Neurodevelopmental Team

Resource Pack for Parents and Carers of Children with ADHD

LONDON BOROUGH OF RICHMOND UPON THAMES
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Introduction

This resource pack has been put together for families with a child who has recently been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). Receiving a diagnosis of ADHD for your child can be a stressful and worrying experience. Don’t panic – you are not alone!

There is increasing awareness, understanding and acceptance of ADHD and a number of sources of help and advice. Accessing the most appropriate information and support for you and your child can sometimes be overwhelming. This pack is a starting point, from which you can understand more about your child’s diagnosis and decide on what sort of information and support will be most helpful for your family.

We have included information relating to treatment and how those surrounding the child can help, and information about various local and national resources and organisations for children with ADHD.

We all know that children diagnosed with ADHD are different from one another, and will need different services to meet their individual needs. You may find one or two services particularly helpful, or you may like to contact a wider range. You will know what is best for your child!
ADHD and Hyperkinetic Disorder

What is ADHD and Hyperkinetic Disorder?

ADHD is a neurodevelopmental disorder which often becomes obvious in early childhood. The behaviours are due to underlying problems of poor attention, hyperactivity and impulsivity.

Many children, especially under-fives, are inattentive and restless. This does not necessarily mean they are suffering from ADHD. The inattention or hyperactivity becomes a problem when they are exaggerated, compared with other children of the same age, and when they impact on the child, their school, social and family life.

How common is it?

About 2 to 5% of school aged children can suffer from ADHD. Boys are more commonly affected than girls; it has been suggested that this is because it is easier to spot in boys compared to girls.
Causes and Symptoms

What causes ADHD?

We do not know exactly what causes these disorders. ADHD can run in families. Sometimes parents feel blamed for not having controlled their child, but there is no evidence that poor parenting directly causes ADHD. However, it is important to note that parents can play a crucial role in helping and managing a child with ADHD.

What are the symptoms?

ADHD can present with different behaviours depending on the age, setting (i.e. school, home, playground) and even motivation (e.g. when doing an activity or something a child likes). Not all children have all the symptoms. This means some can just have problems with poor attention, while others are mainly hyperactive.

Children with problems of attention can appear forgetful, distracted, not seeming to listen, disorganised, take ages to start doing things and then when they do they rarely finish it.

Children with hyperactivity seem restless, fidgety, and full of energy and ‘always on the go’. They may seem loud and noisy with a continuous chatter.

Children with symptoms of impulsivity do things without thinking. They have difficulty waiting for their turn in games or in a queue, and interrupt people in conversation.

What other problems can a person with ADHD have?

Children with ADHD can have other problems such as learning difficulties, autism, conduct disorder, anxiety and depression. Neurological problems like tics, Tourette’s, and epilepsy can also be present. Children with ADHD can have problems with coordination, social skills and seem to be disorganised.
How long will they have ADHD?

Many children diagnosed with ADHD do not require any treatment when they are adults.

The majority who receive treatment tailored to their needs when they are diagnosed may benefit considerably. They will have been able to catch up with their learning, improve their school performance and make friends.

Some are able to cope and manage by adapting their careers and home life.

However, some can have major problems, even as adults, requiring treatment. They may also struggle with difficulties in relationships, at work, in their mood and using drugs or alcohol.
Diagnosis and Treatment

How is it diagnosed?

There is no single, simple, definite test for ADHD. Making a diagnosis requires a specialist assessment, usually done by a child psychiatrist, specialist paediatrician or clinical psychologist. The diagnosis is made by recognising patterns of behaviour, observing the child, obtaining reports of their behaviour at home and at school.

How is it treated?

A child suffering from ADHD needs intervention across all situations where the difficulties occur. This means support and help at home, school, with friends and community.

Firstly it is very important for the family, teachers and professionals to understand the child's condition and how it affects them. As they grow up, the young person themselves needs to be aware of their condition and how to manage it.

Teachers and parents may need to use behavioural support strategies like reward charts. Parents/family may find parent training programmes helpful, especially in managing the defiant behaviours which may arise from their hyperactivity.

At school, children may need specific educational support and plans to help with their daily work in the classroom and also with their homework. They may also need help to build their confidence and develop their social skills. It is important that there is good communication between home, school and the professionals treating the child to ensure that the ADHD symptoms are treated as well as possible, and that the child achieves their best potential.

Medications can play an important role in managing moderate to severe ADHD. Medications can help to reduce hyperactivity and improve concentration. The improved concentration gives the child the opportunity and time to learn and practice new skills. Children often say that medication helps them to get on with people, to think more clearly, to understand things better and to feel more in control of themselves. Not all children with ADHD will need medication.
What can I do?

A child with ADHD can present with very different and difficult behaviours at home, school or outside. However, there still needs to be boundaries and discipline. Having ADHD does not mean they will always disobey you or behave inappropriately (e.g. swearing or being violent). A healthy lifestyle, with balanced diet and activity, can help. Children with ADHD can become easily frustrated because of their poor attention span and high energy levels. Some of the following can help manage these difficulties:

- Give simple instructions. Stand near them, look at them and tell them slowly and calmly what you want them to do, rather than shouting across the room.
- Praise your child when they have done what is required, however small it is.
- If needed, write a list of things to do and put it somewhere where it can be seen clearly (e.g. door of their room, bathroom).
- Break any task, like doing homework or sitting at the dining table, to smaller time spans such as 15-20 minutes.
- Give them time and activities to spend their energy like basketball, swimming.
- Be aware of their diet. There is some evidence about the effect of diet on some children. They may be sensitive to certain food additives and colourings. If parents notice that certain foods worsen hyperactivity, these may be avoided. It is best to discuss this with your doctor or specialist dietician.

Many parents find it helpful to attend parenting programmes, irrespective of whether the child is being treated for ADHD. Some areas offer parenting programmes and support groups specifically for parents of children with ADHD.
Behaviour Support Strategies

Behaviour support strategies can be used to foster engagement in tasks and reduce overt behavioural symptoms of ADHD. In this section antecedent-focused and consequence-oriented strategies are discussed, which can be used to manage behaviour.

Antecedent-focused behaviour support strategies

Children with ADHD benefit from a proactive approach to social skills and behaviour management. Positive practices are related to increases in task engagement and prosocial behavior. Proactive approaches include:

1. Creating an environment that is positive, encouraging, and supportive:

   - Provide your child with more encouragement and positive feedback than negative feedback.
   - Have positive expectations for your child.

2. Teaching rules and reminding your child of the key rules frequently:

   - Make sure your child understands what appropriate behaviour looks and sounds like (for example, explain to them what they need to say or do when they are upset)
     - Be explicit, model the behaviour, give guided practice, and provide reinforcement when your child exhibits the behaviour.
   - Provide your child with visual cues (e.g., poster) to remind them of rules and state rules in a positive manner ("Please keep your room tidy" vs "Don't make your room a mess").
   - Use preventative strategies such as positive reminders (that is, cues) of appropriate behaviours and/or expectations for a given situation, rather than providing negative feedback once the misbehaviour has already occurred. For example, before beginning a bed time routine remind your child of each step they need to complete.

3. Provide your child with positive and specific feedback regarding their ability to show appropriate behaviour:

   - Provide specific feedback about their actions and performance (for example, "Thank you for sitting at the table nicely" vs. "Good job!").
   - Help your child demonstrate appropriate behaviours by giving them cues and prompts. Reinforce the behaviour with specific feedback (for example, "Remember, put your toys away when you’ve finished. Thank you, John, for putting your toys away.").
4. Setting up routines for various home tasks or actions. Children with ADHD may need to review routines frequently and have picture cues illustrating key steps (younger children) or checklists guiding actions (older children):

Create predictable schedules and routines for:

- Transition from school to home
- Doing homework
- Meal times
- Bed time

**Consequence-oriented behaviour support strategies**

Children with ADHD also tend to respond positively to consequence-oriented behaviour management techniques. Consequence-oriented behavioural management techniques include token economies, response cost procedures, and behavioural contracts. Token economy will be discussed here. The important thing to remember when using such types of management techniques is that they do not teach more appropriate skills or behaviours, but either positively or negatively reinforces existing actions and behaviours. Therefore, an instructional approach and behavioural management techniques should be combined to set your child up for success. It is important for you to remember that the frequency and timing of feedback and reinforcement for children with ADHD is important. That is, children with ADHD often need more frequent and immediate feedback than their non-ADHD peers.

**Token economy**

Token economy management systems provide children with "tokens" or secondary reinforcers when a child demonstrates specific target behaviour. The steps for setting up a token economy reinforcement system are:

- Decide on goals to be met (for example, completion of a bed time routine).
- Decide on the type of secondary reinforcer (token) to be used (for example, poker chips, check marks).
- Decide how many tokens are to be earned by demonstrating target behaviours (you can break more complex tasks down into component parts and give tokens for each part).
- You and your child work out the types of activities that the tokens could be exchanged for (for example, five tokens equals five minutes free time at the computer).
- Children are taught the value of the tokens (model what has to happen to earn a token).
- Children can exchange tokens for activities on a daily basis.
- You should monitor this approach to assess its effectiveness — are there increases in appropriate target behaviours?
Medication

What are the medications used in treatment of ADHD?

Medications used to treat ADHD are broadly divided in two groups:

- Stimulants like methylphenidate and dexamphetamine
- Non stimulants like atomoxetine.

**Stimulants** have the effect of making people feel more alert, energetic, and awake. For a person with ADHD, they can improve attention and reduce hyperactivity. The stimulants used in the treatment of ADHD include methylphenidate (previously commonly known by the name ‘Ritalin’) and dexamphetamine.

Methylphenidate is available as different forms. Immediate release methylphenidate is short-acting. It is used for its flexibility in dosing and can be used to determine the correct level of dose during dose changes. Slow or modified release methylphenidate work for 8 – 12 hours and can be given once a day. They are more convenient, and as the child or young person need not take a dose in school, reduces stigma attached to ADHD.

Non stimulant medications by nature do not make people alert or active. However, for people with ADHD they can improve symptoms of inattention and hyperactivity. These include medications like atomoxetine.

Sometimes other medications may be used to help with problems with sleep and challenging behaviours that are associated with ADHD.

How do they work?

Medications act on certain chemicals in the brain called ‘noradrenaline’. They seem to affect the parts of the brain that control attention and organise our behaviour.

They do not cure ADHD. They help to control the symptoms of poor attention, over activity or impulsivity.
Which medication will be used for my child?

Stimulant medication methylphenidate is usually prescribed first. The type of stimulant prescribed will depend on a number of things like the symptoms your child has, your choice of treatment, the ease of giving the medication and even availability/cost of the medication.

If methylphenidate causes unpleasant side-effects or does not work, other stimulant (dexamphetamine) or non-stimulant medications may be prescribed. Sometimes a child may respond to a different form of methylphenidate.
How do I know it is working?

You should find that:

- Your child’s concentration is better
- Their feelings of restlessness or over-activity are less
- They control themselves better.

Sometimes school or teachers notice the improvement before you do.

What are the side-effects?

As with most medications, there may be some unwanted effects. However, not everyone gets side effects and most side effects are mild and disappear with continued use. Side effects are less likely if the dose is increased gradually when the tablets are started. Some parents worry about addiction, but there is no good evidence to suggest that this is a problem.

Some of the common side effects of methylphenidate include:

- Loss of appetite
- Difficulty falling asleep
- Light headedness

Less common side effects to look out for include:

- Being ‘over-focused’, quiet and staring, this may be a sign that the dose is too high
- Anxiety, nervousness, irritability or tearfulness
- Stomach pains or feeling sick
- Headache, dizziness or drowsiness
- Tics or twitches.

In the long term, sometimes growth slows down when children are on methylphenidate.

This list of side-effects is not exhaustive. **If you notice anything unusual, it is important to contact your doctor immediately.**

Is there anything I need to know before giving the medication?

Before you give any medication do tell your doctor about:

- Allergies your child might have
- Any other medicines they take, including vitamins or supplements
- For older girls if they are likely to become pregnant
- If you or anyone in your family suffers from physical health problems, especially high blood pressure, heart problems and repeated movements (called tics)
Are there any special tests before or while taking the medications?

Before taking the medication, your child should be physically checked up especially for their heart rate, blood pressure, growth and any other medical problems. Sometimes they may need blood test or heart tracing test to measure the electrical activity of the heart called an electrocardiogram (ECG).

While taking the medication, your doctor should monitor your child’s heart rate, blood pressure, weight and height on a regular basis along with checking for any side effects.

What do I need to know about giving the medication?

DO's

- Give the medication at the times you were told by your doctor or pharmacist
- Keep appointments for regular review of medication
- Store the medication safely (medication can often be stored in locked cabinets at pharmacies)
- Ensure your child swallows the medication, not chew or crush it
- Make sure your child drinks enough, especially in hot weather and while exercising
- Ensure you have a clinical note if taking the medication abroad

DON'Ts

- Double the dose if they miss a dose of medication
- Stop giving the medication without discussing with the doctor
- Give the medication to anyone else, even if you feel their difficulties are similar to your child’s
How long do they need to be on the medication?

Most children and young people need the medication at least until they finish their education or schooling. A few might need to take it even when they grow up. Some children need medications only at specific times, like for example while attending school, and do not have to take it on weekends or on school holidays, however, this needs to be discussed with your doctor.

Your doctor would regularly check, at least once a year, if they need to continue the medicine.

Taking these medications can affect driving, and even certain careers like joining the army. It is important that the child is aware of this and they will need to discuss it with their doctor as they grow up.

Young people may need explanations and support as they grow up about taking their medication. Stopping medication can cause symptoms to return, and some young people can put themselves at risk in terms of their education, their work, and socially by being impulsive and taking alcohol or drugs.

**Remember: if you have any further questions regarding this medication, do not hesitate to contact your doctor or pharmacist.**
"I was always getting into trouble at school. The teacher used to tell me off for not sitting still, I’d try to sit down but it was hard – I would just want to get up and walk around. I was always getting into trouble for talking. The other children in my class would sit still and finish their work but I found this hard.

Mum and dad said I had a lot of energy. Sometimes my friends would tell me I was over the top. Mum says she couldn’t take me anywhere when I was younger because I was so noisy and always on the go.

In the end, mum and dad took me to a clinic for children who have problems. They said I have ADHD and talked to my parents and teachers about how to help me. They gave me some medication – Ritalin. My mum and dad think it helps. I don’t seem to get told off so much and can do my school work better."
ADHD Foundation, in partnership with individuals, families, doctors, teachers and other agencies, works to:

- Build a positive foundation for life.
- Improve life chances through better understanding and management of ADHD.
- Raise awareness & understanding of ADHD - change the negative perception of ADHD into positive.
- Bring about positive change and inclusion within policy and practice.
- Support schools, GP's, youth justice services and other professionals who work with people with ADHD.
- The ADHD Foundation supports achievement, educational attainment, mental health and employability.
- The Foundation works in a unique way. They work in partnership with those living with ADHD, enabling them understand and manage ADHD.

The team understands first-hand the issues around ADHD, sharing their experience and providing skill support and encouragement.

ADDISS

Address: ADDISS
PO Box 340
Edgware
Middlesex
HA8 9HL

Tele. No: 020 8952 2909
Email: info@addiss.co.uk
Website: www.addiss.co.uk

ADDISS is The National Attention Deficit Disorder Information and Support Service. ADDISS organises local and national seminars and provides information, support, training and resources on ADHD for parents, health workers and teachers. ADDISS works closely with a number of local support groups and can refer parents to these groups. They also have a wide range of information factsheets, books, and special sections for children, parents or professionals.

ADHD Foundation

Address: ADHD Foundation Head Office
151 Dale Street
Liverpool
L2 2AH

Tele. No: 0151 237 2661
Website: www.adhdfoundation.org.uk
Email: info@adhdfoundation.org.uk

ADHD Foundation, in partnership with individuals, families, doctors, teachers and other agencies, works to:

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The team understands first-hand the issues around ADHD, sharing their experience and providing skill support and encouragement.
Hyperactive Children's Support Group

Address: 71 Whyke Lane  
Chichester  
West Sussex  
PO19 7PD  

Contact: Sally Bundy  
Tel: 01243 539966  
Email: hacsg@hacsg.org.uk

The Hyperactive Children's Support Group is a registered charity which has been successfully helping ADHD/Hyperactive children and their families for over 30 years. The HACSG is Britain's leading proponent of a dietary approach to the problem of hyperactivity. The group provides workshops for parents and healthcare professionals to learn more about managing ADHD and hyperactive behaviour and how diet can help. Workshops can cover diet and behaviour, dyslexia behavioural management, autism and brain gym and are tailored made to your needs.

Young Minds

Address: Suite 11,  
Baden Place,  
Crosby Row,  
London,  
SE1 1YW  

Tel: 020 7089 5050  
Email: parents@youngminds.org.uk or ymenquiries@youngminds.org.uk

YoungMinds is the UK’s leading charity committed to improving the emotional wellbeing and mental health of children and young people.

Driven by their experiences they campaign, research and influence policy and practice.

They also provide expert knowledge to professionals, parents and young people through their Parents' Helpline, online resources, training and development, outreach work and publications.

Contact a Family

Address: 209-211 City Road,  
London EC1V 1JN  

Tel: 020 7608 8700  
Email: helpline@cafamily.org.uk  
Website: www.cafamily.org.uk  

Helpline: 0808 808 3555  
(Mon-Fri, 10am-4pm) Freephone

Contact a Family is a UK-wide charity, providing support, advice and information for families with disabled children.
Challenging Behaviour Foundation

Address: The Old Court House, New Road Avenue, Chatham, Kent, ME4 6BE
Tele. No: 01634 838739
Support Line: 0845 602 7885
Email: info@thecbf.org.uk
Website: www.challengingbehaviour.org.uk/

This charitable foundation offers information and support with challenging behaviour.

Royal College of Psychiatrists

Address: 21 Prescot Street
    London
    E1 8BB
Tele. No: 020 7235 2351 or 020 7977 6655
Fax: 0203 701 2761
Email: reception@rcpsych.ac.uk
Website: www.rcpsych.ac.uk/expertadvice/problems/adhdinadults.aspx

The Royal College of Psychiatrists is the professional body responsible for education, training, setting and raising standards in psychiatry.

The College produces a range of materials for mental health professionals and the public for a number of mental health problems, including ADHD.

SOS!SEN

Website: www.sossen.org.uk
Helpline Number: 020 8338 3731

This is an independent telephone helpline for parents and others looking for information and advice about Special Educational Needs (SEN). Support is centred on the legal and procedural processes that are associated with finding provision for children with SEN.
They will be able to advice you about various benefits you may be able to apply for, including Disability Living Allowance. This is a weekly tax-free benefit paid to help with the extra costs of bringing up a child who has special needs. Call the number above to obtain a form.
ADHD Richmond

Website:  www.adhdrichmond.org/
Facebook: www.facebook.com/AdhdRichmond
Twitter:  @AdhdRichmond
YouTube:  www.youtube.com/user/AdhdRichmond
Email:    info@adhdrichmond.org

ADHD Richmond is a support group for families of children with ADHD.

These are the values & aims of ADHD Richmond:
1. Support parents through accurate information and opportunities to meet
2. Bring about change to mainstream services in line with NICE and other legislation
3. Training and awareness of professionals working with children with Adhd (through increasing statutory provision)
4. Develop post diagnosis information (question and answer) event in parallel with parent training

Me too & Co

Address:  Me Too & Co
          The Cross Way Centre
          306 Richmond Road
          East Twickenham TW1 2PD
Tele. No:  07946 646033
Website:  www.metooandco.org.uk

Me too & Co is a parent-led charity covering the Borough of Richmond-upon-Thames and surrounding areas, which aims to help children and young people with additional needs and their families.

The additional needs of the children include autistic spectrum disorder, Down’s syndrome, hearing or visual impairment, cerebral palsy, developmental delay and rare or undiagnosed syndromes.

We offer opportunities for the children and their siblings to play and develop, and provide information and support for their families and carers.
Access

Contact: Access

Opening Hours: 1000-1600 hours,
Monday to Friday

Website: www.accessinfoservice.com

Email: info@accessinfoservice.com

EnhanceAble Information, Advice and Support Service

Contact: Jane Mitchell, Manager
Address: EnhanceAble Children’s Services
The Moor Lane Centre
Moor Lane
Chessington
Surrey
KT9 2AA

Contact: Jane Mitchell, Manager

Address: EnhanceAble Children’s Services
The Moor Lane Centre
Moor Lane
Chessington
Surrey
KT9 2AA

Tele. No: 020 8831 6076

Email: info@accessinfoservice.com

Opening Hours: 1000-1600 hours,
Monday to Friday

Website: www.accessinfoservice.com

If you are a parent and/or carer of a child or young person with additional needs living in the Richmond-upon-Thames area and would like advice on any number of issues to help support your family, however big or small then access could be of assistance.
RichmondAID

Tele. No:  Advice Line: 020 8831 6070  
Richmond AID Mobile/SMS: 07894215835
Email:  For advice & information on disability: advice@richmondaid.org.uk  
For general enquiries: info@richmondaid.org.uk
Address: Richmond AID  
Disability Action & Advice Centre (DAAC)  
4 Waldegrave Road  
Teddington  
TW11 8HT

Richmond AID is a charity run by and for disabled people in the London Borough of Richmond upon Thames and surrounding areas. They support disabled people, families, carers and professionals by providing services such as the Advice Service, Richmond SPADE (gardening service), the Benefits Service and support with employment and training.

They support people of all ages with all kinds of disabilities, including physical and sensory impairments, mental health issues and learning difficulties. Their aim is to support disabled people to live independent lives and to have the same opportunities as non-disabled people.

Richmond Parent Carers Action Group (RPCAG)

Website:  www.rpcag.org.uk

The Richmond Parent Carers Action Group (RPCAG) is an independent forum, set up in the Borough of Richmond-upon-Thames by parents of children with additional needs, in order to help influence the development of services provided by the Local Authority for their children.
Books

Books for parents of children with ADHD

- Taking Charge of ADHD: The Complete, Authoritative Guide for Parents
  By Russell A. Barkley

- How to Talk so Kids Will Listen and Listen so Kids Will Talk
  By Adele Faber, Elaine Mazlich and Kimberly Ann Coe

- Driven to Distraction: Recognizing and Coping with Attention Deficit Disorder from Childhood Through Adulthood
  By Edward M. Hallowell, M.D. and John J. Ratey, M.D.

- The NEW CHADD Information and Resource Guide to AD/HD
  By CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder) chadd.org

- Daredevils and Daydreamers: New Perspectives on Attention-Deficit/Hyperactivity Disorder
  By Barbara D. Ingersoll, Ph.D.

- How to Talk so Kids Can Learn: At Home and in School
  By Adele Faber, Elaine Mazlich, Lisa Nyberg and Rosalyn Templeton

- The Heart of Parenting: How to Raise an Emotionally Intelligent Child
  By John M. Gottman and Joan DeClaire

- The Difficult Child
  By Stanley Turecki and Leslie Tonner

- ADHD: A Complete and Authoritative Guide
  By the American Academy of Pediatrics

Books for children with ADHD

- Everything a child needs to know about ADHD (2006)
  By Dr C R Yemula, ADDISS publications. For children aged 6-12 years

- Putting on the Brakes: Young People’s Guide to Understanding Attention Deficit Hyperactivity Disorder
  By Patricia O. Quinn, Judith M. Stern. For children aged 8-12 years