



Kids Health Matters Transcript

Ep 7: Understanding ADHD part 2

The Child and Adolescent Health Services respects and acknowledges the Whadjuk People as the traditional custodians of the land on which we work and of Elders past and present.

Hi and welcome to Kids Health Matters - a podcast where we meet experts from the Western Australian Child and Adolescent Health Service, which includes Perth Children's Hospital.

Each episode will dive into a range of topics and issues affecting kids' health and wellbeing and provide you with information on how you can best support them through their journey of childhood and adolescence.

Host Dani Shuey (DS)

Welcome back to Kids Health Matters. I'm Dani Shuey and it's a pleasure to be your host today.

This is part two of our ADHD chat with Dr. Brad Jongeling and we are joined in studio again by nurse Danielle Engelbrecht. Hello to both of you.

We unpacked the background of ADHD on the last podcast and talked a little bit about how it presents and how it differs in boys and girls, and now this podcast is about those steps we need to take, the pathways for diagnosis and we want to talk a bit about medication as well.

So Dr. Brad, if a parent is worried about their child's behaviour, and they think there might be some attention challenges or something that's not quite right, what first steps would you suggest that they take?

Guest Dr Brad Jongeling (BJ)

Well, that really depends a little bit on age. Most commonly, the concerns raised by a parent, or a family member, or it might be a teacher or a day care provider, are about the child's behaviour. And as we talked about earlier it might be concerns around hyperactivity or impulsivity or the way they're socialising or engaging with other children.

If they're school age, the important process for parents to follow is to talk to the teacher, develop a relationship with the teacher about what's happening with their child, what supports can be put in place, and potentially involve the school psychologist in providing some observations of the child and changing the supports that are being provided within class. Sometimes that's really all that might be needed for some of those children.

For younger aged children, it is a little bit different because with the younger ones we are usually considering all those other presentations we mentioned in the last episode. Things like does the child have a language impairment or do they have social issues that might make you concerned about developmental autism and for those children it's really important that you engage well with the child health nurse, because they have a great ability to identify children who have problems with early development and they can make some really helpful suggestions around interventions, supports and referrals.

The GP is also really important too because they have a very good knowledge of what normal milestones are and can help provide referrals for assessment of vision or hearing or other sensory issues that may sometimes be underlying presentation issues.

Co-host Danielle Engelbrecht (DE)

And Dr. Brad, if we've done a lot of those initial steps, what are the next pathways to diagnosis?

BJ

It is a staged process and sometimes it takes many years from someone first saying, I'm concerned to actually seeking a referral, and getting an assessment and a diagnosis. That can be both good and bad, because sometimes it's good to give a child the opportunity to mature.

DS

Yes, not jumping to conclusions about what might be going on.

BJ

Exactly and you don't want to do that. You want to put supports and strategies in place, and we'll talk about that later I hope, that provide that child with the right help to continue.

But if you are concerned, the first point of call, particularly for older children, is your GP who can do hearing or vision assessments; they might look at what social supports are around that family, what psychological needs might be required and they can recommend some of the strategies that we would suggest for children with attention related issues.

In addition, if they're concerned that despite doing those things there are still issues, they can make a referral. They can refer to a psychologist for an assessment; they can refer to allied health therapists who can play a role in providing some supports around attention and sensory matters, and if they're particularly concerned, they can also do a referral to a paediatrician or to the Child Development Service where I work, who can do assessments and diagnoses.

But we have to acknowledge that the diagnosis pathway takes time and there are wait lists for much of that across WA.

DE

What does a diagnosis actually involve? It seems like there is quite a variety of skill sets to really formulate the picture of what's happening for that child and to then make a decision around an ADHD diagnosis.

BJ

The most important aspect in diagnosis is obtaining a really detailed developmental medical and psychosocial history, and with younger aged children often doing a formal developmental test as well.

We use standardised questionnaires in the assessment in order to obtain information, often from school and home, so we're able to then compare what we might expect for a child of that age. That helps us understand whether that child's attention or behaviour is out of keeping with what we might normally expect.

DS

That is really interesting, because what a teacher might notice at school compared to what parents or caregivers might notice at home could be completely different because the kids are in their comfort of their home so they might not act the way they do school.

BJ

Exactly. The questionnaires are not diagnostic in themselves, they're an aid to the assessment. So the ADHD diagnosis can often be made because of the history and sometimes observations but you need to be able to see it across settings. It can't just be at school; if it was just at school we might think oh, is it because this child has some educational or learning challenges? If you can't do the work you're going to be off task more often than not and that might need adjustment in that area.



But if it is occurring at school, and it's occurring at home, and it's also occurring during Cubs or at the footy club, then it becomes a slightly different issue and it becomes more, what we call, an issue that shows a cross-setting impairment or difficulty.

So you do need that information. Sometimes though we can see some children, as we talked about earlier when we were talking about girls, where the teacher might fill in a questionnaire that shows some concerns in the classroom, but not a lot, but it's really problematic at home. That's because there are some children who can maintain their attention in class for a while, and it's hard work, and they come home and there's just an explosion because they've been working really hard at school and they've just had enough. Then they explode in that home environment and it's clearer than that they've actually got some significant challenges that need support.

Part of the assessment process is also having a physical examination, which is really important and vision hearing screening is sometimes required for that. And sometimes we will need to do some other investigations like blood tests for iron deficiency if we think it's clinically indicated, and there has to be a reason to do that. And occasionally we'll need to do an ECG if we're worried about the risk of a cardiac issue.

DS

These things take time as you've mentioned; it doesn't just happen overnight that you can get your child assessed and get a diagnosis so how can you support your child while waiting for the assessment?

BJ

The most important aspect of support is really having a loving, caring, supportive home environment.

These children can be challenging and parents need to also look after themselves as well in this process. They need to have their own breaks; they need a supportive partner or family who can coalesce around that family and child and provide supports.

If we were to break down into what things you can do which actually make a difference probably the most important is providing structure in the home environment. By that I mean ensuring that when children come home from school, they can have a bit of a break; that you structure into their day some non-screen activities because screen time is a big problem at the moment for many children, including kids with ADHD; it's quite addictive. So reducing screen time, focusing on outdoor activities, encouraging outdoor play and looking at lifestyle factors like adequate sleep, physical activity and a healthy diet. All of those things are really important in managing them.

And a word I would use is consistency; consistency across settings and that is particularly important in separated families. Consistency around bedtime and the bedtime routine is really important; as well as the use of reinforcements and rewards for children. Sometimes in the younger age groups star charts are really useful, though they're not particularly useful in adolescence, but particularly for the younger age groups they're really important.

Externalising information a little bit, or time in particular. Kids with ADHD are not very good at keeping track of time so if you say you've got half an hour to do this Jack, they're not going to be able to do it, but if you can actually pop a little timer on that they can see, they are much better when able to see that timer going down. They will think 'Oh, I'd better get on and do these things', so that's really important.

Breaking work down into smaller tasks and steps is really helpful. Really what you're doing is trying to help them with their organisational skills.

One of the big areas that we see is kids who are struggling with school and homework. Homework causes quite a bit of distress for everyone in the family. If they get an assignment from school that's due in six weeks, they often leave it until the last minute to complete. The idea here would be that you actually need to break the task down and make them what we call more accountable more often. So expect them maybe at the end of the first week to have a bit of a draft done, and in the second week create another expectation which might be writing the introduction and in the third week, the main body of the assignment. So you actually break it down. The more often you do that and put that structure around them, that can be really helpful.

A supportive, caring and loving home environment, plus consistency, plus structure, can be really helpful.



It's really about helping create a supportive environment for the child and the family, where you, as a parent, can choose those activities that give your child a win. Because they often get negativity at school, you need to become positive and find things that you can concentrate on and say great job Jack, you've done really well today.

The other thing we mentioned was being aware that managing a child with ADHD is stressful, and it can be stressful for everybody, so as a parent you need to take care of yourself. You need to take time out, have that supportive family, focus on your own health as well, because being well in yourself can make a big difference to how you support your family and your child.

DE

Dr. Brad, when we get to the point that we do have an ADHD diagnosis, what are our options in terms of treatment?

BJ

There's a term that we use for treatment, which is called multimodal, and I'll explain what I mean by that.

Treatment isn't just one thing or another, it actually has to involve a combination of approaches and when we talk about multiple approaches, we're talking about behavioural strategies, educational strategies, lifestyle changes and sometimes medications where those things are not sufficient to support that child.

When we do use medications, it's when symptoms impact significantly on a child. By that, I mean they might impact the child's confidence about attending school when they know they can achieve at a level but their actual achievement is much lower, it can impact them socially because they are the child that's described as the clown in class; they're naughty, they're not invited to birthday parties because of their impulsive behaviours, or when it impacts on the family function.

When their behaviour at home is all over the place and nobody's coping with this child, that's when medication has a role and medication, when it's used, is very effective. It works in about 75% to 85% of cases and it makes a really big difference.

I recall when I first started treating children with ADHD, and that's many years ago now, there was one family with a child who was quite hyperactive impulsive, who said to me, says, wow, he's so different, even the dog likes him now. He had been this little tear away; busy, active, pulling the dog's tail, and he wasn't doing it in a mean way, he just conceptually couldn't control those aspects of his impulsivity and attention.

DS

Are you finding parents are hesitant to medicate their children for ADHD because of fear of changing their personality, or is that a silly question?

BJ

No. it's a really important question.

We've been through many phases over time about parents being comfortable about using medication, and there is good reason to be careful about introducing medicines. You do need to do a really thorough assessment and consider a lot of factors in that assessment process. At the moment, certainly in WA, it's a specialist level assessment that's required in making that diagnosis although may change with other training over time.

There are parents who are reluctant and I think for those you need to be supportive on their journey to a diagnosis. Sometimes it is saying it looks like you have ADHD but let's see how we go with these behavioural and educational strategies, let's try some of these lifestyle factors; reduce screen time, improve sleep, do some activities, support in classroom, and then to see where we are in six or 12 months.

And if in six or 12 months we're still having those issues, medication might have a role and it's about taking those parents on that journey to understand what the pros and cons of that medication are and how it can be helpful.



I think the other side of it is talking about the supportive things that others can do. We've spoke a little bit about the role of GPs. GPs have a really important role because they know families well, they've been on that journey with families, often since the children were born, prior to that in many practices so they can identify emerging issues. They can provide support to the family; they can direct them towards allied health supports where needed and they can screen for emerging psychological or other developmental issues. So it's really important that we focus on ensuring there is a really supportive GP in that process, who can do a very detailed referral when required.

DE

And Dr. Brad, you were talking about a lot of other multimodal approaches to the care of children with ADHD and it sounds like we've got an amazing community of professionals around our children with ADHD. What role does our allied health team provide?

BJ

Allied health therapists are really important, particularly with the younger age group; kids aged four to six, but also for older aged group. They can do a quite a bit around supporting a child with attention and behavioural issues.

DS

So these are our speech therapists and our OTs and physios?

BJ

Yes, physios have a role as well. So, for example, ADHD is often associated with some coordination challenges in some children, what we call Developmental Coordination Disorder. Physios can help break down tasks in the area of motor skills that can really help those children. Speech pathologists are very helpful for children who have ADHD with language impairment or some comprehension issues. OTs are particularly helpful in the area of sensory issues, attention regulation and emotional regulation.

And then we've got our clinical psychologists, who can really assist kids with organisational skills, particularly as they move into the upper primary and high school levels, around learning, focus and study skills, and they can support mental health challenges such as anxiety and depression with various techniques.

So there is an important role for all therapists in supporting a child with ADHD.

DE

And what about the role of the school; our children spend so much time at school, how can the school help to support children with ADHD?

BJ

Schools are really essential; they're the first port of call often where it might actually be the teacher who identifies the ADHD.

DS

You often hear that it's the teacher who's picked up on it and as you mentioned all kids are different at home to how they are at school.



BJ

Yes and the demands are different at home. At school there's potentially 25 other kids, in the class, and lots of sensory demand and attention which might be why the child's being noted there, but not at home.

Schools are really important because they can identify kids with ADHD, and they can also put in supportive structures around the child. One of the important things I think to note is that schools need to be aware of the ADHD diagnosis, and I don't mean individually in a child specifically, but as a phenomenon and they need to support children who have attention issues.

Schools can put structure around kids; they can provide additional learning supports within the class setting, and they can try and reduce distractions. There's a whole range of things they can do that are supportive. They often do this but they need to focus more on quality of what the child produces, rather than quantity. Kids with ADHD are not always easily able to get information out onto paper. They might do very good work, but it's very limited, and we don't want a negative feeling for school, if that's the right word. You want children to be successful at school.

The other important thing to realise, and many schools do, is that for some children this is a real disability and they need to accommodate for it. Sometimes there are children who can't finish the work in class and are given that for homework, as well as the homework, and that's just overwhelming for them. So being mindful of what are we seeking here in their learning is really important.

Outside of school sometimes kids benefit from tutoring, particularly if they've got learning challenges and as children become a little bit older, and I'm talking about adolescents and adulthood, there can be a role for ADHD coaches in lifestyle management as well.

DS

We touched on medication earlier, can we briefly talk about what that involves?

BJ

Medication is probably the mainstay of treatment once you've been through those behavioural and educational strategies, and sometimes it's first line where the features of ADHD may be significant or severe or really impactful right at the start and there's quite a process to get to the point of deciding medication.

We mentioned taking families on the journey to that decision and that's really important because as I noted earlier, medication is transformative for many, there are both side effects and positive effects that we need to consider when we're treating ADHD.

We mentioned the diagnostic process and needing a developmental assessment, a good history, and where examination and investigations are required.

Once we have all of that information together, and we can see from the history, the questionnaires and information from school, home and other sites what is really causing significant impairment on the child and where the strategies are not enough to support the child, that is when we decide medication has role. There are two main types of medications that we use in ADHD. There are stimulant medications and there are non-stimulant medications.

The non-stimulant medications are what we call second line, meaning we use them when there are side effects on stimulants, or sometimes if there's severe anxiety, we might look at them. As I've said, they are second line, so we wouldn't normally start by talking about them and the reason for that is they are effective, but not as effective as the stimulant medicines.

There are also main types of stimulant medicines; there's one called methylphenidate and one called dexamphetamine, and as I noted in the first podcast they are used in about 75% to 85% of cases. One or the other will be effective in about 70% to 80% of children in terms of improving attention and focus, reducing impulsivity and hyperactivity, and really helping them to engage in the curriculum or improve their peer interaction.

The decision as to which one is the right one is determined on a case-by-case basis. There is no research to say a child needs this one or the other. Methylphenidate lasts about three or four hours and dexamphetamine lasts a little bit longer, four to five hours, and there are longer acting versions of them, which we will often think about switching



children to so that they don't have to take one at school. That's particularly important as they get into upper primary or high school.

Those medicines when they work are really effective, as we talked about. They're transformative for some children. What we're looking for, once children are on these medicines, is to be much more engaged, much more focused, much more able to be attentive and show the skills that they have underlying their abilities that you often don't see.

But you have to balance that out with those side effects that we know sometimes occur, some of which are very mild and manageable, like a little appetite suppression or not-feeling quite hungry at lunchtime so we monitor weight and height growth every time we see a child. Sometimes they might have trouble getting to sleep, although often ADHD children have trouble getting to sleep anyway and sometimes that's because their mind is so busy at night, so medicine can help that but usually the medication can make it difficult to get to sleep. That normally settles with a bit of time. At other times we might need to change how we use the medicine or use some other things to help with that.

They are some of the really common side effects. There are other things that we monitor like blood pressure and pulse rate, just to make sure those things are okay although we rarely have to do anything about that.

And then there may be effects on emotion. Almost all kids cope quite well with medication, but some get a little bit moody. If you persist with the medication that will settle down and it's manageable. Others can get what we call a wear-off effect in the afternoon, or what is known as rebound effect, which means that if they have a dose morning and lunchtime, around four o'clock in the afternoon their little hyperactive self comes out and they're more busy. Usually that's quite manageable by a dose of one of the medicines after school or by switching to the longer acting.

Almost all of those side effects are quite manageable by changing the medication, changing the timing or moving to a longer acting form.

There's a very small proportion of children who when they are medicated become really moody, upset, withdrawn, or what some people describe as too quiet and too reserved and if that happens, medicine is not really right for them and we would want to stop that and look at different options. It's really important to monitor that carefully.

So when we start a medicine we often get to see them four to six weeks later to see how they're going, with some communication in the meantime and hopefully the GP can play a role with that as well.

DS

Asking as the voice of a concerned parent, once you medicate your child for ADHD, do they have to stay on that medication forever and are there long-term side effects?

BJ

That's a great question.

The answer to that is that medication plays a role as long as it's necessary. So in other words, every year or two, you really do need to re-evaluate and say, okay, let's try without medicine for a week or so, let's see how we're going and often parents are doing this naturally anyway, because they might not use it in the school holidays, or they might not use it on the weekends.

Kids need to be off it for a few days before you can make a judgement because if you stop it on one day, the next day is often a little more hyperactive, particularly in the hyperactive type. So you might want to wait for a little bit longer before you make a judgement, but it's worth stopping it for a little while and seeing how things are going and we expect most parents and clinicians would do that at some point.

As far as long-term side effects are concerned, the main ones we are aware of is watching issues around growth, so the weight and the height. There's evidence that weight is sometimes a little less initially but then they follow along a centile, and height a little bit less, but ultimate adult height is not really so much affected, but it requires monitoring as all medications do. All medications have side effects when there are active ingredients and so you need to watch for that as well.



Some parents worry about risk of substance misuse later on in adulthood or adolescence because of stimulants. By that, I mean, using other substances as they get older. The evidence around that is that ADHD medications do not increase that risk.

DE

Dr. Brad, what about those children who do have a diagnosis of ADHD - do they go on to require treatment as adults? Is it something they learn to manage or is it one of those things that we're talking about managing as you get older, trialling or paring back, stopping medication and withdrawing other supports? How does that work?

BJ

The evidence is about 60% of kids, adolescents or young adults with ADHD, when they move into adulthood may still have ADHD symptomatology, and a proportion of them will need ongoing treatment.

The experience is that it partly depends on what the young adult is doing. If they're off at university, or TAFE, and they've got to do study, they may well still need medication for that aspect, although sometimes they're making career choices for things that they really enjoy and we all know if we really enjoy something, and we're really motivated our focus and attention is so much better.

In school, where they've got to do a whole range of things, some of which they might be less interested in, and so you're ability to stay on task may be much more impaired.

There's a proportion who will go into TAFE or uni and will need medication for that. There's a proportion who go into the workforce, who might be in a job that's outside which they really enjoy and they're not distracted by things around them and are able to focus and they don't need medication.

So it is a case of reassessing, usually by an adult psychiatrist, to make an assessment of whether it is still needed - is the presentation and the symptoms still there and are they still significantly impairing the function of that young adult.

DS

Dr. Brad, you are the Medical Head of the Child Development Service. How is it unique in the service that it provides to children and their families?

BJ

The Child Development Service in Western Australia is one of the only services of its kind of across Australia. We have a combination of paediatric clinicians, including paediatric specialists, speech pathologists, occupational therapists, social workers, clinical psychologists and play learning therapists who can all provide a holistic approach to both assessment and treatment for the whole range of developmental conditions that children present with from birth right through until 16 to 18.

We can step into a void and provide interventions and supports for children presenting with learning and attentional issues.

DE

I think having a child with ADHD is incredibly challenging for our families, and I know even through my journey as a parent and meeting other parents at school, how isolating experiencing this can actually be, without knowing who can provide emotional support during their journey with their child with ADHD.

What resources do you see that families can utilise to help them?



BJ

We really understand that parenting a child with ADHD can be quite a stressful experience and we've compiled a list of excellent and reliable sources of information which you can access and which we have available.

There are particular groups that also play a role. I've mentioned earlier ADHD Western Australia which has some great resources, the Australian Association of ADHD Professionals which has got some really excellent resources including those written with life experience, which can be really useful to read.

And then, of course, the Parenting Network that is tied to our service has information that's really useful.

DS

Dr. Brad are there any final messages you'd like to leave with us?

BJ

Parents should be aware that if they're really struggling themselves, which is completely understandable when managing a child or even many children in a family with ADHD, as we talked about its inheritability. They need support. It's not easy being that parent, you really do need to seek out supportive people around you, both within family and friends.

If they're really struggling and they identify that they also have some challenges it might be that they also may have ADHD and so seeking an assessment via their GP can also be helpful and can make quite a difference to themselves as well as their family.

But it is also important to remember that these are creative, at times delightful and innovative children. They might stretch knowledge in a really positive way so having ADHD is not all bad in itself, in fact, those children can sometimes be the most creative.

DS

Yes, it is so important to recognise that, so you can actually be working to your full potential.

BJ

Exactly, and these children are full of energy and full of life at times but sometimes it can get to that point where it's a bit much for them, it's a bit much those around them, including the teacher and it might be a bit much for their peers, and that's when additional help, sometimes an assessment, sometimes intervention, and sometimes medication treatment might be really helpful.

DS

Dr. Brad, a very big thank you for joining us on the podcast and giving us a fantastic insight into ADHD.

My co-host Danielle Engelbrecht, thank you for being here as always... and thank you for listening to Kids Health Matters - a podcast produced by the Child and Adolescent Health Service.

You can find more information and links to useful resources in the show notes for each episode. You can also email us with any feedback at kidshealthmatters@health.wa.gov.au.

I'm Dani Shuey and I look forward to welcoming you back next time.

