



Cardiff & the Vale Parents' Federation

ADHD Information Event

On Wednesday 24th February 2016 we held an information event which focused on ADHD. This was aimed at professionals and parents/carers and highlighted where you can go for support, as well as debunking the myths that surround the condition.

A variety of speakers from numerous sectors explained different aspects of ADHD and what support is currently available, as well as developments that will be happening in the near future.

48 people attended and we had 6 presentations.

The following report gives a taste of what was discussed along with links to websites and other information.

The Parents' Federation wishes to thank all those who gave their time freely to ensure the event was a success.

We also appreciate the generous support of Cardiff Yacht Club in making the venue available and providing catering.

Presentations

The day commenced with our director, John Cushen, explaining that we were holding this event because we have received a high amount of referrals for ADHD over the past two years.

Cardiff University ADHD Research Team

John was followed by Sharifah Shameem Agha from the Cardiff University ADHD Research Team who explained what ADHD is and the myths around it. She explained that ADHD co-occurs with learning difficulties and autistic traits, and that the symptoms must happen in different settings such as at home, in school etc, for a diagnosis to be made. It affects 5% of the worldwide population, with it being more common in boys than girls. ADHD is not a new concept, with it being around as early as the 18th century. However, there is now more awareness about the condition.

The research team discovered that the condition may not necessarily be due to environmental factors, but that it can be highly heritable and run in families. However, there is no genetic test for ADHD, although genetics play an important part. Sharifah stressed that there is no evidence to claim that it is caused by junk food or bad parenting.

Sharifah concluded by saying that ADHD is a complex disorder without a single cause or definite test to diagnose it. She explained that the National Centre for Mental Health (NCMH) are always looking for parents and children to help with their research and that they can do home visits if necessary. Everyone present had an information leaflet about the centre and where to go if they wanted to help.



Neurodevelopmental Disorder Service – Cardiff and Vale University Health Board

The next speaker was Eleri Probert, the project manager for the Neurodevelopmental Disorder Service, who described the support available from the NHS. She explained the Together for Children and Young People

programme which started in February 2015, a multi-agency service improvement programme which focuses on the emotional and mental health services provided for children and young people in Wales.

There are currently issues surrounding waiting times, lack of information and advice prior to and following diagnosis, communication between services, and understanding of neurodevelopmental conditions.

The service has recently received funding for a new project which will help them to make improvements. Changes will include:

- A single point of access and referral.
- Referral and assessment coordination.
- Recruitment of a specialist team.
- Multi agency care pathways.
- Performance measures put in place.
- Improved waiting lists.

There will also be more integrated care planning, advice and information, and shared care.

April 2016-March 2017 is the planning phase and Eleri gave out questionnaires to gather information on what support needs to be in place. The service is looking to develop a unified care plan for the people and families who have multiple diagnoses and need help from families to go into the next phase.

Parent input and concerns included:

- The risk that local care will be cut significantly e.g the nurses going.
- GPs are only trained in their specialities, not necessarily neurodevelopmental disorders.
- Problems when trying to access medication, e.g medication only prescribed in certain chemists which are hard to get to for some parents.
- CAMHS solely concentrate on weighing etc and giving repeat prescriptions. CAMHS could offer more support if there was someone else to deal with the prescriptions.

A parent stated that her experiences with the adult mental health team was much better than the children's mental health team.



Education – SNAP Cymru

Emma Bailey and Jane McCann from SNAP Cymru explained how they can help when it comes to educational support.

SNAP provide:

- Comprehensive help and advice.
- A national helpline, open 9:30-4:30 Monday to Friday.
- Advocacy.
- Individual support.
- Help with complex cases.

SNAP offer advice and support on different educational issues such as statementing, exclusions and appeals, and they can attend school meetings with families. There is now also an app available for young people called 'Wmff!' which gives them information about choices in education and work, and their rights, etc.

Emma and Jane stated that there does not need to be a diagnosis if there's a real need for help, and you do not have to wait for a diagnosis to contact them via the office or helpline numbers.

A parent thanked SNAP for their help as she had recently contacted them and a school meeting that was meant to take place in 6-7 weeks time was now happening the day after the event.



Kicking ADHD into Touch – Cardiff City Football Club Foundation

Josh Law, the Disability & Health Coordinator for the Cardiff City Football Club Foundation, gave a talk on the sports opportunities that are available for children and young people with ADHD.

They provide impairment specific football sessions for children who have:

- Down's Syndrome
- Physical Disabilities
- Junior & Senior Learning Difficulties
- Use Wheelchairs
- ADHD

Josh stated that 90% of disabled children and young people have tried mainstream sport but it hasn't worked. The foundation acknowledges this and removes the barrier to participation. There is no competitive element and it provides lots of opportunities to socialise. There is normally 8 children to 1 volunteer in a group but 1:1 support is available. The weekly football sessions are £3 or there are sports camps available every school holidays, providing a mixture of sports activities, which are normally funded.

A parent stated that she didn't want her child to go to a disability only club and that there should be inclusion in all clubs. Josh said that the Football Association of Wales are trying to implement this so an individual will be on hand to help in every club.



Barnardo's Neville Street Service

Emily Lewis and Fay Bowring from Barnardo's Neville Street Service gave information on the ADHD parenting programme that they currently provide. They go into communities to provide this course and self-referrals are accepted as well as those from professionals.

The programme is for 2 hours over 6 weeks and covers:

- Learning about everyone
- What is ADHD?
- Parenting styles
- Communication and structure
- Self- Esteem and the dos and don'ts of ADHD
- Guest Speakers

They also provide courses on different topics, such as teenage behaviour and dealing with challenging behaviour.



South Wales Police Mental Health Officer

Claire Thomas, the South Wales Police Mental Health Officer based in Cardiff Bay, described her role in protecting vulnerable adults. She educates other officers on how to deal with people who have learning difficulties or mental health disorders and gives signposting support. They place markers on vulnerable individuals so if they come into contact with the police, there will be appropriate support put in place for them.

Claire gave information about the Keep Safe Card Scheme, which is provided for vulnerable people. A parent praised the PCSOs in the community as a local PCSO helped her disabled son overcome his safety fears after their house was burgled.



Plenary

After the presentations, we held a plenary where parents were given the opportunity to tell us what is working, what could be improved, and how we can help.

There was a general consensus that there is a lack of information provided and that many professionals have to be chased. There is support in some areas of Cardiff and the Vale but not in the others, and some families find it difficult to access certain areas. There was also a suggestion that professionals need to be educated on ADHD.

Parents agreed that they learn a lot from speaking to other parents and would benefit from more peer-to-peer support. One parent stated that her child had been diagnosed a year ago but she had learned more at the event than she had in a year, as information is not provided.

As well as peer support, one mum suggested a group that could also support siblings.

Feedback from parents

- Lack of support groups locally for parents.
- Felt very isolated but now hope I can find support in the Vale. Learnt so much, hoping to find out more about support. Important to get more information out to new diagnosed families. Very little support in the beginning.
- Interested in an ADHD project for siblings.
- Would like to continue to learn about services available. I have included Parents Federation onto my Facebook to ensure I am updated.

Links for ADHD Websites

Contact a Family Cymru

ADHD Information Sheet - <http://www.cafamily.org.uk/medical-information/conditions/a/attention-deficit-hyperactivity-disorder/>

National Autistic Society.

ADHD Page - <http://www.autism.org.uk/adhd>

ADHD Foundation (Based in Liverpool)

What is ADHD? - <http://www.adhdfoundation.org.uk/whatisadhd.php>

NHS Direct – Symptoms, Diagnosis etc

<http://www.nhsdirect.wales.nhs.uk/Encyclopaedia/a/article/adhd/>

NHS Choices – Diagnosing ADHD

<http://www.nhs.uk/Conditions/Attention-deficit-hyperactivity-disorder/Pages/Diagnosis.aspx>

NHS Choices –

<http://www.nhs.uk/conditions/Attention-deficit-hyperactivity-disorder/Pages/Introduction.aspx>

Mind's take on ADHD

<http://www.mind.org.uk/information-support/minds-position-on-adhd/>

Info on BBC from April 2015 re: Ritalin

<http://www.bbc.co.uk/news/uk-wales-26858293>

NCMH – ADHD

<http://ncmh.info/conditions/adhd/>

Royal College of Psychiatrists – ADHD in Adults

<http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/adhdinadults.aspx>

Scouts – What is ADHD, Living with it & a few practical tips

<http://members.scouts.org.uk/supportresources/2449/attention-deficit-hyperactivity-disorder-adhd-or-add>

Carers Trust.

<https://www.carers.org/help-directory/attention-deficit-hyperactivity-disorder-adhd>

Go to See (Health & Therapy Guide)

<http://www.gotosee.co.uk/healtharticles/2011/02/cbt-for-adhd-caerphilly-glamorgan-wales/>

Care for the Family (based in Cardiff)

<http://www.careforthefamily.org.uk/courses/parenting-courses-time-out/time-out-for-parents-children-with-special-needs-asd-adhd>

Patient Info

<http://patient.info/health/attention-deficit-hyperactivity-disorder-leaflet>

Mental Health Foundation – ADHD

<http://www.mentalhealth.org.uk/help-information/mental-health-a-z/A/attention-deficit/>

ADDISS – Fact sheet on ADHD

<http://www.addiss.co.uk/allabout.htm>

UK Adult ADHD Network

<http://www.ukaan.org/support-groups.htm>

Young Minds – The voice for young people's mental health and well-being (a site for parent, children and professionals)

http://www.youngminds.org.uk/for_parents/worried_about_your_child/adhd_children

Documents:

National Collaborating Centre for Mental Health

<http://www.nccmh.org.uk/downloads/ADHD/CG72FullGuideline.pdf>

Edspace – Talking About ADHD (booklet)

<http://edspace.org.uk/cms/wp-content/uploads/2015/08/TalkingaboutADHD.pdf>

City & County of Swansea ADHD Guidelines

<http://www.swanseagfl.gov.uk/inclusion/documents/adhd/ADHDenglish2010.pdf>

Cerebra – What's the Evidence? Complementary and alternative therapies for ADHD.

<http://w3.cerebra.org.uk/research/research-papers/pencru-whats-the-evidence-complementary-and-alternative-therapies-for-adhd/>

ADHD in Historical & Comparative perspective.

http://perso.ens-lyon.fr/neil.vaytet/documents/Reinholdt_thesis.pdf

NHS – National Institute for Health & Clinical Excellence – Document on Methylphenidate, atomoxetine and dexamfetamine for attention deficit hyperactivity disorder (ADHD) in children and adolescents.

<http://www.sochipe.cl/subidos/catalogo1/docs/TA098guidance.pdf>

Young Minds – The voice for young people's mental health and well-being (a site for parent, children and professionals)

http://www.youngminds.org.uk/for_children_young_people/whats_worrying_you/adhd/factsheets

Other resources

<http://www.lifewithadd.org/>

A useful self help website

<http://www.medicalnewstoday.com/info/adhd/>

A US definition – some interesting statistics, also the suggestion that many people either grow out of or learn to cope with it into adulthood

<http://www.theguardian.com/technology/2015/mar/16/adhd-internet-is-there-a-connection-sxsw>

A link to internet use from the guardian

<https://www.psychologytoday.com/blog/suffer-the-children/201203/why-french-kids-dont-have-adhd>

Article on French experience where reportedly only .5% children have a diagnosis of ADHD

<http://www.wellcome.ac.uk/News/Media-office/Press-releases/2010/WTX062886.htm?gclid=CK6KyNWy3cYCFUHJtAodzW8OSA>

Wellcome Trust report based on Cardiff University research that suggests adhd has a genetic cause and as such is a neurological disorder

<http://www.webmd.boots.com/add-adhd/guide/adhd-symptoms?page=2>

Boots chemist resource along with suggested criteria for diagnosis