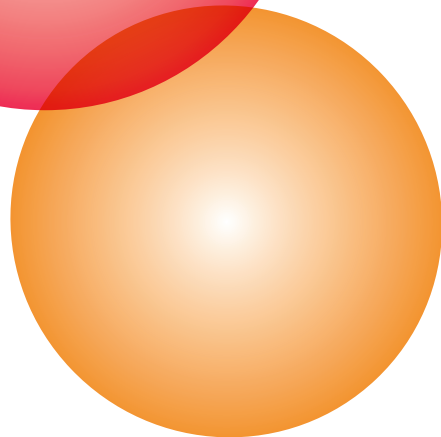
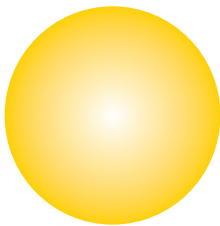


Parent to Parent





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Comment by Parent Team

In working to compile this section of your Rainbow Resource Kit we had many lively discussions about 'tricks of the trade', that have worked well with our individual children. However, the most consistent point that arose time and again is that **there is no one strategy that works for all**. What calmed one child only served to make another hyper. Consequently, we concluded that the effective management of your child's needs is really a case of **knowing your own child**, mixed with a good measure of trial and error. Above all remember that **'tips and strategies are there to serve you, not the other way around.'**

In the immediate period following a diagnosis, many parents query if they can understand the world as their child perceives it. Therefore, they may feel insecure and uncertain about whether you now really know their child and can meet their needs. It is important to recognise that the time following diagnosis is one of adjustments, but that once things begin to settle down (and they will!), and as you gather more knowledge and understanding about your autistic child, your confidence will grow. In addition, the recognition that **you** are the greatest, all-round expert on **your** child.

As is the case so many aspects of parenting, doing your best and making choices for your child is often a balancing act. We have found it important to balance the confidence we have in our own instincts, intuition and knowledge of our own children, with an open mind in respect of what other parents, experts and professionals have to offer.

Actively seek out people who are knowledgeable and consider what they have to say. Keep an open mind about different therapies but tread carefully as not all therapies will be suitable for **your** child and can be expensive. In the early days we are all keen to leap in and be pro active in the way we try to help our children (as a matter of fact, this was our way of staying sane!). **Take your time and above all never lose sight of the individual autistic child.**



Finally, we have all found it immeasurably helpful to remember that our autistic children have many strengths. Many parents have expressed the feeling that their child's character, personality, sense of humour or plain loveliness shines through in their everyday activities. Your child is still the same person that you loved and found pleasure in prior to diagnosis. Anyway, onwards with the 'tips and strategies' sections. Good luck in identifying which ones are for you!

Foundations for Daily Living

- Autistic children have their own personalities.
- Get plenty of support. If there are people you can rely on for respite etc. do use any time or help, they offer you. It may cause anxiety for you to have someone else care for your child but in the long term your child will benefit from socialising.
- **Don't** take things personally when you don't get the feedback you expect from your child. Some autistic children may struggle with reading other people's emotions.
- Trust your own judgement – **you know your child best!**
- Sometimes comments or attitudes of people who don't understand autism or what you are going through will cause distress. It is a case of 'Mind over Matter - Those who Mind, don't Matter and Those who Matter, Don't Mind'.
- There is no such thing as the 'perfect parent' or 'perfect children'. Children don't need perfect parents, just homely, human and realistic parents.
- Accept that you will need to use different methods to help your child learn, socialise and cope.

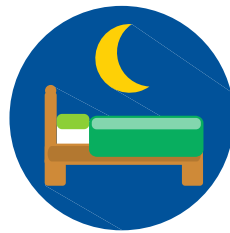
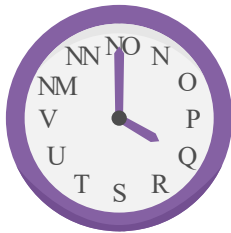
- There are lots of positive attributes in a autistic child. Honesty and directness are part of your child's world. We have a lot to learn from their honesty.
- Value the uniqueness of **your** child, reminding yourself how much you love your child and why you must fight for their rights.
- Keep in mind that the important thing is to **'have the lasting word, not the last'**. Make everything you say count.
- Communicate with everyone involved with your child. Ask questions of professionals and make sure you understand what they are saying. Explain your child's needs clearly to teachers and people working closely with them. Arm yourself with information that will help those who work with your child to make them more comfortable and settled.
- Educate yourself. Join support groups as this will help prevent feelings of isolation but also offers resources to keep you up to date with the law and educational issues.
- Find time away for yourself. Walking, listening to music, visits to the pub, or visiting a friend for even one-half hour can help to restock your energy and enable you to support your child without frustration.

Common Problems

Bedtime and sleeping

As parents, we worry when our children don't sleep or have disrupted sleep. We know our children need sleep to function properly during the day. The best that parents can do is to encourage them to get the rest they need. Here are some tried and tested tips that might work.

Routine – As with most aspects of your child's life, establishing a regular routine will help immeasurably. Set regular times for supper, putting on nightwear etc. Use visual aids e.g. have a picture of a bed and a clock or timer showing the time for bed, as below. You could create a schedule for bedtime showing the main tasks to allow your child to recognize they are going to bed (supper, pjs, teeth, book, sleep).



Make Rules – Autistic children are often very literal and cope well when they know the rules.

- Stay in bed until 7am or
- Stay in bed until you come to get them up

Exercise – Exercise is a great stress/energy buster as it can reduce anxiety and calm the child down. Some ideas for an exercise routine before settling down period for bed are: -

- Bouncing on a trampoline
- Swimming
- Running
- Walking
- Kicking a ball for 10-15 minutes

Check It Out

To make the bedroom more comfortable for your child check out the following: -

- Check the light – Is it too bright/dark? It might be a good idea to change to a dimmer switch, so you can adjust the setting precisely.
- Check if there is too much stimulation – colours on the walls too bright, too many pictures or posters, etc.
- Check out the smell! Do you wash their bedclothes in the same washing powder/fabric conditioner each time?
- Be aware of sensory issues and how these can help or hinder your child. Some parents state that deep pressure and/or hand massages help their child to calm down at bedtime. However, this will not be the case for all children. An Occupational Therapist may be able to assess what interventions would be suitable for your child.
- Check their bedclothes and night wear doesn't irritate them.
- Check out different types of music – Disney, classical or jazz, etc. as this can be relaxing too.

Reward – Make a star chart and reward them. This can be the next morning with something they can see (their favourite biscuit or fruit is a good idea). Treats should be something easily accessible. Other rewards could be a trip to the park or story time.

If it is inevitable that your child will not sleep much during the night, give them something quiet that they can do in the bedroom while awake, but resting. Have rules about this too e.g. they must be quiet, they can only leave the bedroom to use the bathroom, etc.



Toileting

Ok, so you think it is time to toilet train your child – let's hope your child thinks so too! Here are a few ideas:

- 1** If a child refuses to sit on a toilet, then your attempts to coerce them will be in vain – leave for a while and try later if it's stressing you and/or your child too much.
- 2** Many toileting strategies apply to **all** children. There is no magic wand and you will find strategies in time; be realistic and patient.
- 3** Having the associated differences relating to autism (sensory issues), it may take your child much longer to learn the basic skills. You need to put on your detective hat and look for the signs that your child is ready for toileting. How do you go about this? You need patience and a sense of humour.
- 4** Take things one step at a time. You cannot grow from a baby to an adult overnight. It's the same with successfully using the toilet.
- 5** Keep a diary for a week or two before you start. Spot the verbal and non-verbal signs regarding toileting, for example, fidgeting, cross legged or red faced.
- 6** Let your child see you quickly on the toilet – you may be surprised how quickly they start to mimic you.
- 7** Encourage them to sit on the toilet at regular intervals to get used to the process.
- 8** Regular times might be first thing in the morning, before going to school or out, when arriving home, before dinner or before bedtime, etc.
- 9** Establish a routine that they can see with a visual aid. This could be using a photo of the toilet regularly to show them it is time to go, or using a picture sequence of the steps to going to the toilet (pull down trousers and pants, sit on toilet, etc).
- 10** Reward them when they have used the toilet successfully.
- 11** Show them how much toilet paper to use - don't take it for granted that they know. Keep reminding them or use a visual aid. For example, tape a piece of string to the bathroom wall where they will see it so they can use it as a guide.

- 12 Always speak in a positive way; 'good toileting, good sitting'.
- 13 A good visual aid can be a toy that you can say needs to use their own toilet at the same time you want your child to try – you can even do a reward chart for the doll too. Give your child an incentive.
- 14 Your child's diet is also very important – some autistic children have low muscle tone and this makes them prone to constipation. If you have serious problems with toileting, mention it to your child's consultant so that you can rule out any other additional problems.

N.B. Some children can find the additional change or adjustment from potty to toilet difficult as it is a new routine. Some parents consider training straight to toilet to simplify the process.

Some children need expert help of the specialist and there are a number of people who can do this; your GP, Health Visitor, special clinics run by psychologists. There is no failure in asking for help.

Bath Time

Bathing at bedtime can be soothing on its own or with lavender bath products. If bath time is calming for your child, use for 5-10 minutes to help settle them every evening. It is not necessary to wash your child's hair every bath time if it is distressing.

Check the temperature of the water and if appropriate, ask your child if it is ok. Chat with your child in a soothing voice to help calming.

You may need to be literal regarding rules for bathing.

- If your child gets excited and splashes too much in the bath, make a rule 'feet underwater'.
- Use a timer if necessary, to show your child how much time they have in the bath.

Always remember in any task, if something helps to keep your child calm and comfortable, use it.

Eating

Autistic children can have difficulties with their diet due to sensory differences. This could include the smell, taste, texture or even the colour of the food.

Children also discover at an early age that they have the power to accept or reject food, especially if the adults make too much of an issue of food. As a parent you can end up feeling powerless, inadequate and rejected if your child refuses food.

Eating out can also be a problem because of sensory, social and behavioural difficulties. If you receive insensitive comments, remember the mind over matter tip:

'Those who matter don't mind, and those who mind, don't matter!'



Tips on Eating

Go Easy

Use simple, small amounts of new food, as these take little time and effort to prepare.

When introducing new foods, have the child's favourite food as an incentive and a very small amount of the new food (e.g. if introducing peas, just start with one pea on the plate), then build up the amount very gradually. Reward the child for trying even a tiny amount.

Treats

Offer a treat as an incentive but show them the treat as well as telling them they will get one. You could show this on a First and Then Board (first dinner, then treat). Try to offer an activity rather than sweets.

Puréed Food

Puréed food can hide a multitude of nutritious ingredients, especially for the child who hates 'bits' in their food.

Exercise

This can serve as a distraction when the child wants to snack all the time.

Routine

Make mealtimes as routine as possible and encourage the child to come to the table, even if it's only for a short time. Swap bowls and cups regularly and try not to let inflexibility set in.

Seek help

If you need to seek help from a dietician, doctor or an occupational therapist, keep a diary of one week's usual diet including snacks and drinks.

Ideal World

In an ideal world, we would like to have the perfect family setting but if your autistic child eats better alone, don't force them to sit with others, as this may heighten the situation. Try every now and again using strategies from this booklet to see how they can cope but always remember **no one way is the only way.**



Behaviour Management

Always keep situations that are stressful or challenging to a short period of time. Don't keep your child away from these environments completely, but introduce them slowly, maybe minutes at a time gradually building it up.

Use your knowledge of your child's likes and dislikes to encourage social situations.

Every autistic child is different. What works for one will not necessarily work for another.

Ground Rules

- 1 Know your child and what they are capable of, so you can set realistic goals from the outset.
- 2 Always be consistent.
- 3 Have fair and clear boundaries.
- 4 Keep a calm voice and body language.
- 5 Pick your battles – no audience, areas with no danger. Know when to back off (issues should be worked through at a calmer time).
- 6 Praise expected behaviour but remember to be very literal, so the child can understand your meaning e.g. 'good sitting'. (Always name the task the child made an effort in). Don't forget that even an attempt at expected behaviour should be positively acknowledged.
- 7 Present a united front. Make sure that the carers in your child's life agree on the rules and how to handle behaviour that challenges. This will let the child know where they stand and ensure that they cannot 'play one off against the other'.

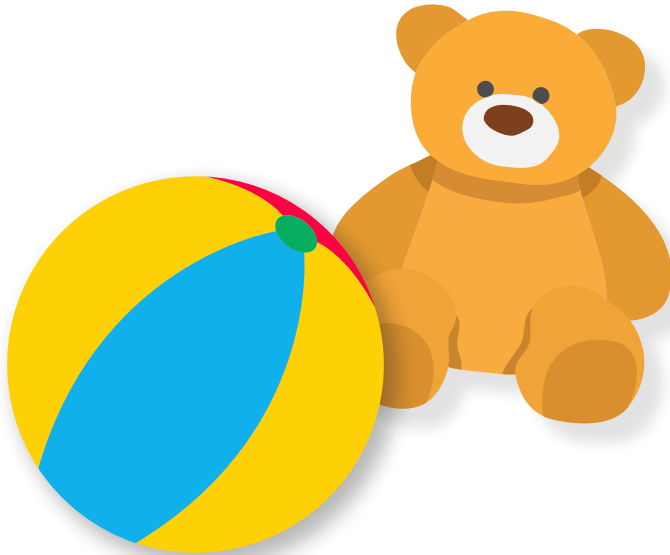
Have a sense of humour!

Distraction Techniques

Distraction is a great pro-active technique for helping children prepare for and cope with any difficult situation. It is particularly useful for medical appointments and procedures. It is often the parents who must initiate distraction for their child. If you find this to be the case, please do not hesitate to take responsibility for your child's anxiety levels. Taking a little extra care and time to put your child at ease is a good investment for you and your child at appointments.

It's always a good idea to test the following techniques out prior to the appointment. Remember that you are the facilitator for the positive coping.

As you read on, you'll see that some of these techniques require prompts and toys while others simply require you to lose some inhibitions!





Distraction Technique	Benefits of Technique
Allow the child to participate	Gives control, allows choice in the procedure.
Talking (singing & dancing)	Allows the child to express themselves, time to listen and hear; offers reassurance and interaction.
Breathing Exercises	Controls breathing and is relaxing to both body and mind; uses concentration; can be practiced and planned; empowers the child.
Counting	Controls breathing; can time limit some procedures; diversion.
Muscle Relaxing	Use of concentration; relaxing to muscles and mind; can be practiced and planned; empowers the child.
Imagery	Safe places; happy thoughts; can be spontaneous or planned; can use prompts e.g. photos.
Making Noises	Distracts from pain; controls breathing; releases energy/frustration. (Be aware of auditory sensitivity).
Praise	Makes the child feel proud; Gives them a sense of achievement; can be verbal or physical e.g. stickers; certificates, prizes.
Hospital Play	Increases control; gives opportunity for explanation/reassurance; uses role play; positive image of staff doing procedure.
Puppets	Role play; diversionary play – attention diverted; shared emotion/expressing emotion; interactive; offers reassurance.
Stress Balls	Physical distraction – uses touch; transfer of pain to the ball; releases frustration/anger.
Magic Wands	Visual; look, count colours and shapes; relaxing.
Bubbles & Balloons (blow – catch – aim)	Controls breathing; blow away the pain; release energy/frustration; diversionary/therapeutic; parents can join in; visual, fun and silly.

Noisy & Musical Toys	Physical; releases energy and frustration; diverts attention; increases control.
Throwing & Catching	Concentration; releases energy/frustration.
Interactive Books	Physical distraction; use concentration; can be age appropriate & interactive.
Phone/tablets	Coping strategy; can be interactive – pictures on screen etc.
Environment	Interactive; visual; good conversation starter.

Once again, these suggestions are only an example of the kind of strategies you can employ at a time of high anxiety for your child and they require supervision. You will know what techniques are compatible with your child and what ones should not even be entertained. For example, one of our children is phobic about puppets, so to use this as a distraction tool would only serve to raise anxieties beyond the point of return. However, he absolutely loves any kind of deep massage, being lightly ‘squished’ (his term not mum’s) under a gym ball while lying on the floor or chilling out in a corner with loads of beanbags on top of him.

There are circumstances during which you can also try to modify some of these suggestions. For example, the mum we spoke of above, when her child was younger and smaller, she used to bring a child’s blanket to appointments and wrap them nice and firmly in it while cuddling him on her lap.

Remember that you’re probably using some pretty effective distraction techniques even now - think about how they could be adapted to a more public environment.





General Tips for Appointments & Outings

- Prepare your child in advance of any appointment to dentist, hairdresser, clinic or hospital, etc. Think about what will happen, prepare your child for what will happen and answer any questions or worries your child has.
- Have rules for the waiting room e.g. sit down or wait, they will be allowed to play until their name is called, etc.
- Try to estimate how much time it will take. Use a timer or any other visual aid that will help your child cope with waiting.
- Be aware of your child's sensory issues and advise adults at each appointment as necessary.
- If necessary, drive to building a few days before, take photos if this helps your child to prepare.
- Speak to any professional you will deal with in advance so that they have an understanding and can prepare. Ask for or take photos of any professionals that your child will see regularly.
- When explaining your child's needs be sensitive and be aware that your child can hear what you're saying.
- Bring your child regularly to help them familiarise with people, smells, sounds, textures and touch etc., so that the child becomes de-sensitised. Build up gradually what is expected of your child (for example, how long they have to sit).
- Be early and know where you are going. Try to use the same hairdresser each time. Familiarise the child with building and use photos if you can.
- Alternatively, as a busy hairdressers can just be too much, find a mobile hairdresser who will come to your home.
- Reward your child for every effort to cope.

Friends and Play Dates

As autistic children experience the world differently, they may require your assistance with socialising, communicating, initiating and maintaining friendships, here are a few tips on how you can help your child.

- Arrange play dates with children your child is familiar with.
- Keep these structured to help your child cope. You can always increase your time gradually.
- When your child is playing with another child, supervise them and support them if there are misunderstandings related to literal interpretations or pretend play.
- Use this time to teach turn taking, stop and start, counting, colours and role play. These will all be invaluable.
- Find common interests and make sure that all children gain knowledge and enjoyment from whatever they do.
- Make a routine out of play dates and vary the location (e.g. park, each other's houses) to encourage varied social interaction.
- Never arrange or force a play date if your child is tired.
- Last but definitely not least, **have fun!**









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