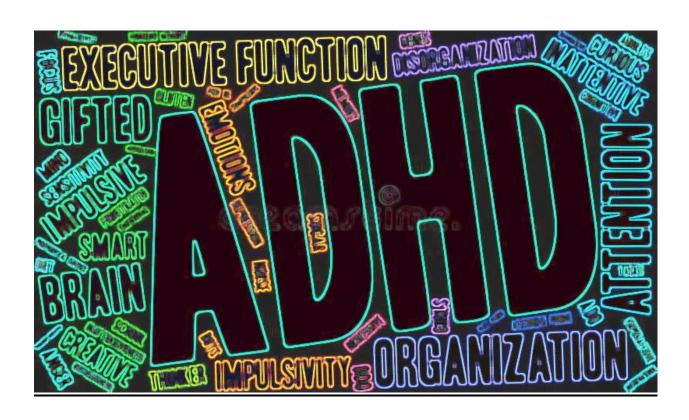


ADHD INFORMATION PACK





For children with a recent diagnosis of Attention Deficit Hyperactivity Disorder (ADHD)

Dear Child/Parents

You have now received the diagnosis of ADHD/ADD from your paediatrician. For some this will be a welcome relief after possibly years of agonising over what you have wrongly perceived has been your fault.

What Happens Next

Commenced on Medication

If you have been commenced on medication by the paediatrician, they will telephone you/your parents a few weeks later to see how this is working. You will then be added to our review list to see one of the ADHD Nurses in clinic. This is our opportunity to meet with you and your parents.

The review follows NICE guidance and involves discussing with you and your parents your response to the medication, whether it is still effective or needs altering, your appetite, sleep and behaviour. As the medications can affect heart rate and blood pressure, these are checked at each appointment along with height and weight. Before your paediatrician agrees to the medication in the first place a pre-medication questionnaire was carried out to ascertain suitability (please refer to mission statement).

Decided Against Medication

Should you have decided against medication at this time, YOU WILL NOT BE CALLED FOR REVIEW. However, telephone consultations can be booked through our Secretary Cora Ryder:

Tel: 01925 946485

Email: bchft.warringtonpaediatricadhd@nhs.net

and we can offer support and advice that way.

• If in the future, you decide to commence medication

Please contact the Community Paediatrician Secretary on 01925 946730

Medication

For those parents/carers choosing to trial medication, this can be a daunting prospect, but we do try to make it as easy and as uncomplicated as we can for you.

We work with two kinds of medication, stimulants and non-stimulants, of which we have a few types of each. Stimulant medication is usually the first port of call and most of your children will have had this for their QB test (see QB test information).

Stimulant medication has names such as Eqyasym XL, Medikinet XL, Concerta XL, Zaggitin XL and Matoride XL. The XL basically stands for extended release meaning that it will last over several hours. These belong to the Methylphenidate group of medications.

The Equasym XL and Medikinet XL last for 6-8 hours which just about covers the primary school day. The Concerta XL and Matoride XL which are almost one and the same, last 10-12 hours. These we like to progress to, as the children move up to high school, due to the possibility that they can all effect sleep onset, if still in the system close to bedtime.

The final stimulant we have at our disposal is Elvanse. This is from a different group of medications. It is a lisdexamphetamine. It lasts 11-13 hours and has a slightly different mode of action, suiting children who haven't had the best response to the methylphenidates.

You will notice the variation in hours that each medication lasts. This is largely due to each individual child. The quick metabolisers will use up the medication faster than their slower metaboliser peers.

Reduced appetite and delayed sleep onset are the most common side effects and these we monitor at your review with advice and support around managing them. We very rarely hear of more than a slight stomach upset/headache in the first few weeks of starting the tablet and always suggest that little fuss is made, but that you make a mental note and if they continue for longer than 2-3 weeks or increase in intensity, that you let us or your GP know. We expect the body to react to the new medication and unless you are concerned, these niggles usually disappear as soon as they start.

The stimulant medications have the flexibility of being stopped at weekends/holidays if you so choose. They don't have to "build up" in the system to be effective. This is great for those children whose appetite is poor whilst taking the medication. It means they can catch up on their eating when not in school.

Non stimulant medications prescribed by our paediatricians are fewer. Atomoxetine (Strattera) or Intuniv. Both last 24 hours in the system and unlike the stimulants cannot be stopped at weekends. They have less of an impact on appetite; indeed the Intuniv appears to boost this. They also tend to have a more positive impact on sleep for some children.

It is important to understand that not every child will suit medication and not every medication will suit each child, but we work with you to find one that will enable your child to be their best self. Medication is not the only answer, it is part of a tripartite approach which also includes good emotional health/self-esteem and good behaviour management and finally positive links and support from schools. You can see here how it fits together, we do our bit, you do your much bigger bit and schools arguably, do the most vital bit, all working together for the future prospects of your child.

Please ensure all medications are kept in their original packaging within a locked tin/ cupboard and out of reach of children as these are classed as controlled drugs. All medication must be administered by an adult and children observed to take the medication. Any lost/ misplaced medication must be reported to the prescription line as this needs to be reported to medicines management within the trust. Any left-over or unwanted medication must be returned to the pharmacy and not placed in bins or flushed down toilets.

Some of these medications are controlled drugs under the <u>Misuse of Drugs Act</u>. This means that stricter rules may apply to these drugs, such as for writing and dispensing prescriptions.

It is very important to look after your medicines. If there is a problem e.g., you lose your prescription or medication, you must contact the service immediately so that we can notify the right people and follow appropriate procedures. For controlled drugs this may mean that we need to inform the police.

A prescription for a controlled drug medicine is only valid for 28 days from the date on the prescription. Medications that are owing from the pharmacy must be dispensed and collected within the 28 days since the date on the prescription.

QB Testing

Your child may well have met Cathy or more recently Beth who carry out our QB Tests. As you know these form part of the evidence to enable the paediatricians to decide on diagnosis or not. This will not be the last time you meet them because at any stage along the journey we may decide to do a QB test in order to assess the effectiveness of the medication or even in some cases to see if it is still necessary.

ADHD and Behaviour

ADHD, whilst it is presents differently in every child, has core components which they all share to a greater or lesser degree. Without medication these can only be managed by good and understanding teachers and very robust strategies at home. It is highly likely that the longer it takes for a child/young person to be diagnosed the longer they have had to develop their "reputation" in school. For most, this is not usually a positive one and results in a child with poor self-esteem and no belief in him/herself or his/her abilities.

The outcome can be poor behaviour, low motivation and in some cases a spiral downwards when more intensive mental health services are required.

We know that children with ADHD have the same level of intelligence that they would have without the condition, but many have the added ingredients of creativity, spontaneity and bravery. They are usually very funny and dislike injustice, standing up for their friends against the odds.

These are skills that need nurturing and progressing by encouraging hobbies that bring out the best in them, giving them a sense of achievement, which will bolster confidence going forward. Praise often and immediately and never shame.

You may notice traits in yourself. This is highly likely and will explain a lot to you. It may be that you have/had ADHD and everything your child is doing, you did and worse? This will enable you to think what would have worked for you when you were his/her age and give you better insight.

Behaviour is learned, copied and inherited. It is also shaped by how it is managed. Your child is 50% of each of his/her parents so will have characteristics of both. Children copy the people they look up to most so setting a good example is so very important.

Getting exercise is hugely important. If you have high energy levels these will not be utilised sitting in front of a screen all day. Instead the pent up energy will be used, either getting up to mischief or as they get older in heated exchanges with the family. Lack of exercise also impacts on sleep and we know how important that is to everyone.

Behaviour will be discussed at review and can also be accessed by telephone consultation which is an option for all our children on or off medication.

The Team

This comprises of the paediatricians at the CDC, any professional currently involved or likely to become involved with your child and the Specialist Nursing Team, predominantly Carol Humphreys, Specialist Nurse ADHD/Team Leader, Ruth McCormack, Specialist Nurse ADHD/LD and Leah James, ADHD/LD Specialist Nurse

You will see below, our Mission Statement which will give you more insight into what we do, and this has contact details to enable you to get in touch with any further questions.

Repeat Prescripton Process

To get a repeat prescription you either need to

email: bchft.warrcompaed-repeatscripts@nhs.net

or telephone: 01925 946970

you need to ensure your GP has a pharmacy linked to the GP surgery so that when the prescription is done by our paediatricians it is electronically forwarded to your pharmacy.



ADHD Mission Statement for Children and Young People

The Team

Carol Humphreys, Ruth McCormack and Leah James are Specialist Nurses for ADHD. We are supported by Jennie Rowles, Specialist Nursery Nurse, Cathy Brown, Support practitioner/LD Transition Lead and Beth Johnson, Support practitioner and of course by our Paediatricians.

We have developed a substantial knowledge about ADHD and between us are committed to supporting you to become your "best self".

What we do

We hold regular reviews to monitor your height, weight and blood pressure and to address any concerns you may have. We also advise and guide if you are having particular challenges in your life relating to ADHD.

We endeavour to offer best advice with regard to medication in order to help you make the right choices. The Paediatricians have the final say in prescribing decisions but we work with you to provide the reasons for our requests.

We consider ourselves to be part of your team which includes your Paediatrician, your teachers and all those people who care about you. We can attend meetings in your support and we can recommend and refer to our partner services should we agree that they could help us in our goal for you to achieve your "best self".

Our pledge to you

To give you full access to our knowledge and experience

To work as part of a team to provide best advice and support

To review you regularly

To be open and honest with you about your choices

To always respect your decisions even if we do not feel they are in your best interests

To empower you to take responsibility for the management of your ADHD

What we need in return from you

To attend your reviews or give us reasonable notice of a cancellation

To be open and honest; we can only help if you tell us how

To research ADHD yourself; maximise the benefit of having a creative and quick mind To give plenty of notice for us to attend meetings

Be respectful and patient; there are in excess of 1200 children and young people like you for whom we want the same successful outcome.

Contact Details

Carol Humphreys, Specialist Nurse ADHD/Team Leader - carol.humphreys@nhs.net Ruth McCormack, Specialist Nurse LD/ADHD - ruth.mccormack@nhs.net Leah James, Specialist Nurse LD/ADHD - leah.james6@nhs.net

ADHD Admin - bchft.warringtonpaediatricadhd@nhs.net

Warrington ADHD Specialist Nurses Website for more information – www.bridgewater.nhs.uk/warrington/childrens-specialist-nursing-team

ADHD Websites and Local Support Agencies

National Attention Deficit Disorder Information and Support Service www.addiss.co.uk

ADHD online-support group with a sense of humour www.adders.org

www.livingwithadhd.co.uk

www.troubledteen.com www.adhdandyou.co.uk

ADHD Foundation www.adhdfoundation.org.uk/resources/

Links to medication used for ADHD

www.medicinesforchildren.org.uk/medicines/methylphenidate-for-adhd/ www.child-adolescentadhd.co.uk/assets/downloads/intuniv-prescribed-patient-leaflet.pdf

Local Support Groups

Warrington Play and Sensory Centre Woolston Neighbourhood Hub Hall Road Woolston Warrington WA1 4PB

Tel: 01925 817347

www.warringtonsensorycentre.org

<u>www.askollie.warrington.gov.uk</u> – Local offer for Warrington children with additional needs

<u>www.warrpac.org</u> – Warrington parents and carers. A forum dedicated to supporting parents/carers of children and young people with additional needs.

ADHD support group tel: **07486124414**. This is a support group specifically for parents/carers of children and young people with ADHD.

Parent partnership supporting parents of children with additional needs in early education settings and schools

Tel: 01925 442978

Books for Children and Young People

Learning to slow down and pay attention: A book for kids about ADHD By Kathleen G. Nadeau. Ellen B Dixon, published by Magination press

Everything a child needs to know about ADHD By Dr CR Yemula published by ADDISS UK, 2nd edition 2007

What's up with Astra: Medikidz explain ADHD By Dr Kim Chilman-Blair & John Taddeo published by Liquid Comics

All dogs have ADHD By Kathy Hoopmann, published by Jessica Kingsley publishers

Toddler taming a present guide for the first four years By Dr Christopher Green

Beyond Toddlerdom – keeping 5-12 year olds on the rail By Dr Christopher Green

25 Things to Love About A Kid with ADHD



Kids with ADHD:

- 1. Rarely lack the energy required to do something
- 2. Are rarely boring
- 3. Tend to think more creatively
- 4. Tend to see solutions neurotypicals don't
- 5. Often grow up to be innovators and entrepreneurs
- 6. Have razor-sharp, unwavering focus on things that interest them
- 7. Are curious
- 8. Are eager
- 9. Are spontaneous
- 10. Are sensitive
- 11. Are ambitious
- 12. Want to help others
- 13. Can find order in chaos
- 14. Are good problem solvers
- 15. Can keep themselves occupied
- 16. Are imaginative
- 17. Are interest in learning new things
- 18. Aren't limited by boundaries
- 19. Are passionate and enthusiastic
- 20. Are persistent
- 21. Are willing to explore
- 22. Think outside the box
- 23. Have a heighted intuition
- 24. Are resilient
- 25. Dream Big