Teenage Life

Supporting your child with difficult behaviour

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- This handbook gives you ideas about how to understand difficult behaviours your child may show as well as suggestions for how to support them

- By difficult behaviour we mean any behaviour that you think you may need to tackle, either because it is dangerous, anti-social or make life harder for them if you don't do something about it at a younger age

- Everything in this handbook is based on the truth: All behaviour happens for a reason

- The reasons for your child's behaviour are often to do with their autism

- Therefore to find ways to manage difficult behaviour it helps to understand your child and how their autism affects them

- Often there aren't quick and easy answers to difficult behaviours

- For some behaviours it may be more about coping with it rather than stopping or changing it (especially in short term)

- It is important to all the adults working in the same direction, so you can try to achieve consistency in responding to the behaviour

- Behaviour you are tackling might get worse before it gets better. This is especially true for "World War Three behaviours"! So called because it may feel like you have started a World War when you talk to your child about making a change in their pattern of doing things. For example, wanting to reduce their hours of screen time or helping a child move into their own bed at night

- Remember some behaviours can take a long time to change but if your strategy doesn't show any signs of working *at all* after several weeks seek further advice eg Bristol autism team hotline (bristol.autism.hotline@bristol.gov.uk) GP or Primary Mental Health Specialist (PMHS – contacts are at end of the Handbook)

- It is hard to know sometimes which behaviours to tackle. Some questions to ask are: is it dangerous or likely to upset others or is it a behaviour that if you don't tackle will make teenage and adult life more difficult eg refusing to talk to anyone, or not washing. Seek further advice eg Bristol autism team hotline (bristol.autism.hotline@bristol.gov.uk) camhs, psychologist

Behaviour – the what, why and how approach

- Think about **what** behaviours your child displays that are difficult or challenging in some way
- Consider **why** your child may be behaving the way they do
- Decide **how** to make things better; how to reduce, replace or manage your child's difficult behaviours

The iceberg way of thinking about behaviour

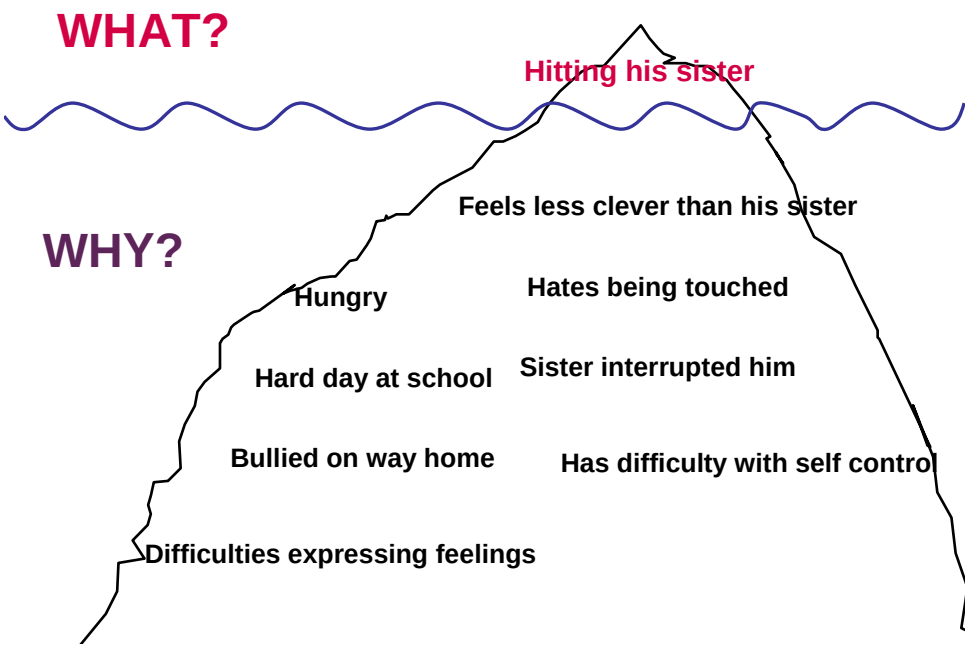
It can be useful to understand a behaviour as being like an iceberg. The tip of an iceberg represents the actual behaviour and the rest of the iceberg under the water are the various different reasons for this behaviour. You need to look beneath the surface to see what is really going on.

WHAT?

WHY?

A quick way to get you thinking about how to tackle a difficult behaviour, if you are stuck for ideas, is using the iceberg. You start by drawing an outline of an iceberg.

What the behaviour is written above the waterline eg hitting his sister.
Why the behaviour is occurring is written underneath the waterline. Write all the possible reasons for why the behaviour might be happening – what caused it- what are the reasons for it. Don't dismiss any possible reason – write them all down…



As well as WHAT behaviour and WHY might it be occurring……

… we want to know HOW we can make things better

For example:

WHAT is the behaviour you want to change? ….Hitting his sister

WHY might it be occurring? …. (all or some of the behaviours listed in the iceberg)

HOW will you help your child change the behaviour?

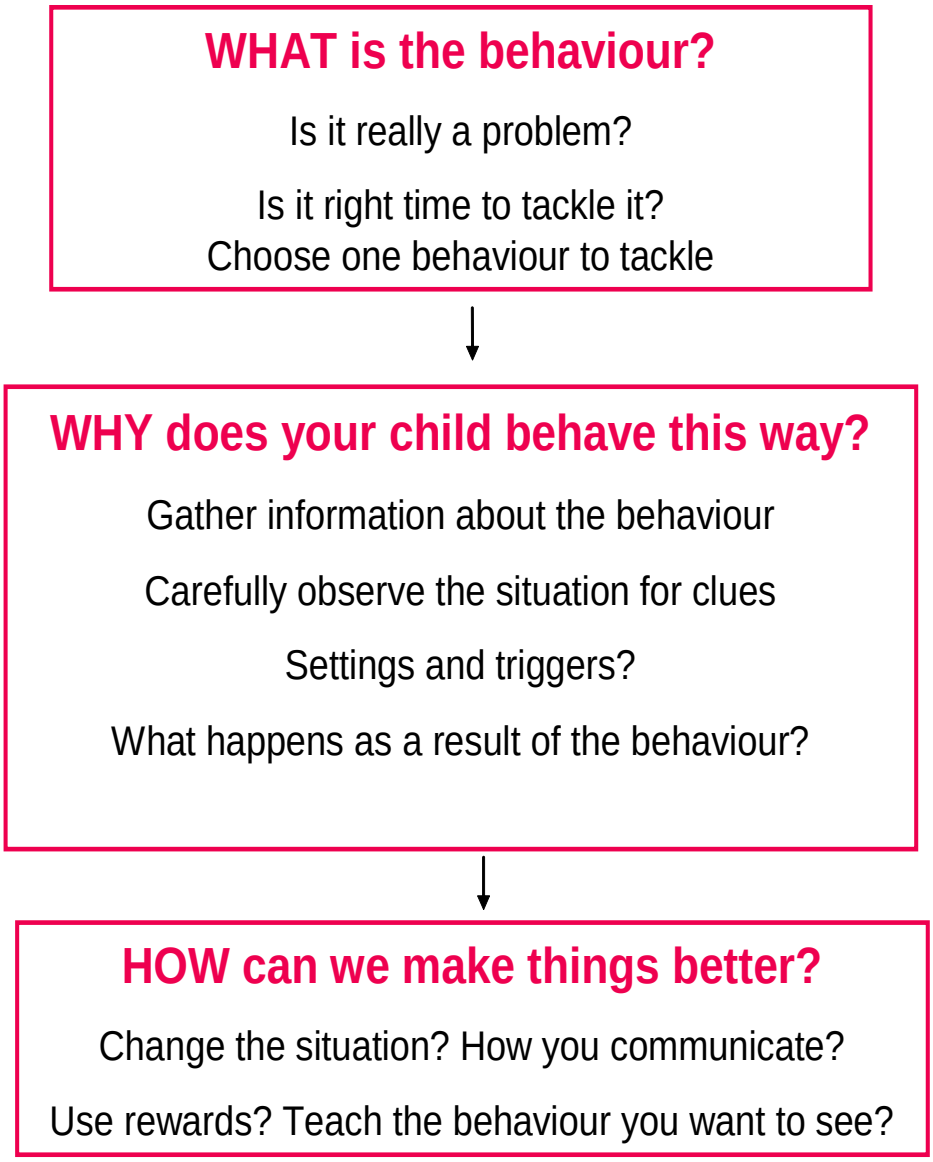
Your behaviour plan might include things like:

1. Agree downtime after school – no sibling contact
2. Investigate bullying
3. Praise all he has achieved and don't compare him to sister
4. Find ways for him to excel and feel good about himself
5. Teach sister about autism

As you can see often with a plan of action you will need to do more than one thing to help with a child's behaviour.

The What, why, how behaviour flowchart

- This flowchart can be a useful way of starting to deal with difficult behaviours that don't have obvious answers!
- You won't need to use the whole flowchart for most behaviours, just when you are stuck for ideas
- Checking through parts of the chart may be enough to give you ideas about your child's behaviour
- For each behaviour try to write precisely what it is your child does that is a problem (eg John kicks his sister about 3-5 times a day rather than John is aggressive)



WHAT is the behaviour that needs changing?

Some difficult behaviours your child may display

It is not just children with autistic behaviour who exhibit difficult or challenging behaviour. Any of us can do so if we are stressed, tired, frustrated, or feel overloaded. However, there are some challenging or difficult behaviours that are fairly common in children with autism:

- Shouting, swearing
- Hitting, kicking
- Uncooperative, temper tantrum
- Meltdowns
- Damaging property
- Inappropriate touching, inappropriate sexual behaviour
- Spitting
- Self harm
- Smearing faeces
- Refusing to eat or over eating
- Attention seeking
- Running away
- Obsessions and rituals
- Lack of sense of danger
- Repetitive and/or inappropriate questions

If any of the behaviours your child has are dangerous or serious in whatever way you should seek professional help eg CAMHS via your GP, Bristol autism team or social services. Also contact the Autism Helpline for more advice on how to manage behaviour.

From the list of difficult behaviours you have made, for each behaviour you have concerns about, ask yourself: is this behaviour really a problem?

You may decide as you consider some of your child's behaviours that whilst embarrassing, odd or not 'age appropriate', they do not require intervention. For example you may decide that the behaviour will probably improve over time naturally, or that it is just part of your child's personality or the pace at which they learn some things.

You may come to the conclusion that some of the behaviours you have listed are more of a problem for you than for your child.

Furthermore if you are thinking about tackling a particular behaviour you need to be honest and ask yourself is it the right time?

- For you? (eg you may feel too tired or stressed to begin putting a behaviour plan into action)
- For your child? (eg they have other behaviours to worry about that are more important at the moment)

You may wish to start with a less difficult behaviour that you already have some ideas on how to tackle.

Always try to get support if you are struggling to understand or manage a behaviour – eg from partner, other family, friends or professionals.

WHY does your child behave this way?

- Remember the iceberg – there may be many reasons for the behaviour (many of them hidden and not necessarily obvious)
- Sometimes it is the details that we miss
- Be a detective – look for all the clues as to why the behaviour is happening (use the "autism lens" – trying to see the world through your child's eyes may give you clues about why the behaviour is occurring)
- Try to stand back from the situation – also ask others why they think the behaviour is occurring
- For behaviours that are confusing keeping a diary can help to make sense of them
- From all the information you have collected, try and think about why the behaviour may have occurred
- There may well be more than one reason a behaviour is happening.
- Write down all the possible reasons you think may be contributing to the behaviour.
- Once you've got some ideas of why the behaviour is happening you can look at what needs to change…

HOW to make things better with your child?

Be kind to yourself

Parents are the most important people in the lives of most people with autism. You are their ally, source of self esteem and information. You are therefore an incredibly valuable person! You deserve and need to be looked after as well as your son/daughter. If you ever get the chance, try to can take some time for yourself. This is not easy for many parents to achieve but sometimes doing something for yourself is vital to your well being as well as your child's.

Reminding yourself that your child's difficult behaviour comes from the fact they have fewer skills to manage daily life, not because of your parenting ability. Of course all parents can make a situation better or worse but we need to remember you can be the best parent in the world and your child can still face behaviour difficulties. This is because the world they live in is not autism friendly at times.

Don't expect to manage every incident successfully, be 'good enough'

There is no such thing as the perfect parent. You will make mistakes – what matters are the long term messages you give your child – that you love them and think they are great.

All of us lose it now and again. Most parents shout at their children. Obviously we are always trying to improve our own behaviour towards our children but we need to realise that there will be days when we get it wrong and we do not have the energy to put it right. If you need to apologise do so, as this earns you respect from your child and also models the behaviour you want them to achieve.

We should aim to be good enough parents and avoid wasting time on feeling guilty or worrying about what is in the past. That time can be better spent thinking of ways to help your son/daughter now.

Do make time for yourself if you can

Parents are the most important resource children have so looking after yourself is a good idea whenever you get the chance. This is not being selfish; it is part of a low-arousal approach because if you are tired or irritable it is harder to avoid losing your temper and your child will pick up on your mood.

The following are some of the many ways parents have said they relax, unwind or recharge their batteries:

- a massage
- a bath
- gardening
- walking the dog
- listening to music
- reading

- TV box set
- working
- alcohol (in moderation)
- sleep.

Your plan to help your child may involve doing several things

When you are putting together an action plan of how to support your child's behaviour, your plan may require you do several things at the same time. For example change how you communicate, use a timetable, talk to school about the behaviour and help their sibling understand autism better. An effective plan often will require you to try several things at once.

Often managing your child's behaviour is about changing our own behaviour

We often place great expectations on children with behavioural problems to change the way they act. We need to teach children how to manage their strong feelings like fear and anger. If we don't help them recognise those feelings and how to manage them we can expect volatile behaviour.

Sometimes we forget that how we behave as adults has a great bearing on how children behave. When we are looking to help a child with autism with their behaviour difficulties we nearly always need to think about what we can do to assist. This could involve changing how we ourselves behave and what we say (or how to say it, or when we say it) or it could involve changing some part of the environment to make the behaviour less likely.

If you are facing confrontational behaviour pretend to be calm

If your child is angry try to avoid making things worse by pouring oil on the fire. In other words if you get angry too it often makes the situation worse. Obviously occasionally there are times when it is necessary to raise your voice but in most daily situations it is better to just act as if you are calm and able to give off the impression of feeling in control of your own reactions and are not fazed by theirs. It isn't the natural way to react for most people and it does not provide overnight behaviour change, but it seems to be the best approach in the long run. It is not 'giving in' to 'bad' behaviour - it is about trying to get the best result for everyone. Acting calmly is sometimes very difficult because as parents when children are misbehaving, rude or confrontational, our brain often goes into 'fight or flight' aswell. Think of what you can do when you are going into fight or flight before it occurs – have a meltdown plan (see later).

Sometimes we can just avoid a situation and that will make the difficult behaviour go away

For some behaviours the simplest way to prevent the behaviour is by avoiding the situation completely or at least for a few months. For example, if every trip to Sainsbury's causes a meltdown you could simply avoid the supermarket at busy times or shop online. Or for example, if they hate the hairdressers you might buy some hair clippers instead.

Think about sensory needs and whether they are causing the behaviour

Many people with autism tell us that they often meltdown when they experience an overload of:

- too many sensory inputs
- too many people
- too many words/ too much information.

We need to take account of these things to make life as comfortable as possible for your son/daughter.

Can you make the situation less stressful with fewer noises, smells, people, clutter, stimulation and distraction? It may be that your son or daughter is upset by a certain sound, touch, voice tone or by seeing a particular object. Consider the place where the behaviour takes place and how much that is contributing to the behaviour.

Can you use rewards/negative consequences to help with the behaviour?

Alongside the above strategies, you may choose to use rewards and/or consequences to tackle certain difficult behaviours. Rewards can work for many children but you need to make sure the reward is something they really want or else it won't work. Also, what a child considers a reward one day may not be the next, so it might be a good idea to let them choose a reward from a list.

Rewards do not have to be toys, food, time alone or money, (though these can all work well), your undivided time and your praise may be a powerful reward in itself. If your child is young, don't make them wait all day for the reward – they probably won't be able to make the link between 'good behaviour' at 10am and getting something at 5pm. Plan and agree in advance how, when and for what behaviour you will give rewards.

Rewards are better than bribes

A bribe is when you give your child something *to stop them doing something you don't like.*

A reward is *agreeing in advance what your child will get if they do a behaviour you approve of*.

So rewards are better because you have control of them and they produce more social behaviour from your child.

However there will be times when you just have to bribe your child to prevent a meltdown or incident! This is fine, so long as you also think about ways to prevent the possible incident occurring in the future.

Give them nice surprises for 'no reason'

We know that many children with autism have low self esteem, so giving them nice things just because is a good message to send them. This is especially important in a world that often seems to be trying to change them and 'make them better'. We need to stop and remind ourselves that they are wonderful as they are.

Discourage the behaviour you do not want to see

As well as using rewards you may find ways to discourage the difficult behaviour. There are various ways of doing this – you could simply ignore it, or have consequences, or explain why the behaviour is not appropriate. For example, telling your son or daughter "I don't like it when you do X because that makes mum feel sad", rather than "will you behave?" is likely to have more impact.

Sometimes you may also discourage difficult behaviour by introducing natural negative consequences (including punishments). For example, if they break their brother's game, they will have to pay some pocket money towards the cost of a replacement.

All these ways of discouraging behaviour can work - the trick is to find which approach works for which behaviour. For example, you might ignore some swearing, and this might help in reducing its frequency, but can you use the same tactic when your child is hitting their sister round the head?

Tell your child what behaviour you would like to see

As well as thinking about what you can do as parents, there are times when it is important for your son or daughter to learn new behaviours to replace the ones you are trying to change. If your child is doing something you dislike, ask yourself what you'd rather your child was doing instead and teach them this, or remind them to do this.

For example, if your child runs around the supermarket causing chaos, it is not realistic to expect that he can just walk around doing nothing instead. He needs an alternative activity, so you could try letting him get a small pastry from the bakery area and then assist you in finding items and ticking them off on a short shopping list.

Think about what behaviour you want your child to be doing instead and teach them or remind them to do this. For example, rather than just telling them not push people, teach them to say "please go away" or put a hand up as an alternative coping strategy. Teaching new skills and behaviours is often about encouraging your child to tell you what they need, eg "stop now", "no more talking" or "I need a hug now".

Find ways for your child to calm and relax

Sometimes difficult behaviour results from stress, so think of ways to relax your child and reduce their anxiety. Methods might include taking a bath, using lavender oil or softer lighting, getting into a sleeping bag, having a massage, or listening to music.

Find ways for your child to release anger and frustration safely

Frustration and anger are common causes of behaviour problems so help him or her to find safe ways of releasing pent up feelings, eg, a trampoline, punch bag, stress ball, going for a swim or walk. Sometimes the best strategy might be to allow them to have a 'rant'. You may need to give your son or daughter more space, re-charging time or breaks.

Help your child to understand their feelings

One of the areas where your son or daughter will require particular support is in understanding emotions. This may be because they find it hard to talk about abstract things like feelings and also because they are less skilled at recognising and managing their own and others feelings.

Giving your child a visual support to point at like the one below can be a good way of letting them tell you what sort of a day they've had or what they feel about a particular event or person.

Some children like to use a simple signalling method such as 'thumbs up/down/level hand' when they are out with their parent, to indicate their level of stress, anxiety or anger.

Other children have learnt to use a 5-point scale to express their feelings and use the idea of a thermometer to explain how they are feeling.

Older children may find that, with help, they are able to identify some of the stages of anxiety before they have 'meltdowns'. By agreeing tactics about what to do in advance, some

meltdowns may be reduced or avoided. The following worksheet can assist with this.

Another useful technique is to use stick people and simple cartoons to get your child to understand other people and how their thoughts and feelings work.

Try to achieve consistency

It is easier to say than to achieve but consistency is often vital in changing a child's behaviour. If you are committed to tackling a particular behaviour, make sure the other key adults who are involved with your child are also committed and agree to the behaviour plan. For example, you might decide to use ignoring as part of your behaviour plan if your child throws a plate on the floor at mealtimes, but if your partner gets really annoyed by this behaviour and raises their voice to tell your child off, it will send a confusing message to your son or daughter.

Remember to do the things that make them happy

Challenging behaviour can arise out of general unhappiness so remember to do those activities that build their self esteem and sense of well being. It is easy to just focus on a difficult behaviour and forget about all the other things in their life that make them feel good which if increased may lead to a decrease in negative behaviour.

Give them the opportunity to feel in control

If frustration is a factor in your child's challenging behaviour, think about ways to give them more control over their day. Find opportunities to offer them choices and don't force them to do things they hate (if you can avoid it). Children with autism have to accept many things in the world that they don't understand or are confusing, so allowing them more chances to take control will build your relationship.

Notice good behaviour

Sometimes it is easy to forget to give your child attention when they are behaving correctly. Try to notice good behaviour and reward them in some way, whether it is by giving them attention, praise or another small reward. This is very important.

Check that your behaviour plan is having an effect

If you do have a behaviour plan, remember that you need to occasionally stop and check whether it is working or not. Sit down with any other adults involved with your child and ask yourselves whether the plan is helping to tackle the behaviour? This is known as 'reviewing your behaviour plan'. If your new approach has shown no signs whatsoever of success after many weeks, think carefully about whether you need to change your approach, but also bear in mind that change can take time. Getting your child to realise that hitting his or her sister is not appropriate behaviour may take years to achieve!

Despite our best efforts there will be times when we just have to react in the moment to difficult or challenging behaviour. The following section provides some ideas for coping with these situations.

Be non-confrontational whenever possible

It is important to recognise the limitations of your son/daughter's ability to think flexibly and manage stressful situations. They are often appear to be at a higher state of anxiety than most of the population and so we need to be calm and avoid confrontation, whenever possible. Direct arguments rarely produce positive outcomes.

Have realistic expectations

People with autism can achieve a lot but it is often the case that we expect too much too soon and this can be stressful.

It is about starting where your child is at. If your son/daughter is able to follow rules then use rules. But if your son/daughter is taking control of many aspects of your home life then you need to consider carefully what the battles that really need fighting are.

You as parents need to remain in control and that means not trying to enforce impossible demands or expecting more than is realistic from your son/daughter. You may at times feel as if you are just giving in to your child – in fact you teaching them that you can listen to them and you are aware of what they can achieve and what is very difficult for them.

If you can compromise and negotiate then do so, not to tell your child that they can do as they please without concern for anyone else but to show them that you are on their side and are realistic about what you expect from them.

If your child is displaying difficult behaviour ask yourself – are you asking too much of your child? Can you make the situation easier for your child to cope with by breaking the task into smaller steps?

Use clear communication

We need to adapt how we use words and non verbal communication. It is vital that we are clear and understandable when we talk and present information. When things make sense to people with autism there are fewer crises.

One instruction at a time, fewer words

If you try to reduce how much you speak and instead concentrate on being more precise in what you want to communicate that will probably help your child. Or put another way use fewer but better chosen words.

Children with autism process spoken words more slowly, so it is important to use fewer words and give one instruction at a time. For example, saying "John…shoes on… coat on… car" may be better than saying "Come on, it's time to go now so please would you mind finding your shoes and put your coat on then get in the car ready to go."

Although very short instructions may seem quite abrupt, most people with an ASD tell us that they prefer simple, clear communication.

Sometimes it is useful to tell your son or daughter that you are about to tell them something, before you actually do. In other words you are preparing them for the information. For example, you might say "John I am going to tell you something. I need you to listen to what I say… (pause)… I want you to go to your bedroom get the laundry basket and bring it downstairs."

Give more time to process information – use the six-second rule

A common mistake when communicating with a child with autism is our tendency to repeat information and requests too frequently. We often repeat our request because the child may not act as if they are listening.

After saying something to your child, allow time for him or her to process what you have just said before you go on to the next piece of information. The time you allow can be counted in your head; for many people counting about six seconds is a good rule of thumb but be prepared to experiment with this. Some people will need about six seconds, some a bit longer and a few less time.

If you do need to repeat your instruction or information, try using more or less the same words again, rather than altering what you have said. For example, say "do you want the TV or computer?" then wait six seconds and repeat "TV or computer?". If your child still does not respond try a different way of phrasing the question.

Remember this is not about a lack of understanding or intelligence - it is about needing slightly longer to process meaning from words.

Using visual methods of communication

When communicating it often helps to back up what you are trying to say with information your child can see. This may take the form of written words or pictures, symbols or gestures. These are all known as 'visual supports'.

Most people with or without autism benefit from using visual methods of learning. For example, we all use calendars, traffic signs, clocks, TV etc. For many people with autism, though, visual supports provide a particularly strong learning method. To support your child, try backing up the things you say with clear visual information.

There are thousands of ways that visual supports can be useful. The following suggestions are just a few ideas; some will be relevant for your child, others not:

- using clear hand gestures
- basic signing (eg Makaton)
- schedules
- timetables
- tick lists
- photos
- diagrams
- mind maps
- drawing cartoons/stick people
- visual stories
- Social Stories™
- Post It™ notes
- calendars
- labelling things
- picture boards
- 1 to 5 scales

- maps
- timers

Be precise about what you are saying

It is also important to be precise and accurate in what you say, otherwise your son or daughter may misunderstand you. Many people with autism ask us to be clearer in our language. For example: "put your shoes under your bed" is more likely to be understood than a vague instruction like "go and tidy your room."

Similarly, "You left a mess by the sink!" is merely a statement of fact. Your child may not be able to infer from it that what you really mean is: "please rinse out your paint cup and put the dirty paper towels in the bin."

Give your child information about the world and always explain the obvious

Unless you tell your child, they will probably never know. Nothing should be taken for granted, so explain simply about the world and the people in it, making sure to keep any impatience out of your voice. What seem like obvious facts to you may come as a complete surprise to your child. So never assume they know anything unless it has been directly and clearly taught them and you have double checked their understanding.

Time alone to re-charge

Most people with autism need more time then the average person alone – re-charging. Build this into your child's day so they are not overloaded and make sure your child has somewhere safe they can retreat to at school when they need a break. Unless people with autism get breaks to recharge it is very difficult for them to manage social contact.

Provide structure to their day

Children with autism benefit from having predictability to their lives. This is often known as providing structure. Structure does not mean doing the same thing every single day or being bored, it means the child is in an environment where he or she feels safe and in control. Providing structure does not mean using the same routines forever, it means that changes are planned for and introduced carefully.

Providing structure can be broken down in a number of questions. Does your child know:

- what will happen during the day?
- what they will need to do and how?
- when each activity will start and how long it will last?

If someone with autism knows the answer to all the above questions they are more likely to feel secure in their surroundings.

Take account of your child's emotional maturity

Children with autism have difficulty with understanding feelings in themselves and other people. They are often considered to be socially and emotionally younger than those not on the

spectrum. Because of this many children with autism find it hard to understand more complex feelings such as embarrassment or sadness, so these feelings often get expressed in difficult behaviour.

Prepare for change and transitions

For children with autism, variety is not always the spice of life. Life can be very confusing for them, causing anxiety and/or aggression, so they will often try to impose some predictability into their lives.

Routines will therefore be important to your child but it is equally important that you gradually introduce variety into their life so they get used to change. We need to introduce changes in such a way that they do not feel they have lost control or that their world has become too unpredictable.

The order for introducing change should be as follows:

1. Make life as predictable as your child needs it to be so they are not in a state of constant stress/anxiety.

2. Once your child does seem more settled, gradually introduce small manageable changes to their routine.

Compromise and negotiate when you can

This means aiming for 'win-win' situations and compromising whenever possible. For example, "If you come out with me, we will go to the games' workshop for twenty minutes on the way back" or "OK, you don't have to go into the supermarket, you can stay in the car".

Or use 'trade' tactics. For example, "If you let me have that DVD for three hours this evening, you can have an ice cream."

Stand your ground only when you really have to

Sometimes, being firm and standing your ground may work, but it is best to reserve this for times when it is *really worth it* and you are sure you won't lose face. Usually, it is best to aim for a win-win situation and avoid a meltdown.

"I was told years ago only to fight the battles with my two that were important. To decide what the important battles are, then, under no circumstances do you give in. Granted, it all gets worse before it gets better, but once they know that, no matter what, you are not going to give in, then I have found it can and does work." *(Parent of two children with autism)*

Use house rules, contracts, and consequences

Many parents find it best to have a few well-chosen house rules for all the family, especially if they have a son or daughter who is very challenging. However, some find their son or daughter responds best to having lots of rules.

For some children, expectations may be better than having too many rules. For example, "I'd like it if you did xyz/when you do xyz it makes me feel really happy/if you do xyz you will earn a reward… " This is because children with autism sometimes find it hard to follow too many rules and you will spend all your time having to carry out the consequences of breaking rules.

Some families sit down and all agree on a family contract. A family contract can include certain house rules and clear consequences for breaking them. Check everyone understands them – don't make up consequences on the spur of the moment

If rules are broken, give your child a couple of warnings, reminding them of the consequences. Don't argue, but simply state the consequence in a calm, neutral voice then carry it out. This is sometimes difficult to achieve especially if your child reacts with more anger. If their reaction puts you or them in danger, then get expert advice from a psychologist.

Words are often confrontational - use non-verbal communication methods

Some children with autism prefer non-verbal methods of communication and find them less confrontational. The spoken word seems to increase anger in some children. Generally, thinking about other methods of communication may be useful at times – using emails, texts, post-it notes, text messages, 'being helpful' cards, wipe boards, rules on walls, etc. One social worker carried out his first two interviews with a young person with Asperger syndrome entirely by mobile phone.

Ask questions to understand them better

Asking questions is often a good way to understand your son or daughter. Whilst your child will often struggle to say why they are annoyed, sad or angry, you can ask questions about other things. Ask questions that make things clearer. For example, "Does it help if I don't talk on the way home from school?"

Ask questions to find out more and try not to 'nag' them. For example, "You like wearing that cap don't you?" rather than "Why do you insist on wearing that cap?"

"Tell me what you feel" (but be careful about asking why)

It is important to get children to begin to find ways to tell you how they feel. It means you avoid stressing them and can find ways to support them. It is a good idea to ask if they are feeling angry, but don't ask why, unless you are almost certain your child knows why and wants to talk about it. Of course, some children will be able to tell you why they are angry or upset, for example because a child at school hit them. Many younger children won't have this ability until they are older.

You may be able to encourage your son or daughter to use a simple thumbs up or down method when they are at home or out in town. Some children use hand gestures or visual supports to show how they are feeling.

Coping with meltdowns

What is a meltdown?

- When a person loses control for a period of time and may cause damage to property, self or others. The damage to people may be physical or verbal

- There seem to be three stages - build up or rumbling stage, meltdown and then recovery period

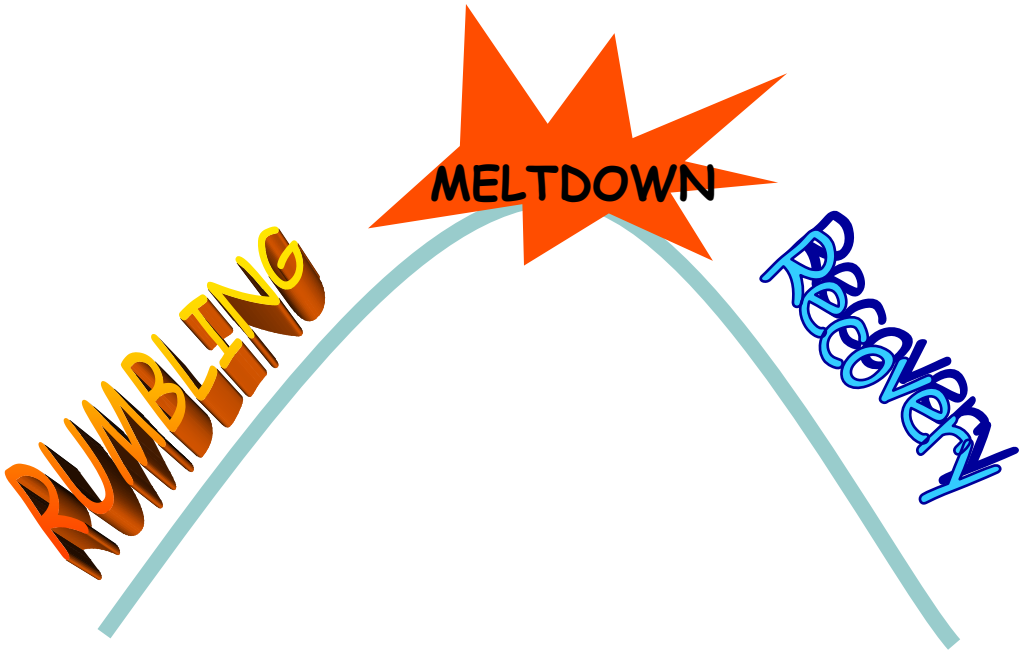
Use low arousal approach:

- Spot the rumbling signs
- In control and non confrontational voice and body
- Don't argue
- Divert, distract or change tack!
- At point of no return - have a meltdown plan

In this section we will look at what to do if your son or daughter seems to be on the verge of losing their temper or going into a 'meltdown'.

Despite all your efforts to use a low-arousal approach, help your son or daughter to relax or stay calm, express feelings more acceptably, and build self-esteem…meltdowns can still happen. In this section, we explain:

- what to do when your child starts to lose it – the rumbling stage
- reacting to outbursts
- what to do when they go into meltdown.



Adapted, with thanks, from *Asperger syndrome and difficult moments: practical solutions for tantrums, rage and meltdown* by Smith Myles and Southwick (www.asperger.net). See *Useful reading* for further details.

Not all children with autism have major meltdowns, but many have regular minor meltdowns, rages, difficult or aggressive outbursts – a low-arousal approach is best whatever the degree of anger.

The rumbling stage

The rumbling stage or build-up are terms used to describe times when your son or daughter is becoming more stressed – and it may lead to a meltdown if no action is taken. It is sometimes very hard to spot the rumbling stage.

What leads to the rumbling stage?

This is a difficult question to answer as hundreds of things may push your child into an increased sense of stress, anger or frustration. But you may be able to identify some of the more obvious things and plan to avoid or better manage these – this will help you to prevent meltdowns.

Adults and children with autism often give us clues about the sorts of things they find very difficult to cope with:

"I went through phases like this when I would attack my parents…I could not understand why they were trying to make me fit in and comply when I didn't want to."
Adult with Asperger syndrome

"The underlying thing he says is that he didn't understand what was happening and no-one listened to him or that he wanted everyone to go away."
Parent of 12-year-old with Asperger syndrome

"I get to a stage where I cannot take in any more information. I can only describe it as my brain appears not to register all that my senses are seeing and feeling, etc. This is where I cannot seem to think, almost as if my mind has gone completely blank."
Adult with Asperger syndrome

What are some signs of the rumbling stage?

It is important to be able to spot signs that your son or daughter is heading for the rumbling stage. If you are able to spot these signs, you may be able to prevent a meltdown by using diversion, distraction or by changing what you do. Parents say that the following are signs that their son or daughter is about to lose their temper:

- pacing
- fiddling
- rocking in chair
- talking to self
- going white
- biting nails
- becoming childish, giggly
- getting hot feet or ears
- making noises like an animal or growling
- flapping hands slightly
- clenching jaw or fist
- being very still
- not feeling well
- having fixed eyes or being wide-eyed
- making facial gestures
- being more or less chatty, or argumentative
- showing more or less eye contact or staring
- frowning a lot
- showing flared nostrils
- looking down
- having tears in their eyes
- showing dilated pupils
- making negative comments about self
- chewing inside of mouth
- showing an increase in grimacing or particular facial expression.

Using low-arousal strategies when your child is close to meltdown

Every parent will find their own way to try to prevent a meltdown when their son or daughter seems to be heading towards one.

Different strategies will work at different points in the rumbling stage. For example, using humour or gently reminding your son or daughter of their options may work very early on in the rumbling stage. But if these tactics are used later they may actually have the opposite effect and tip the child into meltdown.

The following are some of the more common tactics parents have used over the years to try to prevent meltdowns:

- stop arguing – this is always a good tactic as arguing often make things worse
- avoid any words that may 'spark' him or her off, for example 'no' or 'bad'.
- time alone. "You need to have a break from us because we are making you stressed." Important not to make this time alone seem like a failure, backing down or 'time out'. It is simply the best option for when we are stressed – to change tack and do something else for a while. If they don't want to leave, you can leave the room instead.
- suggest a walk – but don't talk very much, if at all
- if possible, compromise. "OK, bet we can do it quickly together, then let's have a sandwich" or "OK, I will do x if will you do y".
- talk about something they are good at and remind them you love them
- give them time on their favourite interest or topic
- offer quick snack
- tell them you can see they are upset or angry, but don't say any more, except something like, "Maybe you'd like a drink?" or other helpful suggestion, but don't blame anyone or analyse the situation
- use silly, obvious humour – check to see if this will make them more likely to go into meltdown. It is often best to make the humour at your own expense and to make sure you catch your child early on in the rumbling stage.
- use a quiet voice or even a whisper so they have to shout less to hear you
- do an activity either together or alone such as making crispie cakes or some cleaning
- try some tidying or washing up – in other words, remove yourself from the stressful situation
- use a code (for example, pulling on your earlobe) or code phrase to get another adult or an older child to help
- get them to use controlled breathing and explain this will make them calmer. This will need to have been something that they have already practised and can do when not in the rumbling stage. This tactic will probably only work very early on in the rumbling stage.

Using low-arousal body language when your child is close to meltdown

The following tips are also useful for situations when you can sense anger is rising to a point and, unless you change something, a meltdown will take place:

- Lower eye contact.
  If you glare at someone, they will become more aggressive. Using less eye contact may help to lessen the confrontation.

- Keep your voice at a lower pitch and volume.

  Usually your voice will get higher and louder when you are being confronted; try to think about your voice pitch and volume and keep it lower to lessen the confrontation.

- Use fewer words.
  Generally, we use too many words when talking to people with autism – this is especially true during a highly stressful situation, close to a meltdown. Use few words and leave long pauses between saying anything. Many parents report that they use no words at all if their son or daughter is in or close to meltdown, as they are unable to process word meaning at that point.

  Some parents find that using basic sign language or simple gestures can help when close to a meltdown. For example, sign for 'chill out'/ 'take a break' in your room. Agree what the signs mean in advance so your son or daughter knows what they mean.

- Slow down your breathing.
  It is very difficult to slow down your breathing when in the actual situation, but just being conscious of your own breathing rate can make a difference.

- Use slower movements, relax your posture and stay at a safe distance that doesn't tower above your child.
  Avoid confrontational stances and think about how to communicate that you are staying as calm as possible. Sometimes it is tempting to try to touch them to reassure them or to calm them down. This is usually not a good idea. Step back, avoid crowding them and think about your exits from the room if necessary.

- Remove the audience.
  If brothers and sisters are in the room, try to get them to leave (unless your plan is to help your son or daughter having the meltdown to leave). Either way, the important thing is to remove an audience. This is for several reasons. One is safety, the other is to avoid sending too many mixed messages to your son or daughter or being wound up even further. Thirdly, it is important to make the situation one-to-one (or sometimes two-to-one) so your child feels less like they are 'losing face'.

- Repeating key phrases, in your head, may help when confronted with aggression.
  For example, repeat to yourself, "I can pretend to be calm" or "I can stay in control of this situation".

Even if your son or daughter is using abusive language or threatening violence, by using these techniques, you are at least doing the 'right' thing, even if on individual occasions it is extremely unpleasant to be at the receiving end.

- Go at your child's pace.
  If your son or daughter is about to have a meltdown, unless you take action, it is best to leave other things and come back to them when or if your child calms down. It may mean making a phone call to say, "Sorry we are going to be late", and then going back to help your child. Usually, trying to 'rush' them will make things worse.

- Listen to your son or daughter.
  Most parents find that saying, "We'll talk when you are calm" or even just "calm down" doesn't work. Every family is different in how they tolerate swearing, abusive language or bad behaviour, etc. By letting them rant, though not necessarily to be abusive, your children will feel you are listening to them, which may stop them getting more angry. Generally, it is best not to interrupt when they are in full angry mode. It is better to take a step back and accept that it will take some time for them to calm down.

Have a plan

It also helps to have a plan to handle the rumbling stage. Here's an example of a plan for a school to help them avoid a meltdown and cope with a pupil who is becoming increasingly stressed. You could talk to your child's school about whether a similar plan would help them. If you write your own version of this plan, make sure it is short and to the point because teachers are busy and clear, straightforward information that is easily accessible will help them.

Example Behaviour plan for school

Check if he is displaying any of the following behaviours:

- Placing his token on the edge of his desk.
- Getting out of his seat.
- Being argumentative.
- Calling out.
- Being very quiet and fiddling more than usual.
- Muttering to himself.

If he shows any of the above behaviours, try some of these tactics:

- Suggest he goes to reception with a note.
- Give him some books to take to another teacher he knows.
- Suggest he goes to his quiet room or the toilet.

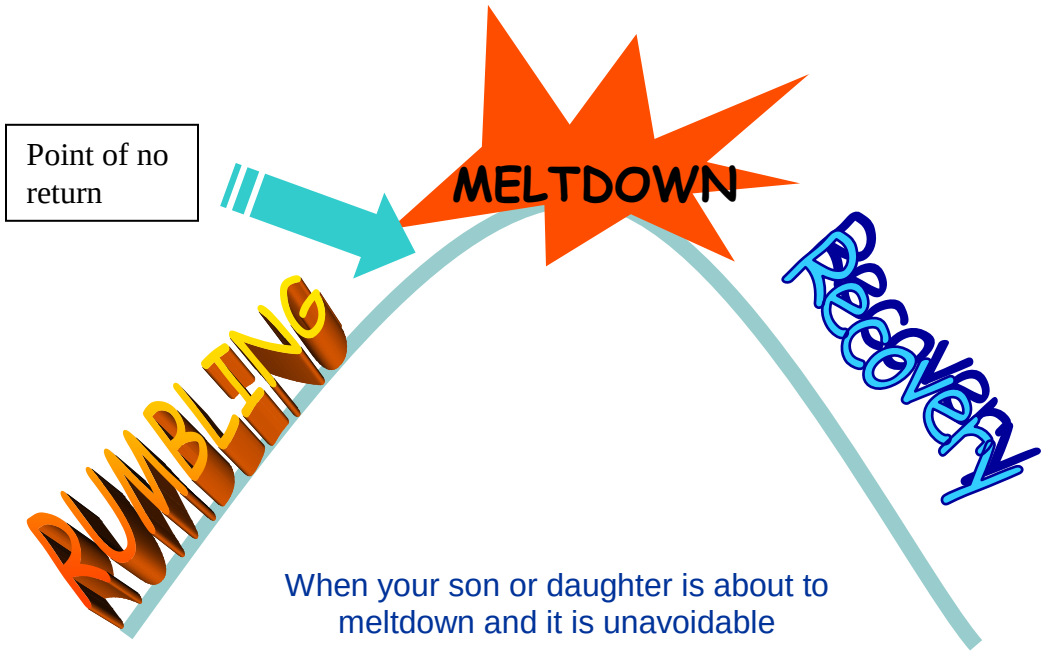
Some important dos and don'ts

- Do make sure a learning support assistant goes with him if he is in a very agitated state.
- Do remain calm and remember he has great difficulty understanding his own feelings and expressing them as well as other children.
- Do not raise your voice.
- Do not confront him.

- Do acknowledge he is looking angry or stressed, but do not ask him why.
- Do ask him in a friendly way, "How can I help you?" if the basic strategies do not work.
- Do say, "You can be excused from the lesson for 10 minutes" if he still doesn't give clues about what to do.
- Do think about removing the other children from the class, if he goes into meltdown – leave one adult with him, at a distance.
- Do not respond to swearing during a meltdown and don't talk to him unless he asks a direct question.

What to do when the meltdown starts

The point of no return is the term given to the moment when you sense that whatever you do, the meltdown cannot be avoided.



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Whilst we know that experiencing meltdowns can be upsetting for all those who are involved or who witness it, once your son or daughter has reached the point where they will have a meltdown whatever you do, it is best to let it happen as safely as possible.

Parents and carers need a plan to prevent meltdowns taking place even if they are common in children with autism. Having a meltdown plan won't stop meltdowns happening, however it will help to have agreed in advance what everyone involved will do, so the meltdown can be managed as safely as possible.

Write a meltdown plan for your home

You might like to write a short meltdown plan for use at home. Think about:

- some of the key things that cause stress, anger or anxiety
- the signs of a build-up in stress, anger or anxiety
- the things that help to reduce stress, anger or anxiety – distract, divert, change tack
- include things to definitely not say or do
- who does what if the child still goes into meltdown?

Agree who does what before it happens. For example, do you remove other children or remove the child with autism? Sometimes, it helps to stay in the room, but you need to think about whether doing this leads to (a) a shorter meltdown (b) less damage to your child or property (c) less damage to you?

"Leaving the room may work for younger son but for older son it increases the stress and he follows me out and swears at me even more."
Parent of two children with autism

Some parents find that it is best to leave the room where the meltdown is taking place. This may be because their child will be more destructive if sent to their room:

"He can't be sent to his room because he'll trash it so me and my other son go upstairs instead."
Parent of a child with autism

Or it may simply be because the child with autism won't leave the room anyway:

"Usually it is best to get his sister out first and then I follow…we can't get him to leave the room."
Parent of a child with autism

Make your home safe

Sometimes, it is necessary to think about making your home safe to prevent injury. Think about:

- removing breakables
- adding soft edging to tables, etc
- having curtain rails that don't come away from the wall – call the NAS's Autism Helpline for details
- removing pictures from walls
- using melamine instead of china, and plastic glasses instead of glass ones – place breakables in the loft for a few years?
- tying a towel around door handles to stop your children slamming doors
- locking cupboards and doors to keep siblings and their possessions safe.

Some children threaten to be violent. In these circumstances, it is best if you lock away any knives, scissors, potato peelers, lighters and matches as the safety of your family is important. If your meltdown plan is making the situation dangerous, stop using that strategy. Always get professional support if you or any family member is at risk of physical harm.

Some parents have had to resort to placing locks on their doors for times when their son or daughter becomes physically violent towards them and walking away provokes further violence. Parents in this situation should write to social services and contact the NAS's Autism Helpline for information.

Example meltdown plan to use at home

John meltdown plan – mum

If John is abusive - shouting, etc, but not physically aggressive, stay in room with him, but don't argue, just sit safely, little or no eye contact.

If verbal rant/meltdown carries on more than few minutes (and if safe to do so), leave the room. If he follows, say "OK I can stay in the room with you" and return to room.

If physically aggressive or threatening, say, "I need to let you have some time" etc and retreat. Lock yourself in bathroom if necessary.

Come out if no noise for several minutes. Don't try to talk to him for at least half hour.

John meltdown plan – dad

Get brother and sister out. Say, "Let's go out for a bit". Stay calm and don't shout back.

Look in if meltdown carries on more than five minutes. If mum says nothing, dad to leave again. If mum says, "I need a cup of tea", this means dad take over.

Meltdown plan for outside your home

If your child has regular meltdowns, it may be useful to create a meltdown plan for all the people who support your child, including family members, friends and clubs as well as their school. You will need to write one that is short and easy to understand. The following is just one example for a child at primary school:

Melissa Smith's eight-point plan for a meltdown

Melissa has had several outbursts recently during which she has hit herself or others or just been very upset and angry.

1. Remember NOT to intervene when she hits or slaps herself as this will make Melissa much worse and she will hit out and scratch whoever is with her or hit out at walls, mirrors or windows, which could be very dangerous.

2. Firmly tell her what you want her to do. Melissa needs support and encouragement to help her control herself at these times. Try saying 'hands down' so she won't lash out or 'sit down' so she is in one place where she can start to calm down.

3. Sometimes it is worth trying to distract Melissa by making silly noises or trying to make her laugh, but this depends on how upset she is and if you can catch things early enough.

4. Do not shout or tell Melissa to shut up or be quiet as it will make things much worse. If Melissa has gone past the point of being able to reason with her, you must make sure she is safe and let her calm down in her own time. This could take five to 20 minutes.

5. Do not try to intervene physically or directly discuss the problem with her, however hard this may be for you. Give Melissa the space she needs without putting her, or others, at risk of danger.

6. Do not leave Melissa until she is completely calm. She shows she is getting calmer when she starts saying things like, "I feel sad" or "Melissa is crying". Do not intervene before this or she will start up again.

7. She may want an arm around her and reassurance when she is calm.

8. Repeat any phrases Melissa may say to herself that reassure her that things are OK. For example, "It's OK Melissa, it's alright Melissa."

Key person, Mr Jones ext 456 Mum, Mrs Smith 07777 777777

After the meltdown – the recovery stage

After the meltdown, give your son or daughter plenty of time to calm down while their brain makes sense of what happened and their body metabolises adrenaline. They may need to sleep, be quiet or be alone – some children take over a day to recover.

Children vary in their need for physical contact after a meltdown. Some will need cuddles for reassurance; others will need you to give them plenty of time alone.

If your child can tolerate it, and when they are calmer after a meltdown, involve them by discussing how you can help them in the future with meltdowns. It is usually best to try and work together to problem solve. And it helps if your child understands you are on their side. For example, "Does it help if I stay out of the room when you feel like that?"

Try using a visual reward chart to tick off whenever your child uses strategies to prevent meltdowns.

One parent felt they had reached a breakthrough moment when her son was mature enough to begin answering questions about his feelings towards meltdowns:

> Parent: "How does your body or head feel just before you have a meltdown?"
>
> Child: "My head hurts…"
>
> Parent: "OK, when your head starts hurting like that next time, that's when it is time to stop doing what you're doing and go to your room."

If there has been an increase in meltdowns over a period of months consider removing more background factors that may be causing general stress.

Conclusion

Managing behaviour difficulties is not easy for young people with autism or you as a parent trying to help them. However the techniques discussed throughout the book are those which are tried and tested to work best over time.

By trying to understand things from your child's point of view, avoiding unnecessary confrontation, using clear communication and creating structure and taking account of sensory needs you will help to reduce some of the day to day behaviour difficulties your child and family faces.

When your child is getting close to a meltdown use some of the techniques we suggest may help to avoid at least some of the crisis situations and when meltdowns do occur, having a support plan will help you feel more in control.

Alongside changing how you as parent communicate with your child, it is important to help them understand how they tick. By knowing more about their own feelings aswell as how other people work your child will develop confidence and self esteem – the most important goal of parenting a child with autism.

Remember yourself in all this. You deserve good things as well as the rest of your family. You are the most important resource your child has so it is vital that you also get opportunities to do the things that help you re-charge. Unless you get an occasional break or even just some time to yourself you become worn out and therefore unable to support your child as well as you'd wish.

Parents often need support during this difficult stage of their child's development so do request support from others including parent support groups, health services such as CAMHS, your local authority and autism charities.

If you would like further information and advice, and to find out about the sources of support available to you and your family, call the NAS Autism Helpline on 0808 800 4104 (10am-4pm, Monday-Friday).

Further help and advice

Getting mental health support

If your child needs help with serious mental health issues talk to your GP, paediatrician, school nurse or primary mental health specialist (PMHS) - each school should have a PMHS attached to it) who may refer you to Child and Adolescent Mental Health Services (CAMHS).

CAMHS provide therapy and useful information on ways to manage anxiety and depression etc for young people and their parents.

If you get stuck contact the PMHS direct:

North Bristol: 0117 4142524
South Bristol: 0117 3408121
Knowle: 0117 9190330
East/Central Bristol: 0117 3408600

Getting education advice contact:

Bristol.autism.hotline@bristol.gov.uk
National Autistic Society education rights line 0808 800 4102

Getting general autism advice contact:

autismfamilycourses@bristol.gov.uk
National Autistic Society helpline 0808 800 4104

Getting social care support

If your child needs social care support from Bristol City Council request this from First Response 0117 903 6444

Recommended reading on behaviour difficulties

Powell, A. (2015) *Autism*: *Understanding and managing anger. (2nd edition.)* London: The National Autistic Society
www.autism.org.uk/products/core-nas-publications/managing-anger.aspx

Smith Myles, B. and Southwick, J. (2005). *Asperger syndrome and difficult moments* (2nd ed.) KS: Autism Asperger Publishing Company

Whitaker, P. (2001). *Challenging behaviour and autism: Making sense - making progress.* London: The National Autistic Society