dance movement therapy
- Other interventions in which physical exercises/movement activities are a significant component such as Brain Gym® and The Movement Program.

Many of these techniques have been reported by parents to bring numerous benefits. Some, like karate or meditation, have also had these positive effects confirmed by scientific studies.

Touch There are some interventions which use touch or which are designed to reduce tactile defensiveness, including:

- Brushing technique
- Hug Machine
- Weighted Items such as weighted vests and weighted blankets

Hearing and Listening Music therapies and programs such as Orff Approach have been shown to improve social and communication skills in autism. In addition to interactive music therapies, some listening interventions use listening to sounds through headphones, and are designed to improve auditory processing, sound sensitivities and other sensory issues. Some of those include The Listening Program®, Auditory Integration Training®, Johansen®, and Tomatis®

Smell and Taste There are some interventions which use smell and taste or which are designed to help with smell and taste problems such as Aromatherapy.

Sight There are a range of interventions which use sight or which are designed to improve visual processing and/or light sensitivity, including:

- Lenses such as Ambient Prism Lenses
- Lights such as Lightwave Stimulation
- Overlays such as Coloured Overlays
- Vision Therapy

Manipulation interventions include a range of treatments and therapies in which someone other than the patient manipulates or moves his or her body. In many cases, manipulative interventions focus primarily on the structures and systems of the body, including the bones and joints, soft tissues, and circulatory and lymphatic systems. Specific manipulative and body-based practices include:

- Acupuncture
- Chiropractic
- Massage such as Tui Na and Qigong massage for autism
- Osteopathy, including Visceral Osteopathy
- Patterning therapies
- HANDLE®
- The Scotson Technique®

Various acupuncture techniques developed specifically for autism have been shown in studies to be effective at reducing disabling symptoms associated with autism and improving executive functioning. Unfortunately those therapies and skilled practitioners are currently not widely available outside of China. However a simpler technique of Qigong massage, which is loosely based on acupuncture and Chinese medical practice, has been developed in recent years and has been shown to help reduce many problem behaviours and symptoms in a large number of children.



Some of the more widely used and better-understood therapies are discussed in more detail below.

Sensory Massage Therapies for autism

Qigong Sensory Treatment (QST) massage for autism is a massage treatment that works by decreasing tactile (touch) and other sensory abnormalities present in almost all children and adults with autism. The QST protocol is a 15-20 minute whole-body massage that is administered by parents at home on a daily basis.

Studies have shown overall reduction in severity of autism-related symptoms after several months of regular QST, including improvements in behaviors, communication, and sensory symptoms. In addition, lots of parents report improved child-to-parent interactions, bonding, and decreased parenting stress.

Qigong massage is suitable for all ages, and although the results are more rapidly achieved in younger children, others can also greatly benefit. Success is influenced by how well parents can learn the technique, adapt it to their individual child, and engage in the massage daily.

“Child-to-parent bonding improved, and the experience of touch and relationship normalized for parent and child. Children were better able to make eye contact, focus, and listen, and parenting stress decreased. **This program can be recommended to parents and early intervention programs at the time of autism diagnosis.** It can be expected to improve educational outcomes for children and reduce stress in the preschool classroom environment.”

[PMID: 25878901]

Parents reported that the massage helped to build a stronger bond and improved the experience of touch and relationship. Children sought out touch and affection from their parents, and parents felt closer and more connected [PMID: 25878901]

● qsti.org includes detailed information on QST, including information to help parents decide if this therapy would be suitable.

Tui Na Massage, which is based on similar principles as QST, also works by reducing touch and other sensory sensitivities in autism. Tui Na, sometimes called ‘Chinese massage’, is a division of traditional Chinese medicine. In

“Massage is our special time with S. We try to talk, we laugh and sometimes struggle but we are very intensely together. I see direct benefits: his sleep improved almost immediately, he communicates better and I am getting reports of improved attention from the school.”

addition to being used to address physical problems and injuries, it is also used widely in China to address chronic problems such as headaches, constipation, irritable bowel and sleep problems, all common in autism.

It is thought that this massage, and touch-therapies in general, reduce stress and balance the autonomic nervous system by reducing anxiety, aggressiveness and irritability (‘fight or flight’ sympathetic responses) and increasing relaxation (‘rest and digest’ parasympathetic responses). Many parents who have implemented regular massage report improvements in sleep, social skills, stress levels, outbursts, speech, repetitive behaviour, sensory and digestive problems. In addition, practising the massage daily can further strengthen the family bond, and so reduce parental stress.

● tuinacentre.co.uk has information on UK training courses for parents.

Visceral Osteopathy

Visceral osteopathy is an osteopathic treatment that focuses on mobilising and improving the function of the gut. This is done in a way that is similar to a simple abdominal massage, but is more specifically applied.

Some of the potential benefits of visceral

osteopathic massage are relieving constipation and improving the frequency of bowel movement. The use of visceral osteopathy has been reported to have a positive effect in many patients suffering from Irritable Bowel Syndrome. Recent studies have suggested that mobilisation of the gut through such manual manipulation techniques may enhance the flow of the lymphatic system, thus improving the overall functioning of the immune system.

The first study on the use of visceral osteopathy in children and adolescents with autism has reported some promising positive results, such as improvements in gut function and overall behaviours, concluding that this treatment may be of benefit to children with autism and GI disturbance.

● ibccare.co.uk for further information

The Scotson Technique® (TST)

TST® was developed by Linda Scotson, based on her research into respiratory systems of children with disabilities that showed that many neurological problems led to deep respiratory problems and that breathing influenced cerebral blood circulation, body structure, posture, speech production, sleep and general health. Children with autism, cerebral palsy and brain injury often have immature and abnormal breathing patterns, which impede the delivery





of oxygen to tissues, including the brain and gut and contributing to abnormal sensory, motor and metabolic function.

The treatment is administered by applying gentle pressure on the child or adult's chest and abdomen, which attempts to mimic the pressures of breathing on the body's internal tissues.

The Advance Centre in West Sussex provides training sessions in TST®. Once trained, parents carry out the daily therapy at home. The exercises are very gentle and can be done when the child/adult is asleep or watching their favourite programme

● treatbreathinginautism.com for further information

The Movement Program (TMP)

TMP is a physical activity program that aims to develop a wide range of fundamental sensory abilities and lead to improved reading, balance and coordination. It is designed for children from around 7 years upwards.

TMP is specifically designed to be easily accessed at home without the need for specialist input from an Occupational Therapist or other movement and sensory specialist.

It is delivered direct to a web-connected device via individual log in details, and followed for 12 weeks, 5 days a week, for around 15 minutes each day.

● movementprogram.com for more information (10% discount with 'learningsolutions' code)

Hearing and Listening programs

The Listening Program (TLP)

People with autism experience sound sensitivities, visual, vestibular and other sensory issues which can affect their ability to communicate and process sensory information in an organised way. In order to listen and function well in daily life we need to be able to process sound as it changes in pitch, volume, spatial location and across time.

TLP is designed to retrain the brain and ear to process sound more effectively. This is seen to reduce sound sensitivities, improve listening and communication and make it easier for the autistic person to function in daily life.

Adding in the use of bone conduction to TLP can improve vestibular function, proprioception and visual skills. This can have a wide range of benefits including reducing the 'stimming' behaviours such as flapping, jumping and spinning that are often seen in autism. (*see published research)

TLP is a technologically advanced listening therapy with specifically designed high definition recordings and music. It is available through iPod Touch or via the TLP Online platform for ease of use.

● learning-solutions.co.uk for further information on TLP and UK providers

● advancedbrain.com/the-listening-program-research/ for research studies.



Sensory and Motor/Physical Interventions

Auditory Integration Training (AIT)

Auditory Integration Training, sometimes called Sound Therapy, aims to improve abnormal sound sensitivity and behaviours that might result from it. It involves listening to electronically modified music through headphones, which provides stimulation to the hearing mechanism. This in turn can improve attention and understanding, and help one be more 'in tune' with the environment.

Some behaviours indicative of abnormal processing and distortion of sound and/or extreme hearing sensitivity are covering of ears, running from, or crying in response to loud sounds; being easily distracted by random

noises; difficulty following verbal instructions or commands; struggling with language delay or disorder.

Some of the reported changes following AIT have included improvements in the child's or adult's disability: reduction of sound sensitivity, being better able to cope with background noise, improved focus and understanding, improved speech/clarity of speech, increased awareness and interest in conversation.

● thesoundlearningcentre.co.uk for further information

● autism.com/understanding_ait_summary for research studies



Nutritional and Biological Therapeutic Approaches

Children and adults with autism suffer from health problems much more commonly than their peers. These health problems include **seizures**, headaches, **gastrointestinal problems**, various **nutritional deficiencies**, **metabolic conditions**, compromised immune system **including allergies** and autoimmune disorders and many more (for references see our scientific review *Medical*

Comorbidities in Autism Spectrum Disorder). It is also a sad fact that mortality is significantly increased in autism, with much higher death rates than in the general population.

Symptoms of health problems in autism are not always visible on the surface or easy to detect, but they may influence the child's

"Problem behavior in patients with autism may be the primary or sole symptom of the underlying medical condition, including some gastrointestinal disorders" [PMID 20048083]



In a survey of 220 people conducted by our charity, more than **95%** of respondents who had used treatments for autism found those treatments to be **beneficial** and **24%** found those benefits to be **life-changing**.

In regard to specific problem areas,

57% saw improvements in sociability,

53% in sleep problems,

50% in anxiety,

50% in aggression,

66% in eye contact,

48% in receptive language,

47% in expressive language,

23% in self-injurious behaviour, and

73% in bowel problems.



behaviour, worsen severity of their autism-related symptoms, and undermine their quality of life. On the other hand, diagnosis and treatment of these medical conditions can often lead to **an improvement in many symptoms, including irritability, aggression, anxiety, self-injurious, self-stimulatory and repetitive and obsessive behaviours**. Improvements in the core symptoms of autism, speech and communication, sociability and imagination have also been reported.

It is crucial never to dismiss concerns regarding self-harming, aggression, night-waking, change in appetite, severe anxiety, tics, and many more as 'just autism'. None of these behaviours are part of the autism diagnosis, and there is much evidence to show that challenging behaviour is often the

result of a physical cause, for example reflux pain or seizures.

Autism is not a single condition but includes many diverse groups of individuals who are affected by autism for different underlying biological reasons and suffer from different comorbid health problems. It is therefore not surprising that **no single health concern will impact every individual with autism, nor is any single treatment approach appropriate for all**. While, for example, dietary intervention in particular is reported to be beneficial in a large number of cases, there is no 'one size fits all' diet. Similarly, treatment with nutritional supplements that address metabolic problems are shown to have life-changing effects in some children and adults with autism, but have no effect

at all in others.

Further information on published studies can be found in our publication **Medical Comorbidities in Autism Spectrum Disorder** and data based on parental reports can be found in our recent survey (available on request).



Gastrointestinal problems are common in autism. They include: reflux, chronic constipation or diarrhoea, colic, digestive enzyme deficiency, low absorption of nutrients, bacterial dysbiosis (presence of harmful bacterial in the gut), food allergies and sensitivities and many others.

These problems often stay hidden and go untreated because they are not visible on the surface, but instead present in unusual ways and through problem behaviours. This is especially true for younger children and those who are not able to communicate effectively. Negative behaviours that are often dismissed as 'just part of autism' but can in fact be signs that the person is suffering health

problems include: irritability, aggression, destructive behaviours, hyperactivity, sleep problems, anxiety, obsessive and rigid behaviours, strange posturing (for example bending over furniture) or movements, bloating, screaming, chest banging, biting and other types of self harm. Recent research has also confirmed that, contrary to commonly-held beliefs, the presence of gut problems in children with autism is in most cases not due to picky eating or receiving medication.

Several very promising treatments are being studied at the moment following many positive reports by parents and doctors. Some of those approaches include daily supplementation with digestive enzymes and probiotics, or special diets that restrict sugar and complex carbohydrates. A diet that excludes gluten (protein found in wheat and some other grains) and casein (protein found in milk) has gained wide popularity amongst parents and clinicians in recent years. The positive effects of this diet in a number of children and adults are likely linked to the recent discovery that some individuals with autism are sensitive to common food proteins such as those found in wheat and milk.

Ketogenic diet was designed almost a hundred years ago by a Mayo Clinic doctor in order to

"Although treatment strategies for children with autism spectrum disorders are under development, the ketogenic diet is available now and could offer multiple benefits. For example, children with autism and uncontrolled seizures have few options, and this research suggests a ketogenic diet could reduce seizures and improve behavior." Susan Masino, PhD, Trinity College, Hartford, Conn. 2013.



When you get your child's diagnosis you can be told that there is no future to look forward to for them. Everything appears bleak. **Thinking Autism** completely turns that on its head. It has **changed not only my son's life but our whole family's life.**

(Feedback from a parent)

control epilepsy in patients, and has gained renewed interest and wide application in recent years. The diet is high in fat, adequate in protein and very low in carbohydrates. This combination changes the body's metabolism and forces it to burn fats rather than carbohydrates for energy. Other known effects of this diet are lowered levels of glucose and improved insulin resistance, reduced levels of inflammation as well as raised levels of ketone bodies in the blood.

All of those effects of ketogenic diet, or some that are still unknown, could be behind improvements in autism symptoms that have been reported by researchers and doctors. For example epilepsy is very common in autism, and latest research has demonstrated that successful treatment of both seizures as well as subclinical epileptiform activity, which is found in the overwhelming majority of individuals with autism even in the absence of convulsive seizures, can often lead to improvements in behaviours and functioning in affected individuals.

There are several variations of this diet, such as the modified Atkins diet, medium-

chain triglyceride diet and low glycemic index treatment. All of them require medical guidance and supervision.

• charlifoundation.org for more information

Some more recent medical approaches aim to improve the natural function of the gut and reduce reflux and inflammation through specific supplementation protocols, rather than to focus on excluding specific food groups. One such approach is the Nemechek protocol, which aims to reverse and control small-intestine bacterial overgrowth, often referred to as SIBO. There is evidence that SIBO is present in a large number of children and adults autism, even in those who do not show any external or obvious gut problems.*(see page 21)

Many individuals with autism have low levels of certain vitamins and minerals, including zinc, magnesium, iron, vitamins B-6 and B-12, vitamins D and E, and folate. Supplementing some of those nutrients can not only normalise their levels but can address some of the underlying biomedical problems frequently found in autism, such as immune abnormalities or metabolic problems. There are clinical reports of supplementation improving autism-related symptoms and behaviours.



It is important to remember that not all individuals with autism suffer gastrointestinal or nutritional deficiency problems, so dietary and other interventions will not be appropriate for all. It is important to always seek advice and recommendations of a qualified practitioner before undertaking any dietary or other intervention.

Allergies and food sensitivities are present in many children and adults with autism, who also often suffer intolerances to various things in their environment. Sometimes their immune system does not work well in comparison with non-ASD people. Those problems are occasionally visible on the surface, as in the case of eczema, asthma, allergic rhinitis (runny or stuffed sinuses, red eyes), or frequent ear infections. On the other hand, these problems can sometimes be hidden, with the only visible signs being worsening of problem symptoms and behaviours—for example, sleep problems, irritability and tantrums, hyperactivity, lack of focus, daytime fatigue, anxiety, obsessiveness—that are often wrongly attributed to 'being autistic'.

Treating allergies and avoiding foods and things in the environment that a person with autism is sensitive to can often result in improvement in negative and challenging behaviours and better

overall functioning. Many parents have reported improvements in their child's behaviour and functioning at school and at home when offending foods are avoided, as for example in the case of foods containing gluten (see previous section).

Problems in the function of the immune system and chronic inflammation have also been found in a subgroup of people with autism, and it is believed that some of the treatment agents that are reported to help reduce autism-related symptoms work by lowering the inflammation and by helping the body defend itself from harm. Sometimes simply correcting nutritional deficiencies, such as the mineral zinc or vitamin D (see previous section), can improve function of the immune system.

It is difficult, however, to know by looking at people if their immune system is balanced and if they suffer allergies. When these issues are suspected it is important to speak with a doctor and specialists to determine what tests should be carried out and whether to address problems with medicines such as antihistamines. In contrast to true allergies, which can be detected through medical tests, some milder sensitivities and intolerances—for example to foods, chemicals, pesticides, perfumes and even scents and detergents—can often only be detected by removing the suspected item from the child's environment or diet and reintroducing it later to observe if there is any worsening of symptoms or behaviours.

"Care providers should be aware of the potential impact of allergic diseases on behavioral symptoms in ASD children."

Dr Jyonouchi, New Jersey Medical School



“Dear Thinking Autism, Just to let you know that information you provided had a **positive outcome**... The introduction of these interventions by our doctor meant that in **just five days our child showed a marked improvement** in behavioural responses, a reduction in OCD rituals and rigidity, reduction in oral defensiveness enabling new foods to be introduced on their first attempt... These interventions have given the **whole family a better quality of life** and more social opportunities to help develop our child, giving them the opportunity to **just be a child like any other!**

(Feedback from a parent)

Abnormal response to stress is very common in children and adults with autism. Their bodies overreact to what other people would not perceive as a fearful or threatening situation, and also take much longer to calm down afterwards. Their hormones and other body systems are often found to be in a state of permanent ‘fight or flight’ response (called autonomic sympathetic activity), with the absence of the much-needed ‘rest and digest’ state (parasympathetic activity).

Aggression, impulsiveness, anxiety and fearfulness, sleep problems, and difficulties in coping with new situations are some of the main signs of dysfunctional autonomic stress response. Medications like low-dose propranolol (which regulates the production of stress hormone adrenalin in the body), calming environments (removing emotional and physical triggers), sports such as karate, mild exercises such as qigong and yoga, and meditation are often reported to have positive effects and help reduce these disabling symptoms. Touch-therapies such as massage for autism (see previous section) also bring positive

effects through calming and lowering the stress responses.

Aromatherapy has often been reported by parents and professionals to have calming and balancing effects, including reducing anxiety and irritability, improved sleep, and even reduction in frequency of seizures. There are many animal and human clinical studies which show that plant essential oils have a positive impact on the autonomic nervous system and can reduce ‘fight or flight’ stress and anxiety by activating the parasympathetic vagus nerve. In addition some essential oils are known to have antiepileptic and neuroprotective effects. It should be noted that inappropriate use of essential oils can have the opposite effects, and it is therefore always best to seek advice of an experienced professional.

Oxidative stress is an imbalance between antioxidants and pro-oxidants in the body that can be damaging to cells and organs. Children and adults with autism often have increased oxidative stress, which is correlated with severity of their autism symptoms – those who are more severely

affected have more oxidative stress in their bodies.

Several treatment agents that target the problem of oxidative stress have already shown great promise for reducing negative symptoms in autism. For example, the amino acid N-acetylcysteine (NAC), which is safe and available over the counter, has been found to reduce irritability in autism. In another small study, a subset of children who supplemented with vitamin B12 showed improvements in both oxidative stress levels and severity of autism related symptoms.

A powder extract derived from broccoli sprouts, called sulforaphane, is another dietary supplement whose potential for improving both the metabolic dysfunction as well as behavioural symptoms in some cases of autism is under active investigation. Similarly, omega-3 fatty acid supplements also show good promise in helping lower hyperactivity and repetitive behaviours, and improving socialisation. Fatty acids are essential for the development and function of the brain. Omega-3 fatty acids and fish oils are popular nutritional supplements and widely considered safe. It is believed that the powerful antioxidant properties of these agents is one of the reasons for their positive effect in some people with autism.

Various other metabolic and mitochondrial problems are frequently present in children and adults with autism, in addition to oxidative stress, showing that they struggle to clear environmental toxins and to produce enough energy to fuel their

bodies and their brains. It is becoming increasingly common to investigate minute variations in DNA called single nucleotide polymorphisms (SNPs) when planning treatment pathways.

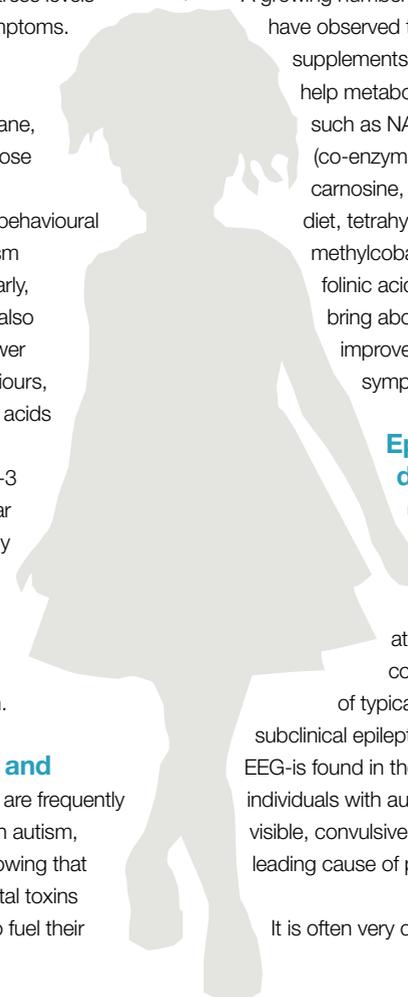
In the majority of investigated cases abnormal metabolism is not linked to genetic causes, and correct identification and treatment of metabolic and mitochondrial issues can bring about improvement in behaviours and functioning.

A growing number of published studies have observed that various nutritional supplements and interventions that help metabolic energy production such as NAC (see above), ubiquinol (co-enzyme Q10), carnitine, carnosine, biotin, thiamine, ketogenic diet, tetrahydrobiopterin (BH4), methylcobalamin (vitamin b12) and folinic acid have the potential to bring about mild or substantial improvements in autism-related symptoms in some individuals.

Epilepsy and seizure disorders are

unfortunately very common in autism – almost one third of children with autism will suffer seizures at some point in their lives, compared to only two percent of typical children. In addition, subclinical epileptiform activity-abnormal EEG-is found in the overwhelming majority of individuals with autism even in the absence of visible, convulsive seizures. Seizures are the leading cause of premature death in autism.

It is often very difficult to know without





Research has shown that people with autism often suffer from various health problems which are not always visible on the surface or easy to detect but which may affect their behaviour, impact severity of autism and undermine their quality of life.

proper testing if a person is suffering from abnormal brain activity; apart from whole-body convulsions, seizures can also manifest simply as a child 'momentarily blanking, or appearing to be daydreaming' or having tics, crying spells, facial grimacing or 'weird' body movements.

There is some evidence that treatments that are generally used for some seizure types, such as ketogenic diet (see previous section) and cannabidiol, also have a potential for reducing autism-related problems and behaviours in some individuals. Autoimmune cause should also be ruled out in some cases, especially in sudden-onset epilepsy and where there is a history of autoimmune disease in child's family.

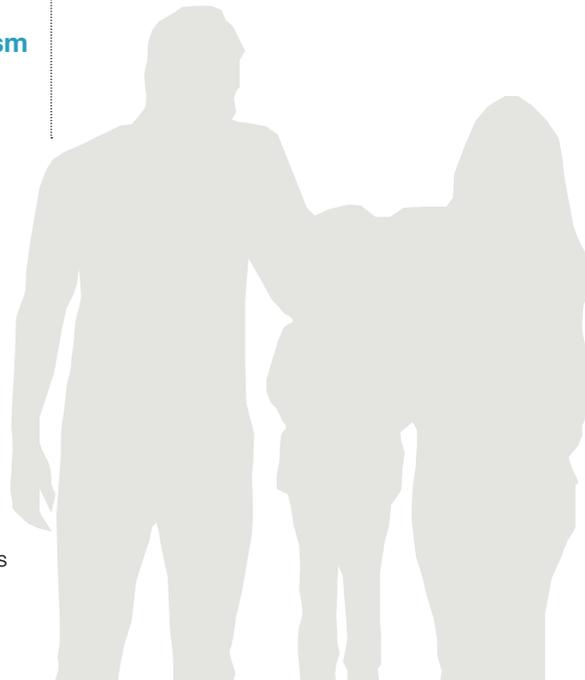
Other promising therapies for autism symptoms and difficulties

are also available and are being intensively studied, like those that address the brain and its workings more directly, such as Transcranial Magnetic Stimulation (TMS), Transcranial Direct Current Stimulation (tDCS) and Neurofeedback. TMS and tDCS have excellent safety profiles and are being used successfully in many parts of the world as treatments for major depression, and recent studies are showing very good results in reducing autism-related symptoms, lowering stress responses, and improving general functioning. Unfortunately, TMS and tDCS are not widely available in the UK at present; NHS hospitals and centres that do have TMS usually restrict its use to treating depression. This

situation may change in the near future, as more studies emerge.

Neurofeedback (sometimes called neurobiofeedback or EEG biofeedback)

is a form of biofeedback, a non-invasive therapeutic approach that is being used to treat a number of psychological conditions, including anxiety, depression, obsessive-compulsive disorder, attention deficit hyperactivity disorder and other conditions which are frequently present in individuals with autism. During sessions brain activity is monitored by recording electrodes placed at designated locations on the head and presented on a screen in front of the user. There is growing evidence that neurofeedback is effective for



controlling epileptic seizures and balancing abnormal brain electrical activity. Abnormal subclinical epileptiform activity has been observed in a large majority of individuals with autism. Several types of neurofeedback are in existence, including some that do not require active participation of the subject and are thus suitable for individuals with autism who are non-compliant or unable to follow instructions.

Several other novel and promising treatment approaches are currently being studied for autism, including:

- **oxytocin nasal spray** tinyurl.com/zefy3yj
- **suramin** tinyurl.com/ydxex9ns
- **fecal transplants** tinyurl.com/ydxex9ns
- **stem cells** tinyurl.com/yrcp9653
- **medicinal cannabis** tinyurl.com/n7afogx
- **high-dose folinic acid** tinyurl.com/zefy3yj
- **bumetanide** tinyurl.com/ydxex9ns
- **everolimus** tinyurl.com/yblv3yso
- **arbaclofen** tinyurl.com/ya9bfugs
- **CM-AT digestive enzyme** tinyurl.com/ycw42asv

***Our publication 'Diagnostic Toolkit for Medical Comorbidities in Autism Spectrum Disorders' outlines signs and symptoms, diagnosis and treatment of various medical conditions, including gastrointestinal issues, which are common in children and adults with autism.**

DISCLAIMER Thinking Autism does not offer medical advice and we do not endorse any practitioners or treatments. It is always important to seek appropriate professional advice before initiating any treatment. Some interventions like diets, probiotics and simple nutritional supplements are inexpensive and easy to implement, but parents should always seek help and guidance from a qualified practitioner. Your medical doctor or nutritionist and other specialists can advise on tests and help guide treatments. (Thinking Autism can provide, on request, a list of qualified UK practitioners as recommended by members, but do not endorse or directly recommend any individual or organisation)

RECOMMENDED READS

- *Navigating the Medical Maze with Autism Spectrum Disorder.* Sue Ming MD and Beth Pletcher MD [ISBN-10: 1849059713]
- *How nutritional status, diet and dietary supplements can affect autism. A review.* Anna Kawicka and Bozena Regulska-Ilow [PMID 23789306]
- *Autism: Effective Biomedical Treatments?* Jon Pangborn PhD and Sidney Baker MD [ISBN-10: 0974036099]
- *Autism: Exploring the Benefits of a Gluten- and Casein-Free Diet: A practical guide for families and professionals.* Paul Whiteley, Mark Earnden and Elouise Robinson [ISBN-10: 0415727634]

The above titles, and many more, can be borrowed through Thinking Autism members' library



Communication Strategies and Teaching Therapies

Difficulties with speech and communication are one of the most disabling features of autism. While some individuals with autism suffer from total lack of speech, others are able to express themselves verbally but have problems understanding finer aspects of communication and social rules and expectations. In all cases these communication problems negatively affect a person's independence and quality of life.

There are many strategies and therapies that can be used to improve the child or adult's ability to communicate. These range from therapies aimed at improving the strength and ability of the muscles needed to produce sounds, to 'social skills' strategies that focus on developing understanding of the ways people behave and teaching appropriate behaviours and ways to react and communicate in social situations.

Speech therapists and/or occupational therapists can recommend oral motor exercises, such as blowing sucking, tongue movements, breath control exercises and others, with the aim of enhancing control of oral movements and encouraging a child to take part in therapy. These are presented as games and can be carried out in a group therapy session, or at home.

Some programmes such as computer-based **Fast ForWord**, or the intensive therapist-led **Lindamood Bell** therapy, focus instead on developing and strengthening cognitive skills and improving vocabulary, reading, comprehension, numeracy, as well as memory, speaking and self

confidence. **GemlIni** is another such programme, providing teaching videos for learning and retaining of language. It offers an online system of recording the child's activities and progress, and creating video lessons to practise in various environments, which can be accessed by therapists, teachers and parents involved with the child.

There is a growing variety of methods that can be used by people with communication problems to assist or replace spoken speech. They come under an umbrella term of **Augmentative and Alternative Communication (AAC)** and range from sign language (**Makaton™**) symbols and pictures, to computer programmes, apps and complex electronic devices. A type of ACC popular for autism is **Picture Exchange Communication System (PECS)**, designed to teach functional communication. A student is taught to exchange a picture of a desired item for the actual object. Once mastered, the student moves on to using symbols, constructed phrases and sentences, making spontaneous requests and comments. Augmentative devices such as the programme Proloquo2Go (used on an iPad or iPod) are now relatively affordable and have proved successful.

Rapid Prompting Method (RPM), is a teaching method developed by Soma Mukhopadhyay while working with her severely autistic non-verbal son, Tito. He is a published author who now types independently.

The starting assumption of RPM is that individuals with autism are cognitively intact – the problem is that their sensory systems (visual, auditory, tactile, kinaesthetic) have developed differently and may also have motor planning challenges. Many RPM students have typed that their body does not co-operate with what their brain is thinking, and verbal students have typed that what they are 'saying' is not what they are thinking.

During RPM sessions, age-appropriate educational information is presented by the parent/teacher to provide intellectual stimulation and develop reasoning skills. The student is taught how to respond by independently pointing –beginning with written choices and then to gradually independently spell out responses on various letterboards. This empowers the student to express their thoughts, opinions, learning and reasoning. In addition to teaching the skill of purposeful pointing RPM principles can be used to teach reading, writing, and life skills.

RPM is a relatively low cost method. There is no need for high-tech equipment and parents/helpers can learn how to use RPM by reading books and joining the parent support forums. There are

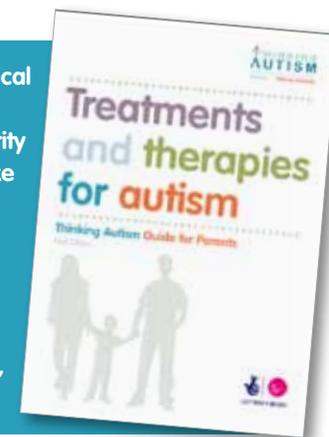
certified RPM practitioners in the USA, UK and Eire. There is also an international parent support facebook group 'Unlocking Voices—Using RPM', offering lots of free learning resources and instructional videos.

• **Further information** halo-soma.org and unlockingvoices.com

Examples of techniques for improving social awareness and communication include **TALKABOUT**, a social communication skills package aimed at improving self-awareness and self-esteem, body language, social and friendship skills. **Social Stories** were developed to help people with autism to understand and behave appropriately in social situations. A social story describes a social situation in a clear and easy to understand way, in order to improve the person's understanding of social expectations, routines, situations, upcoming events or abstract concepts. The understanding of a particular situation helps the person find an appropriate response in a particular social situation. **The Social Thinking Program™** developed by Michele Garcia Winner offers further insight on social problem solving, social emotional interpretation and social skills

Autism is a diagnosis of symptoms. These symptoms and medical comorbidities common to autism are all potentially treatable through a combination of approaches. Thinking Autism, a charity run by parents, arms you with information and support to make positive changes to your child's life.

This booklet discusses only a small number of approaches parents of children with ASD have found helpful. For more information and the latest research in autism treatments, visit our website and social media, read our other free publications, and consider attending one of our events for parents.





Learn about the latest scientific **breakthroughs** in the field of autism



Build your **support** network and become a part of our growing **community**



Join us for parent **groups**, information days, **workshops**, conferences and other **events**



Learn and share **knowledge** & experiences with others on how to best **help** your **child**

Thinking Autism is for

- parents, carers and family members of children and adults with autism
- teachers and teaching assistants
- medical practitioners and nurses
- speech and language and occupational therapists and other specialists
- researchers and students
- adults with autism spectrum disorders
- advocates

At Thinking Autism we

- run local parent groups and workshops
- hold conferences presenting the latest scientific research and treatments
- create and publish booklets and documents, available free of charge
- organise and promote webinars on the latest research and practical approaches to everyday autism-related problems
- participate in and facilitate research projects
- liaise with official bodies and charitable organisations to provide better support for people with autism spectrum disorders and their families.

Thinking Autism is a membership society, although non-members can access many of our services for free. Our members benefit from special offers and discounts and are regularly kept in touch with the very latest discoveries in the treatment of autism.



Website: www.thinkingautism.org.uk
Email: mail@thinkingautism.org.uk

Thinking Autism is a registered charity run by parents and carers of children with autism. The information in this guide is for general purposes only and should not be construed as medical advice. Thinking Autism does not take any responsibility or liability for any decision taken as a result of the information contained herein or the external links provided. If you need medical advice, please seek it from a suitably qualified practitioner.

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