



A Practical Approach
at Home for
Parents and Carers

Aspergers Syndrome (Teenagers)



Falkirk **Child**
Protection Committee



Falkirk Council
Children's Services

Children with Disabilities Team
Occupational Therapy



Contents

	pages
Creating a Supportive Environment	
1. Understanding Aspergers Syndrome and the Importance of Creating a Supportive Environment	2-3
2. Advice Strategies for Parents and Carers of Young People with AS	4-16
Creating a Supportive Leisure Environment at home	17-22
Creating a Social Family Environment	23-29
Thinking about Environmental Changes for School Leavers	30-32

A background image of a clear blue sky with scattered white, fluffy clouds. The clouds are more concentrated in the lower half of the frame, with the top half being a solid, clear blue.

Creating a Supportive Environment

1. Understanding Aspergers Syndrome and the Importance of Creating a Supportive Environment

People with Aspergers Syndrome (AS) are part of a distinctive group with common characteristics. In order to assist individuals to learn and develop, it is crucial that those around them understand AS and assist the individual to develop by providing structured teaching. This includes organising the physical environment and developing schedules and work systems which incorporate the use of visual material to make expectations clear and explicit.

With regard to the physical environment, people with AS perceive the world differently and many have difficulties making sense out of a lot of details.

People with AS first of all see the detail, and then try to get the meaning. It is therefore necessary to adapt the environment to suit each individual, to ensure that everything abstract (vague or theoretical e.g the concept of time) is made concrete and to ensure that structured teaching is carried out in the appropriate context.

If too much stimulation (something that produces a reaction/response) is available, people with AS are unable to grasp the meaning, particularly if stimuli change all the time. Consistency in the environment, approaches and positive routines may assist the young person to cope with daily living.

When adapting the environment, it is important to clear rooms of any unnecessary stimuli in order to allow the individual to understand the task and focus on what is expected of him.

When moving to new environments (e.g. leaving school) changes need to be looked at well ahead of time.

Some young people with AS may:

- Have a need for consistency of approach and for environment and routines to remain unchanged.
- Need flexibility to be specifically introduced to them to complement the consistent routines.
- Need a visual supportive environment encouraged.
- Have difficulty knowing how to spend time if it is unstructured.
- Have difficulty socially interacting,
- Find it difficult to think in a flexible style.
- Exhibit unusual or repetitive behaviours, such as hand flapping or fidgeting with clothes etc.
- Have sensory processing difficulties which lead to an extremely high tolerance to heat and/or pain.
- Be over sensitive and become overwhelmed by the noises of equipment or other people, smells and/or visual stimulation.
- Be sensitive to movement and have strong preferences and/or avoid certain movement which affects daily life.
- Not be aware of the consequences of actions or of danger.
- Display difficult behaviour in specific stressful situations.
- Have gross or fine motor difficulties e.g. find it difficult to manipulate objects.
- Be very dominating in a conversation, talking about their interests.
- Be unable to read non-verbal signals in conversation with others.
- Find sharing/turn-taking difficult.
- Have different motivators from others, often more concrete in nature.
- Need time and practice to transfer skills gained in one environment to another e.g. school to college.
- Need to have safety issues considered due to limited awareness of danger.

People with AS
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2. Advice Strategies for Parents and Carers of Young People with AS

Sensory information from their body and environment may not be processed accurately for a young person who has an AS. Information from all the senses, e.g. touch, taste, smell as well as planned physical movement requires to be organised to do tasks successfully.

Performing self care tasks involves a series of complex processes, such as sequencing, motor planning and body awareness, for example toothpaste has to be put on the brush before it enters your mouth. Other areas also have to be considered: adequate attention levels are required if the activity is to be achieved and a number of sensitivities to tactile experiences have to be overcome e.g. from clothes and towels.

Young people who have an AS may not be able to adapt to their environment, therefore changes may have to be made for them to maximise their potential. These changes will be applicable at home and any other environment in which the young person spends a substantial period of time. In teenage years people

may be learning self care skills as a priority. These may have previously been supported by parents or support staff for speed and to reduce stressful situations. Leaving school or home to go to college or new leisure environments may also require accurate knowledge of sensory strengths and sensitivities e.g. noise of different heating systems or new showers, colour or detail of new bedroom decoration. The following are suggestions of possible strategies and are split into sensory and general strategies. Each young person is an individual and the strategy which works for one may not work for another. Families and carers often know 'at a glance' which strategies will work and the young people themselves often recognise ideas which suit them. Occupational Therapist will be happy to advise if required.

Activities of Daily Living

Dressing



Sensory:

- Use comfortable clothes, consider type of fabric and length of sleeves.
- If the young person cannot tolerate labels, cut them out.
- If the young person cannot tolerate seams, undergarments can be worn to reduce friction.
- Try washing and drying clothes in unscented products.
- Dressing can be done in front of a mirror so as to provide visual cues to assist with sequencing, motor planning and body awareness.
- Be aware of other visual or auditory noises in the room which may be off-putting.
- If moving to a new environment small changes should be checked e.g. new washing powder, toothpaste, air freshener.
- Try an exercise routine of push-ups etc. to allow the young person to wake up their system.

General:

- Practise dressing skills in any new environment when there is plenty of time to complete the activity.
- Choose shoes with velcro or add velcro to button backs and zips.
- Organise drawers and put a picture label, if necessary, in front to enable the young person to choose their own clothes.
- If the young person has balance difficulties, try dressing sitting down.
- A dressing chart with pictures or "shopping list" effect may assist to sequence the activity.
- Organise a 'liked' activity at the end of dressing or sticker chart towards a goal to motivate if this helps the young person to focus.
- Time might be required for the young person to become familiar with a new social setting and to be fully independent e.g. new swimming pool or bowling alley etc.
- Social Stories to look at suitable clothing for different settings might help if the young person sees no need for style or blending in with dress sense.

Personal Hygiene

Sensory:

- Use non-perfumed soap.
- Be aware of bathroom lighting levels and minimise any noises, e.g. run the bath prior to entering the bathroom.
- Use deep touch when shampooing or drying with a towel.
- Before bath time some young people may benefit from activities that provide deep touch input, for example, a heavy blanket on shoulders applying moderate pressure.
- Make the transition from undressing and getting into the bath as quick and smooth as possible.
- If, as a young person disliked having his face or body washed when young, self-initiated touch produces a less defensive reaction and may now help towards independence.
- Use a large sponge or loofah sponge. Rub firmly to decrease defensiveness.
- If the young person is showering, use a hand held shower nozzle. This lets the young person control the direction and force of the water which may lessen defensive reaction.
- Keeping shower nosel close to body giving a solid jet of water might help deep pressure on skin and be a preferred showering style.
- Use a large towel and suggest quick, firm wrap round the young person. Avoid exposure of the wet skin to the air: the light touch may trigger a defensive reaction.
- Provide deep-touch using a towel to the head, hands and feet to decrease defensiveness. If the young person will tolerate it, provide a firm massage, using lotion to avoid skin irritation.
- Give a young person massage with lotion or oils to hands/feet etc. as part of routine. This might be an aid to de-stressing and a calming influence.

General:

- Choice of colour of facecloth, toothbrush etc may give a sense of more control.
- Where the choice is available, allow the young person to choose a bath or a shower. (A larger showerhead is often more acceptable to the young person, as it distributes the water more evenly)
- Try to incorporate bathing into a relaxing activity, for example jacuzzi, music, coloured lights.
- Talk to the young person and explain every step, particularly if you are going to touch them with soap or a towel to help. This may help them keep relaxed.
- Visual aids can be used in order to help the young person understand the activity, timescales and specific requirements.
- Consider adaptive equipment that may make the task easier, for example a grab rail may offer more support getting in/out the bath.
- After dressing consider an enjoyable activity as part of the routine.

Hair - Grooming Cutting Washing



- Set up clear routine for grooming.
- Encourage the young person to put their hands onto their head and exert gentle pressure for a few minutes before brushing.
- Encourage firm stroke or pressure as young person combs or washes hair.
- Count or have the young person count as you comb, wash, rinse or cut the hair.
- Give definite time limits to the task e.g. let's count to 10, then we will stop cutting your hair, provide deep pressure immediately after e.g. firm head massage.
- Break the task into small steps and eliminate any unnecessary steps or stages.
- Practise each step in isolation in a stress-free environment.
- Gradually combine these steps and perform the task in the natural environment.
- Try charts with motivational interest.
- Give choice of colour, shape etc. of brush.
- If going to hairdressers try and arrange for a quieter time. Check for environmental sensory difficulties e.g. colour and décor.
- Use Social Stories for events like hair cutting.
- Let young person try head massages to see if this helps to calm before cutting.

Toileting

Sensory:

- The young person may be sensitive to toilet tissue, try using moist toilet roll.
- Consider visual and auditory stimulation around and keep it to a minimum.
- New environments with transition to college or leisure activities can mean changes e.g. new toilet décor, hand dryers etc. may all affect a young person.

General:

- Visual aids can be used to explain task.
- Consider adaptive equipment e.g. would an extra rail be helpful.

Eating

Sensory:

- Certain textures may be avoided by the young person.
- Practise imitation games with tongue, lips and cheeks.
- Weighted cutlery may give an increase in sensory feedback so as to make the young person more aware of the appropriate movement.
- Give the young person a personal stereo, ipod to wear with calming music, this may make it more tolerable for them to sit at the table.
- Before meal times, provide deep touch and total body exercises to decrease touch defensiveness. This may help calm.
- Try to make mealtimes a relaxed, pleasurable experience. It may not be useful to introduce new challenges at meal times.
- Try to limit the number of new foods introduced at any one time.
- If eating out, try out new places at a quiet time. Think about the décor of restaurant and how it may affect the young person.

Oral Challenges



Sleeping

General:

- Try cutlery that is in a particular colour or theme to create interest.
- Try plates and cutlery with words on them to associate to task if eating is still a major issue.
- In new environment, check cutlery type etc. to see if there is a possible effect.

Picky eaters, specific intolerance such as not having different food on the same plate might be part of their routine. Chewing clothes, hands or other items might also be present. There may be a sensory element contributing to the development of these behaviours which an Occupational Therapist may assess for. In this case the following strategies may be helpful: (See also touch challenges, social and emotional environment)

- Redirect the need to chew to a more positive sensory activity i.e. chewy gum, crunchy foodstuffs.
- Substitute another item for the hand that is readily available e.g. wristband of suitable robust material.
- Provide a range of oral experiences throughout the day e.g. hot, sour, sweet, salty, cold, different textures.
- Try electric toothbrushes in a tooth brushing routine.
- Include some sensory experiences as part of daily routine e.g. massage, facial sauna etc.
- Develop a calming routine before bedtime. Encourage quiet activities.
- Use a heavy/weighted blanket or flannel sheets to provide deep-pressure and a calming environment.
- Use older fashioned layers of blankets rather than duvets.
- Try using tight sleeping bag.
- Check visually all bed spreads for too much detail or colour.
- Check all bed linen for texture and smell i.e. conditioners, washing powder etc. may irritate.

Adapting Environments

Developing a routine and a consistent way of doing things can reduce the impact of their difficulty with language or attention. Organisation can give the young person a sense of control in how they plan their day.

Inside

Sensory:

- Provide a place where the young person can take themselves for time out, for example a small area in the room. Young people with an AS often find dark and enclosed spaces calming.
- Avoid visual and auditory stimulation.
- If the young person has a positive response to movement try a rocking chair or hammock swing.
- Paint the young person's room soft, pastel colours and put dark blinds or lined curtains on windows to prevent light distracting the young person.
- If possible, situate the young person's room in a quiet corner of your house.
- Give the young person "heavy" tasks around the house, for example carrying the shopping, arranging tins on shelves. This may have a calming and organising effect.
- Provide a three sided work station for the person to work independently.
- Young people can learn to tolerate and anticipate such activities such as vacuuming but be aware it can raise stress.

General:

- Label cupboards in the kitchen or bathroom with pictures so that the young person knows where to find things.
- Minimise clutter.
- Try using a diary or photo book with familiar pictures, such as buildings, family members, to ease the transition to different situations.
- Try to structure the child's time and consider introducing an 'activity schedule'
- Build a daily routine to give clear structure to changes such as leaving school.
- Create a weekly/monthly calendar with what is happening in house or out and about, and with whom, use pictures.

- When sharing a bedroom with a sibling, setting clear boundaries between personal space may be helpful.
- Provide a range of favourite activities that can be engaged in independently for short times.
- Store equipment in closed containers which can be moved to a designated area when it is time to move to another environment/activity e.g. from leisure time to bathtime.
- Consider clearly marking a work area in any environment.
- Use structured charts to leisure as well as other activities.
- Timers, clocks, egg timers etc. might help set time limits to special interest activities, topic of conversation etc.
- New technology e.g. palm top planners etc. can be investigated.

Outside

Large leisure equipment can be used at home, e.g. garden bench with swing effect. Local park or leisure centre could be an area where a young person can exercise and use energy. Accessing local facilities may be more suitable at less popular times to reduce noise levels and distractions. Leisure areas that have clearly defined boundaries may be preferable. The following pieces of equipment can help the young person with positive sensory experiences.

- Swing, therapy balls, trampoline or space hoppers for movement.
- Swimming for tactile and movement experiences.
- Shed or tent to provide a safe and calming area.
- Small summer houses with their own choice of activities inside.

Noisy Public Environments

- Whenever possible consider additional planning for special events such as firework displays, birthday parties, football matches.
- Is there a quick exit route if the young person becomes stressed? Is there a special fidget toy/routine/contact that can be used to calm the young person?

Walking

- Consider lack of awareness of direction, if young person is getting lost and plan for this.
- Consider when to carry out everyday activities. Is there a less busy supermarket, or off-peak time? Is there a quiet space available e.g. dining booth?
- Consider having the young person wear snug clothing e.g. lycra undergarments.
- Consider having the young person wear earplugs or ipod. This may help to drown out environmental noises and help the young person stay focused on an activity.
- Consider larger, heavier earplugs if they cannot tolerate small ear sets.
- Young people may not see the point in going for a walk without clear purpose.
- Have a clear route that can be described, or use pictures of your route.
- Have a clear timescale – e.g. we are going on a 10 minute walk round the pond.
- Consider taking a fidget toy along in their pocket.
- Use motivators, charts or special interest after walk.
- Walking is good to incorporate into routines as it can be exercise, calming and time-filling in a positive, low maintenance way.

Garden Creativity

The garden can provide positive experience to give a young person calming times, time alone or with friends. Time to 'let off steam' is essential to all young people but especially people with AS. It can be planned to meet individual needs unique to the young person and their family.

An assessment can be done by an Occupational Therapist to look at this with families.

A number of positive calming activities in the garden for young people with AS can be discussed with an Occupational Therapist by families who wish to design a garden or buy outdoor leisure equipment.



Falkirk Council Social Work Services - Community Service has an interest in assisting in garden development. If parents wish to enlist assistance with design and practical manual work this can be arranged via the Local Authority Occupational Therapist.

Although funding for practical ideas which families may feel beneficial in the garden, is not available, many charities will support this for families and applications/referrals can be made by the Occupational Therapist.

Some of the following may be helpful to consider:-

- Creating sensory areas - small safe hidden areas or use of garden sheds with suitable activities can create a calming experience.
- Large climbing frames, trampolines, chutes and swings may give the young person the experiences of movement they need.
- The dislikes, likes, motivations and pleasures can be carefully looked at to give a unique experience which a young person can have in their garden environment which is vital to family life and support at home.
- Night lighting, gazebos and sheds allow the experiences not to be curtailed by weather or the dark.
- Small water features can be extremely calming or give something to distract when things are difficult for a young person. Likewise, small wind chimes, musical chimes, light reflector ornaments or spinning activities may be both aesthetic and enjoyable.

The garden may be an area where, as a family, a shared experience with a young person can take place or simply be pleasurable for the rest of the family as a calm, quiet area.

Functional Communication to Access the Environment

Young people will benefit from visual schedules for the day even when they have no apparent verbal difficulties. These may be pictorial, symbolic or written. Sometimes a sensory element to this can be helpful to reinforce other senses e.g. music associated with set routine. This is crucial in the home or other environment. The young person in school should be using this to some degree. At times of change e.g. leaving school, it is important to pass on clear information about the most beneficial supports to communication. These almost always include visual supports.

It may:-

- help the young people predict what will happen.
- support spoken instruction regarding transitions.
- provide a constant reminder.
- support their understanding of the sequence of events.
- introduce new activities in the context of familiar activities.
- introduce planned change to their daily/weekly routines.
- support the young person's independence.
- give motivation to see point of activities.
- enable to work out timescales.

It should be used when:-

- The young person needs structure.
- The young person struggles to self-occupy.
- The young person has limited sense of his/her day.
- The young person needs help to predict or organise his day.
- The young person needs to know what is expected of them.
- The young person is limited in what they see the point of.
- The young person is moving to a more adult environment to help them understand what is happening and what is expected of them in the new setting.

It can be carried out simply in the home by:-

- Choosing the visual system e.g. concrete objects, photographs, symbols, written word - this can be with advice from the Speech & Language Therapist.
- Organising and sequencing timetables, before the start of the day/evening.
- Keeping the timetable in a recognisable place for each young person.
- Keeping the timetable portable. When the young person makes any physical transitions, help them retrieve their timetable.
- Reviewing daily timetable at start of each day/evening, with each young person.
- Employing 'Point-Say-Do' principle for each activity on the timetable.
- Actively showing and reinforcing when each activity is finished by turning over the symbol/ticking the word/putting the object in the 'finished' box.
- Gradually fading your physical/gestural prompting, allowing them to develop their responsibility to use and learn from their timetable.
- Using the timetable to emphasise clear beginnings and ends to activities.
- Using calendars and planning in advance may reduce anxiety of not knowing what is happening. It might also help with timescales.
- Using new technology - palm tops, mobile phones etc. in innovative ways to suit young person's support needs in communication.



Creating a Supportive
Leisure Environment
at Home

Leisure In The Home

Leisure at home is something all young people have as part of growing up. Sometimes this is spent alone, sometimes with siblings, friends, relatives or parents. It can be planned or spontaneous. It can involve the whole family. Leisure experiences are often the occupation of young people at home. It happens so spontaneously families do not notice it or how it happens. Young people with Aspergers Syndrome (AS) need help to learn to access leisure and/or engage with others. Often for them it is a skill to learn. Often families need to understand leisure from their young person's world.

Children with AS may:

- Need a routine to leisure activities similar to other daily task routines.
- Need to be taught the rules in detail.
- Enjoy activities in different ways, which families need to understand and value.
- Need someone supporting alongside if they are to begin to develop a new interest meaningfully and are to have the potential to be more socially involved with others.
- Be distracted by a lot of detail or sensory difficulties.
- Need encouraged to extend from only one activity or occupation by introducing a second experience for short periods.
- Need only one sensory channel to attend to at a time e.g. something to see only or something to listen to or something to smell etc.
- Need communication in activities at an appropriate level.
- Need no more than a few choices presented at a time.
- Need support engaging with peers.

Leisure for most young people regularly includes games and activities. Young people with AS often do not see the point of activities or enjoy the social interaction if often involves.

Young people with AS may:-

- Have set ways of enjoying activities and need help to develop new pursuits.
- Not be motivated by activities like their peers.
- Become overloaded with too many people and choices.
- Have difficulty jointly interacting in leisure activities.
- Easily end activities when first interest has gone even if others still enjoying them.
- Have difficulty with imagination games.
- Require games which are easily built or have few small parts due to co ordination challenges or, conversely, love lots of small detail and pieces to fix.
- Need others to value activities which interest them.
- Need support to socialise with peers.
- Need help to learn and understand unwritten social rules which others find come naturally.

Leisure Environment

Leisure needs to be in an environment with safety checks as young people may not perceive danger that others see easily. Any possible sensory overload needs to be looked at in the environment. Activities in the outdoors need time with others supporting. This encourages joint activities but also stops a young person becoming too isolated or withdrawn. The activity needs to motivate the young person. Often a lot of movement, jumping, swinging etc. can help a young person calm down and they benefit from daily exercise, motor skills and positive sensory stimulation. Familiar layouts need to be available to relax a young person enough to engage in the serious business of leisure pursuits.

Bedroom

- Structured activities.
- Reduce clutter to a minimum.
- Boxed and labelled games.
- Change game boxes available in a routine.
- Consider creating a “den” area with enjoyable activities.
- Consider aromatherapy at bed time or other helpful routine if smell is a motivator.
- Consider colour and décor of room.
- Consider visual daily routine, including leisure, on bedroom wall.
- Use large cardboard box with lots of different ideas inside e.g. sensory box.
- Consider carefully sensory distractions or pleasures to build enjoyable, relaxed atmosphere.

Family Area

- Have activities in a box your young person likes to take out and explore as a family or with one other family member.
- Have a box for special visits i.e. “gran’s” box.
- Set time limits for family times in routine. This helps the family feel there are clear boundaries but time together.
- Trying different music together or with cards with happy or sad faces if you like or the young person likes the music.
- Rough and tumble for all - try using large balls or adult sized space hoppers to reduce the amount of time adults have to take the weight of everyone i.e piggy-backs.

Outside

Large play equipment - try out swings, hammocks, trampolines etc. before you buy to see if your young person enjoys certain experiences - often certain movements are very motivating for a young person.

Activity Challenges/ Reinforcers

Split in your mind activities which reinforce and motivate your young person (these would be activities they would voluntarily engage in) and activities that challenge and they would not normally initiate themselves or keep up without help.

Use reinforcers after a short period of challenging activity.

Reinforcers are often special interests, sensory activities or liked activities i.e. computer, games console.

Leisure Challenges/ Reinforcers

Playing with peers is often very challenging for a young person with AS. Understanding hidden rules of games, confusion as other children change their minds/fall out etc. are bewildering. You need to be the supporting person to play with friends to build up skills in this area.

Having a friend for tea or attending a school friend party do not come naturally to children with AS and need your help planning and developing strategies. As the teenage years have their own "teen culture" you need to be very aware of this and teach your young person the "rules". A circle of trusted friends about your young person's age or an older sibling or cousin may help with this.



Leisure challenges you may encounter, with ideas for you to consider:-

Play Challenges	Ideas
Times when they are not able to focus on any activity	A small calm area with textured cushions etc might be the best place with one preferred activity e.g. "special interest".
Hates activities others love	If you feel this helps them work with others, keep it to only a few minutes at first and then gradually increase the time. Consider visual schedule with favourite activity straight after. You might however accept that they don't wish to be involved.
New activities are engaged in rigidly one way	Don't give a new activity to be explored until you both sit down with the activity and open its secrets.
Finds return from school hard to join in with family	Give time out. A young person in school all day needs time to relax. Perhaps time on the trampoline or swing or a walk might help. Time alone or a set homecoming routine before they face mixing with friends.
Specific social events like parties are stressful and not a pleasure for my child but they want to go	Using social stories are helpful. These explain simply the unwritten, confusing rules to young person's experience. Using cartoon drawing with speech bubbles/think bubbles can help a young person understand.
Having someone to 'tea' is stressful	Plan the event carefully. Do something you can do with the young people i.e. a game. Only gradually increase 'free play' as it can be bewildering if you don't know how to relate to someone. Activities like trampolines are good for being together without much conversation being required.
"Special Interest" take over, talking about it or constantly engaging in it	Try setting time limits as to how long the young person can talk about it. Set routine for the interest. Remember the special interest often calms a young person so do not try and get rid of it altogether. Most likely it will change many times over the years.



Creating a
Social Family
Environment

The Social and Emotional

Research shows that a young person with Aspergers Syndrome (AS) can cause a great deal of extra stress in family life, particularly for mothers, and over holiday times. Families may benefit from support from services and their extended family to help them meet these challenges.

Siblings require support and time with their parents and may also benefit from support from other services.

Short Breaks schemes, befriending and young carers support groups all give space and time to families. The home environment however can be designed to allow families to get the best out of their time together.

The following are practical, environmental supports which might be helpful:-

- Co-ordinating services where possible so that the choice is not either/or but both e.g. befriending and play schemes. Planning in advance with school dates and service providers giving the most family friendly package.
- Help to co-ordinate and plan schedules in the most appropriate visual format can be provided. These are often used in school but are seldom available for families to use at home. If this support works well in one environment, it can be used to support the young person in all environments.
- Planning family routines to include time with activities for each person, different combinations of family members and as a family may help bring predictability for the young person.
- Planning in advance special events, either social or of more practical or care needs e.g. shopping, hairdresser etc..
- When planning leisure experiences either with parents, siblings, extended family or carers activity boxes with individual, liked activities may be helpful.

Keeping a diary of any challenging incidents can help identify trigger times or situations.

- Using choice in small things may be helpful in preventing difficulties in daily life tasks e.g. a choice of blue or red face cloth, the green or blue toothbrush today. This may also help build in flexibility.
- Using emotion cards to display how someone is feeling may help families not only express how they feel but get the message across.
- Planning "free" or "down" time for a young person. Young people with AS often do not cope well with unplanned time. To afford the family the opportunity to have this "down" time it can help to make a number of choices available for the young person to self-select.
- Keeping a diary of any challenging incidents can help identify trigger times or situations directing alternative ways of doing something.
- Family life is not normally as structured as school. Many families feel that they would like this time to relax and not rely on fixed routines which resemble work. Young people with AS however, thrive on routine and it should be seen as a challenge to get the balance right. Achieving this for individual families means that everyone feels supported. Often professional support is helpful here to suggest a diversity of ideas.
- Returning home after a period of intense social concentration e.g. from school, is often a critically difficult time. Planning and thought to using this time is particularly important. It may be that carer support will be the most helpful at this time, or that the young person needs directed to an activity they particularly enjoy, or to use a quiet area.

Each family member needs time to relax

- Transitions between activities often does not seem relevant to the home environment. However, if transition cards, objects or counters are used elsewhere, this may be helpful also to reduce stress moving on to different times of the day within the home.
- The young person's bedroom is often a source of stress or a place of relaxation. Use of the bedroom during the day for activity can be planned and activities, games and layout considered. Routines or changes in layout (e.g. tidying up in boxes at night) may help night to be different.
- Often more unusual routines begin due to young people growing up and developing unique ways of managing their world. All these unique features need to be considered in the light of their developmental stage. The family may need support to help the young person manage their world, to prevent unhelpful routines being established.
- Each family member needs time to relax. Parents often feel guilty taking time to care for themselves. It is essential that this time is taken to build a strength and inner support to be enabled to meet the care challenges. Often families need help realising and accepting this.

Response to physical touch can also affect emotional attachments in a family. Sometimes this is affected by the young person's ability to tolerate touch or need for touch. This can have great impact on the social and emotional wellbeing of the relationships with family and friends.

The following may be helpful to consider to help improve physical tolerance:-

Touch Challenges	Suggested Strategies
<p>Young person withdraws or punches others who touch him lightly. Young person reacts negatively and emotionally when touched lightly (exhibits anxiety, hostility or aggression).</p>	<ul style="list-style-type: none"> • Teach others to touch the young person firmly. Explain that the young person feels light touch more strongly and as if he/she were being hit. • Approach the young person from within his/her visual field. • Teach friends and relatives to show affection firmly and directly.
<p>Young person reacts negatively when touched from behind or when touched by others.</p>	<ul style="list-style-type: none"> • Tell the young person when you are going to touch him/her. Always touch firmly. Assure the young person that you will touch firmly and that you will not move your hands unpredictably.
<p>Young person may prefer the father's firm touch to the mother's firm touch.</p>	<ul style="list-style-type: none"> • Tell the young person what you will do and how you will do it. ("I'm going to hug you really hard."). Respect the young person's need for control.
<p>Young person may pull away when approached for a friendly pat or caress from a relative or friend.</p>	<ul style="list-style-type: none"> • Make relatives aware this is hard for a young person. Find alternatives both happy with.
<p>Young person may reject touch altogether from anyone but his mother or primary care-giver.</p>	<ul style="list-style-type: none"> • Teach people always to approach the young person from the front and always make sure the young person is able to anticipate the hug or expression of affection.
<p>Self-stimulatory behaviours are often oral e.g. hand-biting, spitting and prompted by anxiety. This can deter other people from building relationships.</p>	<ul style="list-style-type: none"> • Provide as much explanation of the situation as possible. • Use of alternative oral stimulus e.g chewing gum, crunchy foodstuffs.

Challenging Behaviour and Environment

Often families are aware that many difficult times with their young person can be as a result of frustration, confusion, altered routine and poor communication. Supporting families to give a full home environmental assessment and alterations to day or building can still leave families with times when incidents of challenging behaviour can be displayed. Close liaison between all agencies is vital to support behaviour. However, the routine, environment or communication challenges can also be a vital part. In the home with each family's unique needs, likes, enjoyments and challenges the support should be ongoing and altered to suit these needs.

All the environments the young person is in should share experiences which might reduce the behaviour challenge in one or other environment.

People with AS often find there is an innate weakness in empathising with others' feelings, understanding their

motivation and predicting others' behaviour. Specific features which help make life calmer like routines, time alone or rituals when anxious often clash with what is happening in family environments.

Understanding that their behaviour is often communicating stress or anxiety or, perhaps, bewilderment at others' behaviour is difficult for a busy family to bear in mind.

As young people develop, each stage may see a change of behaviour. Adolescence is a time when challenging behaviour may be affected by mood swings, puberty, sense of wellbeing, mental health. Depression particularly affects many young people with AS and may need careful monitoring.

Crisis situations when a young person displays severely challenging behaviour or distress at home can affect the whole family. Support of Psychology and Psychiatry may be essential.




Challenges may be supported in the home environment by looking at the behaviour at its different stages.

- **Triggers** - The cause of the situation. For young people with AS it may involve their routine being interrupted, a sensory overload of sound or light etc., relating to too many people at once or a demanding situation which is difficult for the young person and where they cannot ask for help. Times of the day - like the return home from school. At school leaving age the change may be a source of stress and can trigger difficulties.
- **Escalation time** - Sometimes the stress of socially interacting e.g. school, may mean that suddenly when a young person returns home they lose control for a time. Other times a longer period of building up anxiety is a pattern and reading the signs at an early stage could prevent escalation. Teaching the young person to look at the escalation in terms of a visual scale of number or traffic lights of red, amber and green or some other scale with strategies to reduce anxiety and de-escalate at an earlier time may be helpful.
- **Crisis** - A clear view of how families are going to handle the problem may need to be planned. Calm and consistent responses by families are hard but essential.
- **Recovery** - Time it takes and best method of achieving this needs clearly stated. It may be time alone or doing enjoyable activities needs to be in place.
- **Discussion & Planning** - Talking about the incident with the young person later may be best supported visually. Showing pictures of feelings displayed and looking at how things can be done differently may help the young person understand. Consider using social stories or cartoon pictures.

Calm and consistent responses by families are hard but essential

Escalation Time

Examples of individual agreed strategies:-

Picture Feeling	What I do
 Calm	Feel positive and able to attend to tasks
 Slightly anxious	Helps to play with fidget toy or Gameboy (likely if waiting in queue)
 Very anxious and angry	Will tell mum and get out of situation for a few minutes.

Number Feeling	What I do
1 Calm	Feel positive and able to attend to tasks
2 Slightly anxious, anxious	Helps to play with fidget toy or Gameboy (likely if waiting in queue)
3 Quite anxious, feel hot and flustered	Helps to ask for a drink of water to calm down.
4 Anxious, angry, very fidgety	Need to tell someone I need to get out for a few minutes.

Thinking about
environments that
change for
school leavers



The changing environment of the school leaver

When young people are leaving school they become involved in more adult environments e.g. college, work/voluntary work, places of leisure. This is a time of change for all young people.

Young people with AS have specific challenges. Difficulties such as new experiences, changing physical environments, routines, structures and people are stressful.

New sensory experiences both positive and negative are evident. Higher anxiety levels and social behavioural norms all present challenges. Time spent on planning the transition from known to new environment is essential.

The young person may:-

- Need planned changes to start earlier than most other young people.
- Need clear likes and dislikes to be considered and incorporated into new environments.
- Not be motivated or understand the need for the change and need help to move on.
- Require time to practice independence skills in new environment.
- Need everyone to be aware of triggers to anxiety/stress clearly known so they can be avoided or a plan to support can be designed.
- Need individual communication system clearly logged and all new people made aware of it.
- Need skills and practice in new travel routes.
- Need clearly designated space and time alone to de-stress.

- Need control of organising laying out of new room or new environment to help feel safe and calm.
- Need clear routine/structure in new activities set up.
- Need calming activities built into new routine to de-stress.
- Need exercise routine to allow calming or letting off steam in new daily routine.
- Need lots of time to familiarise themselves with new situation.
- Have non-negotiable routines which must be present to help adjustment.
- Need one-to-one support of carer for a time to adjust even when this has not been needed in school.

Think Checklist

An audit of the young person's new environment may require to be done to reduce possible trigger stressors and help positive experiences. Home, leisure activities, colleges, clubs etc, times alone and with others need to be investigated. Thinking about this carefully will make a positive difference.

Be a detective to look at the environment in the light of sensitivities and preferences of young person and the needs of other people in their world.

Think 'Sensory'

	Preferences	Sensitivity
Light	<input type="checkbox"/>	<input type="checkbox"/>
Sound	<input type="checkbox"/>	<input type="checkbox"/>
Touch	<input type="checkbox"/>	<input type="checkbox"/>
Smell	<input type="checkbox"/>	<input type="checkbox"/>
Taste	<input type="checkbox"/>	<input type="checkbox"/>
Movement	<input type="checkbox"/>	<input type="checkbox"/>

Think 'Thinking Style'

Visual learner
Attends to detail
Routine
Structure
Concrete concepts

Think 'Communication'

Oral
Written
Picture
Symbol

Think 'Social'

Time alone
Strategies for social setting
'Special interest' time
Social cues/hidden rules
Understanding of social boundaries

Think 'Emotion'

Anxiety levels
Stressor factors
Calming strategies

Think – Ritualistic/obsessional behaviour

Non-negotiable rituals
Time needed in behaviour
Change in amount of time when anxious

Think The needs of those who care or support.

Family
Befrienders
Carers

The time of change can be a positive time when a young person's family feels that they are moving forward together to independence and new stage of life. Thinking about the environment helps this progress smoothly.

This booklet was compiled by:

Children with Disabilities Team
Camelon Social Work Office
108B Glasgow Road, Camelon
Falkirk FK1 4HS
Tel No: 01324 506400
Fax No: 01324 501201

If you would like this information
in another language, Braille, LARGE
PRINT or audio, please contact your
local Social Work office.

Polish

Jeżeli chciałbyś/chciałabyś uzyskać owe informacje w języku innym aniżeli język angielski, w języku Braille'a, w DUŻYM FORMACIE lub zapisane na kasetach audio skontaktuj się z lokalnym biurem Opieki Społecznej (social work office).

Lithuanian

Jeigu jūs norėtumėte gauti šią informaciją kita kalba, Brailio šriftu, stambiu šriftu ar įgarsintą, prašome susisiekti su jūsų vietiniu socialines rūpybos ofisu.

Arabic

إذا كنت بحاجة الى هذه المعلومات بلغة اخرى، بلغة حروفية
وا مسجلة صوتيا جوا منك لأصل بتب الخدمات لتعليم المحلي.

Urdu

اگر آپ یہ معلومات دوسری زبان، بریل، بڑے حروف کی چھپائی یا آڈیو میں چاہتے ہیں تو برائے مہربانی اپنے لوکل سوشل ورک آفس سے
رابطہ کریں۔

Chinese

如果你希望獲得此份資料的其他語言、凸字、大號字印刷或者錄音格式，
請與你附近的社會工作辦公室聯絡。

Punjabi

ਜੇਕਰ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਜ਼ਬਾਨ, ਬਰੇਲ, ਵੱਡੀ ਛਪਾਈ ਜਾਂ ਆਡੀਓ ਤੇ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਕ੍ਰਿਪਾ ਕਰਕੇ ਆਪਣੇ ਸਥਾਨਕ ਸੋਸ਼ਲ ਵਰਕ ਆਫਿਸ ਨਾਲ ਸੰਪਰਕ ਕਰੋ