



talking about
Attention Deficit
Hyperactivity
Disorder (ADHD)

This booklet reflects many discussions, suggestions and comments made by health professionals, professional bodies, lay and voluntary organisations, people with ADHD and their friends and family.

Health Scotland would like to thank all of those who contributed in any way to the development of this booklet, for so willingly giving their time, and sharing their expertise and experience.

All the quotes in this booklet are from real people.

Disclaimer

Every effort has been made to ensure that this publication is as up-to-date and accurate as possible. However, new research can sometimes mean that information and recommendations change very quickly. Changes and alterations will be made at the next reprint to reflect any new information.

While the booklet represents the consensus of good practice, please remember that different circumstances and clinical judgement may mean that you have slightly different experiences.

If you have any doubts, worries or fears, then do not hesitate to contact your doctor for reassurance and further explanations.

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introduction

Attention Deficit Hyperactivity Disorder, or ADHD, affects up to 5 out of every 100 schoolchildren. Although it is generally associated with children, it does not always disappear when those young people grow up. *Some* of the symptoms of ADHD persist in *most* cases.

This booklet is for adults and young people who have ADHD. It's also for families and friends, and for people who would like to know more about how ADHD affects people. It contains information on how to get help and tells you about books you can read. A selection of useful sites on the internet has also been included.

what is ADHD?

ADHD is noticeable in some children in the pre-school and early school years. It can affect as many as 5% of school-age children in Scotland, which means that in a class of 33 children, it is likely that 2 of them will have ADHD. Boys are four times more likely to be diagnosed than girls. It is now known that at least two-thirds of those children who have ADHD continue to experience the symptoms when they become adults.

"Teachers have never liked me."

"I was constantly in trouble at home and at school and my exam grades were always terrible."

"Why does no one want to play with me?"

There are several different types of ADHD and they vary considerably. While the most obvious example would be the hyperactive/impulsive type, there is also the daydreaming-inattentive type, and some children and adults with ADHD can have a combination of both. Some types of ADHD display anxious, sad or inflexible behaviour.

All children are naturally boisterous and energetic but for children with ADHD, such behaviour is exaggerated and that makes it a problem. Children with ADHD can be disruptive. They can take a long time to settle into a task, sometimes have difficulty concentrating and it is not unusual for them to have specific learning problems. (Around 20% of children have co-morbid specific learning difficulties whereas most children's learning is affected by their ADHD, because they cannot concentrate). They are often easily distracted, failing to pay attention to what is being said, and not always managing to finish what

they are doing. They can be impulsive, responding too quickly before they have taken time to consider things properly. They often find it hard to sit still for any length of time, constantly talking and interrupting, and they can be clumsy in the way they relate to people. People with ADHD sometimes have short-term memory problems and learn to overcome that by making lists. Having trouble sleeping is also relatively common and is generally the result of taking stimulant medications for their condition.

Their behaviour can be very frustrating for other people, especially those who do not understand what is causing it. Other children will leave them out of things because they find their behaviour annoying, and adults are quick to condemn and judge without examining the reasons behind what they see as 'over the top' behaviour.

"I love my brother but I don't like being seen with him because he keeps picking fights with bigger boys and it gets me in trouble."

Children with ADHD are often aware that they are different and they are very sensitive to all the criticism they receive. That can have a very negative effect on their self-esteem. Being rejected and misunderstood can be very hurtful and can have a very negative impact on them. When their condition is not recognised and therefore not treated, they are known to under-perform at school. As the situation worsens, they can become depressed and often have problems with relationships or keeping a job, and sometimes resort to criminal behaviour.

"I'm sad about all the time I've lost."

"I feel worthless."

early professional diagnosis is vital

It can be difficult to recognise ADHD because there are so many possible symptoms, and many of them could be put down to other conditions or problems. Some children with autism can have ADHD as well, and it calls for highly-trained professionals to recognise whether certain

behaviour is caused by autism or ADHD. While the conditions of both autism and ADHD might be affected adversely by sensory stimulation, for example, the autistic child is more likely to settle down once that stimulation or irritant has been removed. The process of diagnosing ADHD usually begins with your doctor who may offer some advice and support before referring you to a

specialist. An assessment is then carried out, usually by a child psychiatrist or specialist paediatrician. They will observe, and examine the different patterns of behaviour before making a thorough assessment of your needs and recommending treatment.

“All the time I was growing up, everybody talked about me being hyperactive but nobody ever thought of getting me tested. I went through school being totally miserable.”

“Getting tested, diagnosed, and put on medication, was like a miracle to me.”

Inattention, hyperactive and/or impulsive behaviour present for at least six months are key to the professional diagnosis of ADHD.

Inattention includes not paying close attention to detail in schoolwork or other activities, not listening when told something, not following instructions or completing tasks and avoiding those that take a mental effort, having trouble organising activities, losing necessary things like assignments or books, being forgetful and being distracted by irrelevant information.

Hyperactivity is more physical. It includes fidgeting, moving from the seat, running or climbing when it is unsuitable, being unable to play quietly, talking too much and always being 'on the go'.

Impulsivity means answering questions before they have been completely asked, impatience at having to wait for things and interrupting other people.

ADHD in adults

We tend to think of ADHD as something only children experience, but over the past 20 years, it has been recognised that many older adolescents and adults have ADHD too. The obvious signs of ADHD in children are not the same for adults, who have to deal with more complex and less easily-defined issues.

"It seemed I was always walking around in a blur. I couldn't concentrate on what people were saying and I couldn't seem to remember anything, no matter how hard I tried. I felt angry and irritated a lot of the time, especially when there was a lot of noise or too many people around."

When ADHD has been unrecognised in children, it can have repercussions when they develop into adults. They may see themselves as undependable, worthless and as failures, and have to learn all over again how to cover up their symptoms. They can be bored with repetitive tasks, fail to focus, plan or organise their lives effectively. They often put off doing things, demonstrate impetuous temper and frustration and have difficulty committing to jobs and relationships, which makes others resentful and critical.

understanding ADHD

There is no single cause of ADHD but there is growing scientific evidence that points to both neuro-biological and genetic factors. It is thought that a chemical imbalance in the part of the brain that controls attention, concentration and impulsivity, makes it hard to sort out all the information being received. In addition, there is evidence showing that ADHD often runs in families. Many children with ADHD will have relatives, usually male, who also have ADHD. It is also believed that environmental factors influence the severity and the course of the disorder.

Many parents feel guilty when their child is diagnosed as having ADHD, but it is not caused by poor child rearing methods. However, parents can help their children by being attentive to any changes in their children's behaviour. Early recognition will give a much greater chance of successful treatment and ultimately to the children fulfilling their potential and going on to lead full and satisfying adult lives. It is very important that families, teachers and mental health practitioners work together to assess the behaviour and work out the best ways to manage it.

getting help

Before ADHD can be treated, it has to be diagnosed. To diagnose ADHD, mental health professionals ask parents and teachers to observe children and rate their behaviour using specific questionnaires or checklists. These checklists rate behaviours present in most people with ADHD: distractibility, inattention, free associations to other ideas, impulsivity and moodiness, insatiability, temper outbursts and hyperactivity.

The best way to treat the symptoms of ADHD and associated problems is by a combination of approaches. Depending on need, the mix may include medication, behavioural therapy, psychotherapy and various educational techniques. A treatment plan unique to each individual should be devised so that people with ADHD can lead as normal a life as possible, enjoy good relationships and foster harmony within the family.

It is likely that the treatment will be set up by a specialist child psychiatrist or paediatrician who will then liaise with the family doctor. They may all decide to share the care, provide regular progress reviews and arrange follow-ups. It is really important to access as much information and advice as possible in order to make the best treatment choices.

In the case of adults, once diagnosed, many adults learn how to manage ADHD by educating themselves on methods of coping. They often use the same medication as prescribed to children, in a different dosage. Creating a stable structure in their lives, organising and building in time-management and planning skills, is crucial for adults with ADHD. So too is living and working in a positive environment.

medical treatment

Medication is not always necessary and the decision about whether or not a child should take anything should be down to the family in consultation with specialist child psychiatrist or paediatrician. Generally, the medications prescribed for ADHD are psychostimulants. Psychostimulants work by changing or re-balancing the levels of natural chemicals in the brain. These treatments help the controlling and inhibiting part of the brain to work in a more normal way. They increase concentration and induce calmer behaviour. Antidepressants are usually used when individuals do not respond to stimulants or have intolerable side effects from them. They are not as effective however, for those who experience impulsive behaviour. Atomoxetine hydrochloride is the first non-stimulant option for treating ADHD. It works by increasing the levels of a natural chemical called noradrenaline which is involved in passing messages between brain cells. Noradrenaline is important for regulating attention, impulsiveness and activity levels.

"I felt I was acting like a zombie when I was taking the medication but to be honest, I still preferred being like that than the other way."

Medication, which is always given alongside psychological and educational support, does not provide a permanent cure. It does however create a breathing space for children to learn and practice new skills. Not all children with ADHD need medication but those who take

it often report that they can think more clearly, understand things better and feel more in control. They also talk about getting on much better with other people.

However psychostimulants should not be taken lightly and it is advisable to talk over any concerns with healthcare professionals. Different medication produces different side effects, including excessive sleepiness or difficulty in sleeping, loss of appetite and stomach ache. Some people react better to medication than others. Every individual should have an independent treatment plan.

In the past, there was a reluctance to prescribe psychostimulants to adults but that has changed. However, when treating adults, physical deterioration including bouts of insomnia, loss of appetite, palpitations, nausea, constipation, blurred vision and dizziness, and the possible presence of other medical conditions, must be taken into account.

“It was a wonderful feeling, sitting down and watching a thirty-minute TV programme without feeling like I was going to burst.”

therapies and educational techniques

Behavioural therapy and *psychotherapy* can be used together with medication to control difficult behaviour, and improve self-esteem and achievement by encouraging correct behaviour and discouraging problem behaviour.

Cognitive Behavioural Therapy (CBT) and Dialectic Behavioural Therapy (see Talking about Personality Disorders) help to recognise then break the relationship between upsetting situations and the conditioned reaction to them, relaxing the mind and body so that they can deal better with the mix of emotions they feel.

“I was always saying really stupid things and acting too wild. I couldn’t settle down to study and I only got by because I was clever.”

Educational techniques are used to help the child perform better at school. To be effective, parents and teachers need to work together. The techniques are designed to teach self-control, improve confidence and educational performance through developing positive rather than negative behaviour. Assigning short tasks, helping with study skills and offering regular reminders, for example, can all help.

In school, children with ADHD can be offered support with reading, spelling, maths and organisation of their work. Some also profit from working with other health professionals, overcoming language difficulties with a speech and language therapist, or learning to coordinate their movements better with an occupational therapist.

For children with ADHD, the problem does not stop at the classroom door. Social skills training can help those children with ADHD who have difficulty understanding the social rules. It can be hurtful and unnerving when they make mistakes and the other children tease them, but they can be taught in groups to think about how their words and behaviour affect those around them.

A lot has been said in the press about complementary therapies that can be used alongside or instead of drug treatment. Many of them focus on food. Some parents have noted definite improvements when they take caffeine or artificial colourings out of their child's diet. However, there is very little medical evidence to suggest that changing eating habits or using certain herbal remedies, will necessarily benefit those with ADHD. And while therapeutic massage, relaxation training, meditation or hypnosis are effective in helping reduce stress in everybody, there is very little evidence to suggest that they will do much more than that for people with ADHD.

what you can do

Like everyone else, people with ADHD need to look after themselves. That means eating healthily, being physically active and for adults with ADHD, drinking in moderation. The 'feel good' factor can also be helped by learning new skills, taking time to relax, enjoying different creative activities and keeping in touch with friends or making new ones by joining a club or volunteering.

practical help

It is not only those with ADHD who find it lonely and difficult dealing with the problem. Families and friends need a great deal of support in coping too and it can be very comforting for them to meet other people in similar circumstances and to find out how they manage.

Support groups offering a drop-in facility, advocacy, a helpline and group meetings can often provide that kind of reinforcement and can also be an important source of practical advice and information.

Parents can also attend parenting classes, as well as join associations and self-help groups to ensure their concerns and opinions are heard. Another type of support includes befrienders, a network of people who volunteer to spend time to support people in a crisis. And when families feel overwhelmed, they can seek relief from the stress of caring for someone with ADHD by taking respite breaks. Befrienders and respite breaks can often be accessed through the Social Work Department. Because each individual case is different, the care and support offered to those with ADHD, and to their families, has to be based on their own specific needs.

the role of partners, family and friends

"I worried all the time about being in trouble. I hated it so much when the teacher shouted at me and then I got home and my mum shouted at me too. I knew I was clever but I stopped believing it. I just saw myself as someone who was lazy and who was a real pain for everyone."

Life can be very difficult for the families of children and young people affected by ADHD. Some cope better than others with the pressures.

Parents are the single most important people in the lives of young people with ADHD, and how they deal with it helps determine how well the condition will be managed and how much easier life may be for those

children. Although their lives may be chaotic, it is essential that parents somehow find the strength to provide consistent discipline and a stable, structured family unit.

Maintaining strong links with those professionals, the educational, social and medical practitioners who are working together to help the children, is also vital. Their assessment of the treatment's success will be based on the information parents can give on any noticeable behavioural changes, improvements or setbacks.

"She's driving us all crazy. She's breaking up the family because the others don't want to live in the mess she creates around her. The weird thing is, she doesn't think she's doing anything wrong. I just can't make her see how hacked off we all feel."

some tips for worried parents

- Work with the teacher to make simple changes that can help your child.
- Keep a record of what your child is experiencing.
- Talk to the family doctor about your child's symptoms.
- If there is no other physical explanation, ask for your child to be referred to child and adolescent mental health services or to paediatricians.
- Start reading up on ADHD and the available treatments yourself.

"I realise now that it's OK not to like my child on the difficult days. I just make sure she knows I love her."

- Make a trial run with the recommended treatment and watch your child closely to see if there are any obvious changes.
- Make your house an ADHD-friendly space by providing as much structure and predictability as possible, and make rooms accessible so that books, etc. can be easily located.
- Make rules, complete with rewards and consequences.

For adults with ADHD, relationships can be problematic and their partner, friends and families need enormous patience in dealing with it. Partners often feel that they are forced to take the main organiser role and the stress of that can cause problems. One way of addressing such a situation could be to make lists for both and decide which partner is best suited to each task.

It can be very difficult too for family and friends of adults with ADHD who deny that they have it. To be really supportive, they have to find a way of persuading that person to seek a diagnosis. It is important to note that people with ADHD can have other conditions like depression and anxiety disorders as well (see *Talking about Depression* and *Talking about Anxiety*) and that can make diagnosis difficult. However, if the diagnosis suggests ADHD, friends and family should encourage treatment.

the future

There has been a tremendous breakthrough in the understanding of ADHD and in the research and provision of treatment for managing it. This is likely to continue, and the policy of promoting early diagnosis is likely to result in huge numbers of children and young people being able to live relatively 'normal' lives.

"I'm probably going to be on medication for the rest of my life, and I'm not really too happy about that, but I would never want to go back to the way I was before. I know I have a future now."

With help, most children with ADHD should have settled down by the time they are teenagers and, with the right kind of support, they should be able to catch up on their work and learn how to make friends. As they grow into adults, most learn to channel some of the energy into more socially acceptable activities.

useful addresses

The national organisations listed below can put you in touch with local sources of help in your area.

ADD Information Services (ADDISS)

ADDISS Resource Centre
10 Station Road
London NW7 2JU
Tel: 020 8906 9068
www.addiss.co.uk

Thanet ADDers ADD/ADHD Support Group

45 Vincent Close
Broadstairs
Kent CT10 2ND
Tel: 0870 950 3693
Email: support@adders.org
www.adders.org.uk

ADHD Ayrshire Support Group (ADD It Up)

ADD It Up
Cranberry Moss Community Centre
Cambusdoon Place
Kilwinning
Ayrshire KA13 6SL
Tel: 01294 557146

Breathing Space Scotland

Tel: 0800 83 85 87
www.breathingspacescotland.co.uk

Confidential telephone line for people to call when they are feeling down or distressed.

Hyperactive Children's Support Group

71 Whyke Lane
Chichester
West Sussex PO19 2PD
Tel: 01243 551313
www.hacsg.org.uk

Scottish Intercollegiate Guidelines Network

9 Queen Street
Edinburgh EH2 1JQ
Tel: 0131-225 7324
www.sign.ac.uk/guidelines/

The Young Minds Parents' Information Service

102-108 Clerkenwell Road
London EC1M 5SA
Tel: 0800 018 2138
www.youngminds.org.uk

Scottish Association for Mental Health

Cumbræ House
15 Carlton Court
Glasgow G5 9JP
Tel: 0141 568 7000
www.samh.org.uk

NHS 24

Delta House
50 West Nile Street
Glasgow G1 2NP
Tel: 08454 24 24 24
www.nhs24.com

Round the clock health advice and support.

suggestions for reading

There are many publications about ADHD and your doctor or local library will be able to suggest some for you. Here are a few that might help.

Joey Pigza Swallowed the Key

by Jack Gantos.

Published by Corgi Yearling, 2000.

Reading level: 9-11 years.

ISBN 044-086433-X

Putting on the Brakes: Young People's Guide to Understanding Attention Deficit Hyperactivity Disorder

by Patrick O'Quinn, Judith M Stern and Neil Russell.

Published by Imagination Press, 2001. Reading level: 9-12 years.

ISBN 155-798795-5

Teenagers with ADD: A Parent's Guide

by Chris A Dendy.

Published by Woodbine House, 1995.

ISBN 093-314969-7

Zipper the Kid with ADHD

by Caroline Janover.

Published by Woodbine House, 1997.

ISBN 093-314995-6

Willie: Raising and Loving a Child with Attention Deficit Disorder

by Ann Colin.

Published by Penguin Books, 1998.

ISBN 061-419867-4

Hyperactive Child: Attention Deficit Hyperactivity Disorder – A practical self-help guide for parents

by Belinda Barnes and

Irene Colquhoun.

Published by Thorsons, 1997.

ISBN 072-253531-7

Understanding ADHD: A Parents' Guide to Attention Deficit Hyperactivity Disorder in Children

by Christopher Green and

Kit Chee.

Published by Vermillion, 1997.

ISBN 009-181700-5

What Works with Children and Adolescents?: A Critical Review of Psychological Interventions with Children, Adolescents and their Families

by Alan Carr.

Published by Brunner-Routledge, 2000.

ISBN 041-523350-X

**Attention Deficit and
Hyperkinetic Disorders in
Children and Young People: A
National Clinical Guideline.**

Published by Scottish Intercollegiate
Guidelines Network, 2001.

ISBN 189-989362-8

**Attention Deficit Hyperactivity
Disorder: Recognition, Reality
and Resolution**

by Dr Geoffrey Douglas Kewley.

Published by Learning Assessment
Centre Press, 1999.

ISBN 095-347480-1

books for adults
with ADHD

**Out of the Fog: Treatment
Options and Strategies for
Adult Attention Deficit
Disorder**

by Kevin Murphy and
Suzanne LeVert.

Published by Hyperion Books,
1995.

ISBN 078-688087-2

**You Mean I'm Not Lazy, Stupid
or Crazy?!: Self-help Book for
Adults with Attention Deficit
Disorder**

by Larry Silver, Kate Kelly and
Peggy Ramundo.

Published by Simon & Schuster,
1996.

ISBN 068-481531-1

**Driven to Distraction:
Recognising and Coping with
Attention Deficit Disorder
from Childhood through
Adolescence**

by Edward Hallowell and
John Ratey.

Published by Touchstone, 1995.

ISBN 068-480128-0

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