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AD/HD - An Overview

AD/HD is a condition in which there is developmentally inappropriate attention and/or hyperactivity and/or impulsive difficulties that are so pervasive and persistent as to significantly interfere with a child's daily life. It is more common in boys than girls and affects between 3-5% of the school age population.

The core AD/HD symptoms are:

- Excessive distractibility or inattentiveness trouble paying attention, being easily distracted, not remaining focused, procrastinating and not listening.
- Impulsiveness all children are impulsive to some extent, however, the impulsiveness with AD/HD excessive and causes ongoing difficulties with physical or verbal impulsiveness. Such children speak without thinking of the consequences of their words, call out in class or interrupt their parents' phone conversations. They also do not see the consequences of their physical actions and will run on the road or do other things impulsively rather than maliciously.
- Hyperactivity is the other core AD/HD symptom. This frequently lessens with time but nevertheless in many children it is persistent and severe. Such children are always on the go, cannot sit still at mealtimes, are fidgety and restless in the classroom and are often very rough in their physical play.

As your Consultant will discuss, these are the core AD/HD symptoms. Some children have all of them, some are just inattentive and have never been impulsive or hyperactive, and some are more hyperactive/impulsive and less inattentive. There is a wide range of ways in which a child with AD/HD comes to the attention of his parents or teachers as having difficulties. Nevertheless, for a diagnosis of AD/HD to be made there must be excessive problems with one or other of the core AD/HD symptoms.

Having been through an initial diagnostic assessment as to whether or not a child has AD/HD the Consultant will have evaluated whether or not there are also complications of your child's AD/HD. Frequent complications include Oppositional Defiant Disorder (being excessively like a teenager in behaviour, even from a very young age), having Conduct Disorder or antisocial behaviour, being anxious, depressed or obsessive, having tics, features of an autistic spectrum difficulty, or excessive moodswings, specific learning difficulties such as dyslexia or speech and language or coordination problems. Not all children with AD/HD have these complications but many children have one or other, and sometimes a number of these difficulties.

Other problems that frequently occur with AD/HD and are more problematic the longer the AD/HD goes untreated, are problems such as low self-esteem, socialising difficulties, demotivation, hypersensitivity or relative academic underachievement.

Long term studies show that about 70% of children with AD/HD will continue to exhibit features into adulthood. They also show that children who receive adequate treatment for AD/HD tend to have fewer problems at school with peers, with substance abuse or with overall behavioural and educational difficulties. Whilst the problems experienced by people with AD/HD vary enormously, at the very least they significantly underachieve in a wide range of areas if their condition is not adequately managed.

It is very important that as parents you and your child become empowered in the management of your child's condition. This means that you must become well informed on the condition, able to make management decisions within parameters that will be spelled out for you by your Consultant, and able to act as your child's advocate so that all members of the team, including the school and the physician, are able to work together in your child's best interests.

There are a wide range of books available, some of which are detailed below. There are also a number of websites mentioned below from which you may obtain further information. It is important, however, to note that on the internet there are also a number of websites with fallacious and misleading information. The websites listed below are generally those where factual and informed information is available.

Many parents also feel somewhat helpless and confused in the initial weeks following a diagnostic assessment. There has been a great deal of misinformation in the media about the condition and it is important that you obtain factual information. There are now clear international guidelines on the existence and management of AD/HD. In the UK the guidance from the National Institute of Clinical Excellence 2000 is particularly informative and can be accessed via the website below. European guidelines on the management of AD/HD have now been published and there are guidelines from the American Academy of Pediatrics. These will help reassure you that the approaches taken by your Consultant are very much in keeping with international opinion on the management of this condition and are based on research and clinical practice which enables your child to be helped to the fullest.

Management of AD/HD

There are a range of management options available and most experts agree that the combination of treatments that are best suited to the individual child should be utilised. Prior to starting effective management, many parents have trialled alternative therapy. Whilst there is no objection to this, benefits of these treatments have generally not been scientifically evaluated or proven to be helpful in the treatment of AD/HD. You will be advised to discuss such treatments with your Consultant in an informed way prior to proceeding. Such treatments could include biofeedback, dietary restrictions or supplemental diets, mega-vitamins, herbal supplements, sensory integration therapy, and allergy treatments.

A <u>Parent Education</u>. As outlined above, becoming informed about the true facts of AD/HD and avoiding the misunderstandings and misinformation is a critical part of overall management. Parents

must be able to distinguish between fact and fiction and between good and bad advice. This is a never-ending process – there is an enormous amount of information available about AD/HD and the co-existing conditions. The field continues to develop rapidly on an ongoing basis.

Behavioural Management. Behavioural management has been shown in controlled studies to be an effective treatment available for AD/HD. Behavioural modification therapies include social skills training, behavioural therapy and parent training. Details of these are available on other LANC handouts. Such strategies can also be useful at school and information is available for teachers.

At home it is often difficult for parents as well as others to view a child's apparently wilful misbehaviour as being due to a valid medical disorder. It is important to emphasis that AD/HD is not an excuse – rather an explanation. Having a 'disability perspective' is often helpful. Protecting and enhancing self-esteem is always essential and it is important as much as possible to try to avoid being overly-critical and to emphasise the child's 'islets of competence'. A supportive and empathetic communication style is helpful. Recognising that structure is critical for children with AD/HD with daily routines, consistency and organisation being present. Behavioural management strategies are very helpful and help parents feel better prepared to deal with the daily challenges of parenting a child with AD/HD.

C <u>Educational Strategies</u>. It is important that as a parent you develop a good rapport with the school. Generally schools are recognising AD/HD as a valid condition and this is very helpful. In situations where this is not the case attempts should be made to introduce an evidence-based approach to the school. The LANC has a School's Liaison Officer who would be able to assist with this. It is important that as a parent you become an information source on AD/HD so that you are able to work with the school in your child's best interests.

Not only is feedback from the school essential in helping to guide effective management, but an understanding of schooling strategies, behavioural management and the reasons why a child with AD/HD, especially if there are complications, may act in a certain way at school, must be understood. For example ongoing detentions for a child who is always late or who does not turn in his homework can be counter-productive. Much better would be to arrange accommodations to enable the child to perform adequately in these areas with a resulting improvement in self-esteem. The LANC has a separate advice leaflet for schools.

- Counselling. Although this has not been shown to treat the core symptoms of AD/HD, it may help the child better understand the disorder and its impact on those around him/her. It can be particularly helpful if there are issues relating to self-esteem or social skills, or overall family issues. Siblings frequently suffer also because of the other child's AD/HD and may need help in their own right.
- <u>Medication</u>. Details of medication are discussed in the accompanying medication handout. In essence, medication is frequently suggested as part of a multi-modal management plan in a child with significant AD/HD. This is based on a wide range of international data that shows clear improvement in core symptoms and complications when AD/HD is effectively managed as part of an overall treatment plan. In addition there is very strong evidence that the basis of most children's AD/HD is an underlying neurobiological or brain chemistry difference. The use of medication should be seen as

providing a window of opportunity to put a floor into the situation and stabilise it so that educational, behavioural and other strategies can be more effective.

The media have tended to grossly over-emphasise the side effects of these medications and only rarely point out the reasons why medication is considered in an individual child. It is therefore critical that parents place side effects in perspective, look at the relatively low incidence of short term side effects with these medications, the paucity of evidence of long term side effects, and the fact that at least 90% of children with significant AD/HD can be effectively helped with the use of medication. It is also important to recognise that AD/HD is rarely a static condition, its difficulties frequently persist and often magnify with time. The long term for many children with AD/HD can be quite serious in terms of the risk of psychiatric disorder, antisocial behaviour, long term underachievement as well as problems with relationships, jobs and academic underachievement.

The decision to medicate is never one that is taken lightly and should always be done, as at the LANC, after a comprehensive assessment to assess whether or not the child has AD/HD. Ongoing monitoring is also essential and your child will be seen on a regular basis at the LANC. Communication between appointments is always available by phone, e-mail or letter. The clinic's ethos is to aim to empower patients as much as possible so that they can be informed and proactive partners in their child's management. In doing this, however, they must not the limitations and be trained to recognise when they need to seek help from the LANC.

The child may well benefit from medication for several years. Whilst some children outgrow the need for medication and their symptoms improve with time, in the majority clinical experience shows that medication is generally helpful on an ongoing basis throughout school years – especially until the child has passed GCSEs. Depending on other environmental supports then available, the child's intelligence, the adolescent may possibly outgrow the need for medication, however, in others the need for medication persists into adulthood. It is always important at that stage to try to encourage your child to become good at topics that interest him/her as many children with AD/HD are able to over-focus in such areas.

The medications most commonly used to treat AD/HD are as follows:

The various methylphenidate preparations – Ritalin, which has a short-acting effect lasting about four hours, Slow Release Ritalin, which lasts six to eight hours, or Concerta XL, which lasts ten to twelve hours.

Other preparations used are Dexedrine, or Strattera. Strattera has recently obtained a UK product licence and its place in the overall management of AD/HD is still under scrutiny. It appears to have an advantage in its length of action and its general calming of behaviour.

Other medications may be considered for possible use, usually later, by your child's Consultant. Such medications may include Clonidine, which can be helpful with impulsive or oppositional behaviour or tics; Risperidone, for impulsive aggression and occasionally antidepressants may be used. However, such medications should only be used by experienced Consultants, such as at the LANC, and you would be fully informed if such medications are being considered.

F Other Complications. For other specific comorbidities, or complications, such as specific learning difficulties, speech and language problems, coordination problems etc., specific further assessments or therapies may be suggested. For example LANC has an Occupational Therapist who is able to assess and help children with coordination problems and at times can visit the classroom to observe the child in class. The clinic is also able to access specific help for learning difficulties and speech and language problems.

Whatever combination of treatments is eventually decided on, in conjunction with yourself, it is crucial that the child's progress is monitored. This will involve monitoring of their own views on their progress, as well as the view of their teachers and parents. However, remember that all children with AD/HD – and no doubt your own child – have very marked strengths as well as the difficulties of their AD/HD. It is important that the effective management of your child's AD/HD effectively addresses these difficulties, whilst enabling his/her very real strengths to show through.

Also remember that AD/HD is frequently genetic and that quite often one or other, or both, parents might have AD/HD. An awareness of this sometimes does not happen until the child is diagnosed, but it can be very useful, both in helping the parent's life, and also that of the family as a whole.

Some resources that you might find helpful are detailed below:

Kewley GD (1999) Attention Deficit Hyperactivity Disorder: Recognition, Reality and Resolution. Reprinted by David Fulton Publishers 2001

Green C, Chee K (1997) Understanding AD/HD London: Vermilion Press

Barkley, RA. (1998) Taking Charge of AD/HD: The complete authoritative guide for parents New York, Guilford Press

www.chadd.org www.addiss.co.uk www.lanc.uk.com www.help4adhd.com