Part 3:

Advice for Family and Carers

Glossary of Terms
Advice for family and carers

We would like to acknowledge the following text on advice to family, carers and teachers to the Oxford ADHD Protocol Group who kindly gave us full permission to adapt it as part of this document. This was from the version of January 2005 devised by Oxfordshire Child and Adolescent Mental Health Service and Oxfordshire County Council’s Learning & Culture Directorate.

Attention Deficit and Hyperactivity Disorder (ADHD)

Advice for Parents from the Oxfordshire Educational Psychology Service

Some children are difficult to parent. When such a child is the first child in the family, it’s all too easy for parents to feel that it is their fault, their inexperience, and feel bad as a consequence. When the child is not the first child in the family, and other children have proved to be more amenable to guidance, it may be easier to recognise that the child has specific difficulties. It can happen that parents, family members or friends may see the child as deliberately wilful and difficult. Whatever the child’s position in the family, there will have been a period of time when the extent of the child’s difficult behaviour has become clear and some strategies have been tried and been found to be unsuccessful, and the growing sense of feelings of guilt and failure lead to parents seeking outside help. While an assessment and a diagnosis of ADHD can come initially as a relief to parents, it is actually only a point in time where there stands a signpost indicating the way forward.

As you begin to prepare for your journey, it is essential to be realistic about what has gone before. Your child has been difficult to parent, you, your family and your friends, have had all kinds of ideas about why that might be the case and these ideas have led to feelings about your child, about yourselves as parents, and about the help you get from your network of support in your family and community. It might help you to discuss these feelings with someone you trust, so you can be clear that they are based on the difficulties you have had in the past and do not write a script for the future. As a parent you will have tried a variety of strategies in the past and have felt moments of despair when you have been quite sure that nothing has worked. Hard though it is, you need to look at strategies again with a belief that you can be successful and while your child is difficult to parent, she/he can be managed more effectively.

There is no ‘magic wand’ or one way to deal with children who are diagnosed as having ADHD. Like all children, children with ADHD are first and foremost individuals. Each one is different. Their difficult behaviour and the ways significant adults in their lives have sought to manage them, have been incorporated in their self image and are a complicating factor in their responses in the future. The impact of those difficulties on parents, siblings, school friends, and local community, form some of the hazards that lie ahead to be negotiated as you journey with your child and family, to manage this
special child in your midst. Advice can seem simplistic, but it can be a way for you to develop your own path forward.

**Structure**

Before you make any changes to the way you manage your child, you need to reflect on the times when the difficulties have been most pronounced. Often you will find that these are times in the day or the week, when you are very busy, or tired, or the expectations placed on your child are complex. For example, it could be getting ready for school, settling to go to bed, or when it is the end of playtime and you want your child to shift from one activity to another. Think through these difficult times looking at:-

- The sequence of events.
- Timing.
- The extent to which you were able to give undivided attention to the child.
- What else was happening at the time.
- How much of what you sought to achieve is essential and what you can put to one side.

You may be able to restructure some parts of the day to support your efforts to manage your child. For example, having a bedtime routine which has short achievable steps that can be consistently followed by everyone who has to manage the child, is likely to lead to more successes. Children with ADHD have had feelings of being out of control and seeing those around them fail to manage. Clear consistent structures will help them be in touch with what is being expected of them and will be a basis on which they can develop self control.

**Routine**

Children need routines and children with ADHD need routines more than most. Children with ADHD have difficulties with personal organisation and particularly with changes. What routine does is bring stability and predictability into their lives, thereby reducing the extent to which they are faced with complex demands. It’s helpful to plan routines with some thoughts about encouraging the kind of behaviours that you want. For example, having a routine of expecting your child to get dressed in the morning, eat breakfast, and pack his/her school bag before being allowed to play or watch television, means your requests to get ready are more likely to be successful because they are followed by the ‘reward’ of play or television. Planning stable routines makes demands on adults too. Continuing with this example, it could well be that you as parents need to get up earlier to establish the steps of the routine and have time for some positive consequences before you leave the home for school. Children with ADHD need routines with clear instructions and adults with time to ensure that these are followed up.
Being Calm

The more you can use structure and routine to organise the expectations of your child, the more likely you are to be successful. However, there will be times when your child is particularly difficult. It could be when she/he is presented with facing changing demands, or when other family members are having difficulties, when the child with ADHD can behave in ways which are particularly challenging and difficult to manage. At these times, it's important to remember that success in managing your child is something that will come gradually and there will be days or times when you feel that things are worse than ever. If your child is behaving in a way which is particularly difficult, it's important that you don't overreact. The following can help:

- Being still and calm yourself.
- Looking carefully at what your child is doing and the situation in which you find yourself so that you are aware of the range of influences on your child and the options for you.
- Being clear with yourself if there is any intrinsic danger in the situation so that you will have to act immediately. If there is no actual danger, and you are not clear what to do, quietly restate an achievable expectation for your child, for example ‘talk quietly now...be careful with your toys...If you want a drink sit down’.
- Sometimes a diversion can help, for example, ‘We could have a drink together when you've picked up the Lego’. 'Could I help you finish that so...
- Remember that most of us take time to calm down and your child will too. Going over what has just happened only prolongs the situation. Far better to say, 'I like it when you're calm...I like it when you smile at me.'

Children with ADHD can be very loud, vigorous, and unpredictable. If we mirror this then we make the situation worse.

Avoid confrontation

Confrontations are essentially sudden challenges where there is often no obvious way to go forward by negotiation. If you think about it, confrontations are the opposite of the structure, routine, and calm atmosphere that we have been talking about. There will be times when your child’s difficult and impulsive behaviour challenges you and catapults you both into a situation which has the features of a confrontation.

As adults and parents we have high expectations of ourselves. We expect that we should know what to do. Actually, confrontation is a situation where it is not obvious what to do next. One golden rule in such a situation is that if you don’t know what to do, don’t do anything at all. This is not you being weak, you are being strong to resist the temptation to ‘put your foot down’ and you are modelling calm, thoughtful behaviour. It can help to say out loud, ‘This is very difficult. I am going to think about what to do.’ You can make it clear that while the situation is ongoing, you are unlikely to give in to
demands, for example, ‘While you are kicking the chair, we will need to have the television off’.

If you recognise patterns in the situations where there are confrontations between you and your child, you can plan beforehand how to manage them. For example, if it’s at the end of a playtime when the expectation is that the child clears up, you could talk to your child before the toys come out saying, ‘It’s difficult to end playing with toys. I’m going to give you a 5 minute warning when it’s time to tidy up and I’ll be there to help you do it’. Then remembering to give the 5 minute warning and being ready with your undivided attention to help the child manage the transition time from playing to whatever is next.

Clear positive communications

Children with ADHD are difficult to manage, they tax our resources, and when we are busy or tired, it’s all too easy to lapse into being quite negative and blaming the child. We have all caught ourselves saying in a raised voice, ‘Stop shouting!’ Children with ADHD need clear, achievable instructions and this means that we as adults and parents need to think about how we speak to them. If we are to help them manage their own behaviour, then we need to be clear what it is that we want them to do. We need to be in the habit of making it clear to them, particularly when they are very young. We also need to recognise that they may only be able to manage what we ask of them for a short period of time and that we as adults must plan to have other activities rather than expecting too much of them, for example, having sat down we can’t expect them to sit there too long. It’s far better to say, ‘Sit down to play with the farm animals, and then you can play with your ball for a time’.

Notice good behaviour

How often do we all as parents find that when our children are behaving themselves and occupied in what they are doing, that we heave a sigh of relief and get on with things we need to do? It can often be the case that it is difficult behaviour that draws us into intervening with our children. We are then paying attention to inappropriate behaviour. This pattern is all the more likely for parents with children who have ADHD. They can be so tiring and taxing to supervise and manage, that when they do behave themselves, it’s hard for us to recognise the short period of appropriate behaviour and reward it, albeit that it might be 5 or 10 minutes in a day which has felt like a battleground.

As we talked about earlier, your child’s difficult behaviour and the ways adults have dealt with this in the past, will have undermined his or her self esteem. Finding times in the day to recognise and praise the child with ADHD for appropriate behaviour is vital to encouraging more of that behaviour and building self esteem. Like any other child they need to feel good about themselves and they need to feel that they can do well. So however insignificant or brief is the behaviour, it needs to be noticed and the child needs to be praised. Most of the time, some clear acknowledgement of their
achievement is all that is needed, for example ‘I really like the way you played with your brother’.

It is important not to overdo using tangible rewards or you can get locked into a cycle of ‘payment’ for good behaviour. A smile or praise from a parent is powerful encouragement. When you do use rewards, it would be more manageable for you if you can incorporate them into part of your routine, for example, ‘You have played so nicely with your brother, perhaps you would like to come and help me choose what we will have for pudding after tea.’ Don’t assume or expect a short period of appropriate behaviour can continue for too long and don’t use it as a basis for you highlighting how difficult your child can be. For example, saying things such as, ‘You spoiled it all now you have upturned the game’… or, ‘Why can’t you always be like this’. Try to remember that paying attention to good behaviour means it is all the more likely to happen again. It is a basis for building your child’s self esteem, and it is an experience of positive interaction with an adult, all of which your child needs.

When all else fails

No strategies for managing children with ADHD work all the time. Children with ADHD are difficult to manage and we as parents are all human! For all of us there will be the time when your child’s behaviour is out of control. Learning to recognise when a situation is escalating to a point where control will be difficult, is a task for you. If you can see such a situation looming, then practising what we talked about earlier with regard to looking, being calm and quiet, and stepping back, might be useful. There will be times when you feel that all else has failed. It helps if you have thought out strategies beforehand. Helpful strategies can include:-

• Effective use of ‘time out’ for example, insisting that the child sit for 5 minutes on a stair in the hallway or counts to 20 (or more) out loud with you as a way of breaking in to the outburst.

• It’s a matter of judgement whether it would be useful to remind the child of the likely consequences of the outburst. Sometimes this can only make the child more cross and desperate. If you are going to do this, it can help to give the child some leeway. You can make it clear there is an obvious gain to calming down, for example, ‘If you could stop this before I count to 10, then you won’t lose your pocket money or have to go to bed early or’…

• If the outburst is extreme but the child is in no danger, it may well help if you can just take yourself out of the situation. This isn’t giving in, it’s recognising that your child is at a point whereby self control has gone. While you remain in the room the implication is that you as the adult/parent are in control. Leaving the room, if it is safe to do so, means the message is the child must control themselves and there is no one to fight with about that.
• When you are not at home, outbursts are very difficult to deal with. Don’t feel pushed into doing something to manage your child because of what you imagine other people might think. More people than you realise will be remembering times when they have been in your situation, understanding how you feel and wishing you well. Outbursts that happen outside the home need to be dealt with then and there. Threats of consequences later when the child is in a different situation are unlikely to be effective. You will have to use the experience to plan strategies for when it happens next time and/or to avoid the circumstances/situation that led to the outburst.

**Look after yourself**

Children with ADHD are difficult to manage. They tax our resources as parents, undermine our self esteem, and tire us out. Sometimes, your child may be hitting siblings and/or you. Perhaps the most important suggestion anyone can make is that you look after yourself. You need to do this in ways which increase the likelihood that you will manage your child successfully. Ideas for doing this include:-

• Make sure your partner, family, or friends, understand that you need some time to yourself and a break from managing your child with ADHD. People want to help, be clear what would be useful to you to give you some respite and a rest.

• Try to meet up with other parents who have children who have been diagnosed as ADHD. Nothing helps so much as knowing that you are not alone. Talk to your Health Visitor, G.P., staff at your local Family Centre, or ask at the library, where there might be a support group where you could meet other parents in the same situation.

• Your child with ADHD is difficult to manage and you need to avoid expecting too much of your child, but also expecting too much of yourself. Looking for the things that have gone well in a day is more likely to help you, than dwelling on the situations that have gone badly. Being able to recognise the times when you have been able to take a good step forward with your child, will refresh and encourage you to continue along the path from that signpost which was at the start of your journey.
References


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Surrey Educational Psychology Service (1995) *Current issues, research and developments in Attention Deficit Disorder (ADD)*. Kingston upon Thames: Surrey EPS.

Surrey Educational Psychology Service (1996) *ADHD: Guidelines for Good Practice*. Kingston upon Thames: Surrey EPS.


[www.santa.inuk.com/indexpage.htm](http://www.santa.inuk.com/indexpage.htm) site for those wishing to look at approaches opposed to medication.
Glossary

Attention Deficit Hyperactivity Disorder (ADHD), refers to young people whose behaviour appears to be impulsive, overactive and/or inattentive to an extent that it is unusual for their developmental age and is a hindrance to their social and educational success.

Behaviour Support Teacher (BST), a specialist teacher who visits schools on a regular basis to support pupils, staff and parents with pupils’ emotional, social and behaviour issues.

Child and Adolescent Mental Health Service (CAMHS), a team of psychiatrists, clinical psychologists, psychiatric nurses and family therapists who assess and treat people with mental health difficulties/issues.

General Practitioner (GP), a family doctor who advises and treats general illnesses, and refers to other medical services.

Educational Psychologist (EP), visits schools, nurseries and family centres on a regular basis working with teachers and parents in a joint problem solving capacity to assist children’s learning and behaviour, assess psychological development and special educational needs.

Emotional and Behavioural Difficulties (EBD), is a term used about young people whose emotions and behaviour are presenting significant hindrance to their social and educational success.

Health Visitor, a nurse who has had extra training in advising parents on child development issues such as feeding problems, immunisations, behaviour difficulties, support, and local services.

Individual Education Plan (IEP), is a way of planning and reviewing what is arranged in school for pupils with special educational needs. It is a working document for all teaching staff recording key short-term targets and strategies for an individual pupil that are different from or additional to those in place for the rest of the group or class. The interventions are geared towards different levels of need: school action, school action plus, and statements of SEN.

Initial action, an optional first level of intervention when the class or subject teacher believes the pupil stands out from others and is not helped by the normal range of provision in the class/school.

Multi-agency, when professionals from more than one agency work together.

Pastoral Support Programme (PSP), is set up to help a pupil who is at serious risk of disaffection or exclusion. If, in addition, the pupil has SEN the IEP should reflect appropriate strategies to meet their learning needs.
Personal Education Plan (PEP), some pupils in public care have underperformed in school. The PEP is led by the Social Worker and is aimed at ensuring that these pupils achieve as well as possible in school.

Pre-school Teacher Counsellor (PSTC), supports and advises parents of pre-school children with significant special needs, developing home-based learning programmes with them and other early years professionals.

Request for statutory assessment of SEN, if a pupil’s difficulties are severe and persistent despite a well planned and consistent intervention package, it may be appropriate for the school, in consultation with the parent/carers and the school's link EP, to request a formal assessment of the pupil’s Special Educational Needs in line with the SEN Code of Practice (2001).

School action, when a class or subject teacher identifies that a pupil has special educational needs they provide interventions that are additional to or different from those provided as part of the school’s usual curriculum and strategies. An IEP will usually be written.

School action plus, when the class or subject teacher and the SENCo are provided with advice or support from outside specialists. At this stage of action, additional interventions and different strategies to those provided for the pupil through school action can be put in place. The SENCo usually takes the lead although day-to-day provision continues to be the responsibility of the class or subject teacher. A new IEP will usually be written.

School Nurse, visits school on a regular basis to ensure the health needs of children in school are met, and who acts as a link to other services.

Social Workers, advise families about services available and assess children and families' needs for support including respite care and short-term care.

Special Educational Needs (SEN), refers to any difficulty a young person may have that affects their educational achievement or behaviour in school.

Special Educational Needs co-ordinator (SENC0), there is one in every school and s/he has responsibility for ensuring pupils’ additional needs are met by: liaising with staff; organising teaching assistants; arranging reviews; giving advice about assessment, targets and interventions; and, completing paperwork.

SEN Code of Practice, a legal document from the Department for Education and Skills (2001) that describes a graduated response to recognising and then supporting pupils with SEN, with the school intervening as described under school action and school action plus.

SEN Register, found in each school and records the pupils with SEN on the SEN Code of Practice.