

A Snapshot of ADHD

A CONSUMER AND COMMUNITY DISCUSSION



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Introduction

The challenges that people with ADHD face are complex, including managing the transition from childhood to adulthood, seeking effective treatment and finding a long-term support network. Recently a panel of people with, or who treat, ADHD met to discuss issues related to patient advocacy, support and the successful management of ADHD. Dr John D'Arcy facilitated the discussion.



A report on a panel discussion about ADHD in the community on 15 March 2014, sponsored by Shire



Facilitator and participants



Dr John D'Arcy has mixed and matched the practice of medicine and the media for 30 years. He was the first medical practitioner appointed to an Australian newsroom and today produces a daily health blog, "Health Check" heard on radio weekdays around Australia. He is a key note speaker and is in family practice at Beecroft in Sydney.



Dr Ernst Eiselen is a general practitioner from the northern suburbs of Perth where he established the Clarkson Medical Practice. He covers all aspects of medicine and sees a number of patients with ADHD.



Dr Shane Langsford is a registered psychologist and Managing Director of Psychological and Educational Consultancy Services (PECS), which conducts psychological and educational assessments for both children and adults and provides appropriate intervention relative to the outcome of the assessment, or as requested by the referring health professional.



Dr Michele Toner who was originally a high school teacher, completed a Master's degree of Special Education in 2001. She was awarded a PhD in 2009. Michele is a credentialed ADHD coach, and has worked in the area of ADHD since 1995.



Ms Annabel Blake is a professional freestyle skier and took part in the 2013 and 2014 skiing World Cups. Following injury in the 2014 World Cup, Annabel was forced to withdraw from consideration for the Australian team for the Sochi Olympic Games. Annabel was diagnosed with ADHD in high school. After leaving school she worked as a camp counsellor for children with developmental disorders and is studying for a degree in psychology at the University of Wollongong.



Ms Shelley Blakers has worked in education for more than 35 years across all departments and age levels. Shelley has been involved in ADHD for the past 25 years. She has developed extensive knowledge in the area, particularly with relation to children. Shelley has presented at many workshops, assisted in the development of courses, written papers regarding ADHD and held support meetings for adults.



Ms Marian Maughan is President of the Learning and Attentional Disorders Society of Western Australia (LADS). Marian initially entered the workforce as a primary school teacher and joined LADS in 2000 after working for many years in the State welfare department as a social worker and Social Work Supervisor.



Mr Ray Steele is the Secretary of the ADDults with ADHD (New South Wales), a not-for-profit, volunteer-run organisation established to address the needs of adults with ADHD (and related conditions) and their families. The organisation is committed to reducing the stigma associated with ADHD and dispelling the myths and misinformation that are prominent in the media and the community at large. In addition to his role as Secretary of the organisation, Ray is a trained counsellor and TAFE teacher working with students with disabilities.

Section 1: ADHD – an individual perspective

“ I tell people it’s like a million ping-pong ball games going on in my head. I feel I’m two steps in front of everybody else. I’m moving so fast it is hard to think. It’s exhausting ” Annabel Blake

Common characteristics and traits of people with ADHD

ADHD is a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development. Individuals with ADHD are classified with one of the following: ADHD predominantly hyperactive-impulsive presentation; ADHD predominantly inattentive presentation; or ADHD combined presentation ie. both hyperactive-impulsive and inattentive traits. Panel members believed that the media selectively portrays the hyperactive-impulsive end of the spectrum rather than the attention deficit and learning aspects of ADHD; these children have difficulty marshalling their attention to a learning task and are easily distracted. “It is a shame that there is a group of really bright kids that can get overlooked,” said Michele Toner

Annabel Blake, who was diagnosed at 17 years of age, likened ADHD to “a million ping-pong ball games” going on in her head. “I feel I’m two steps in front of everybody else. I’m moving so fast it is hard to think. It’s exhausting,” she said. Marian Maughan, who was diagnosed later in life, had difficulties throughout childhood and found school difficult. “I failed quite successfully throughout my entire school career,” she said. “I couldn’t understand it, because I felt I ought to be able to do things but it didn’t happen. I could see other people managing. They were doing the same things as me and it worked for them but it didn’t work for me.” Her ADHD diagnosis was pure luck when seeking professional help for another problem. “It was a relief to know that there was an answer for my life,” she said.

Ray Steele pointed out that one of the significant things for adults with ADHD is that the stereotypical childhood ADHD behaviour does not necessarily continue into adulthood. Certainly the hyperactivity is not there. “By the time they are adults, they have been beaten into submission or they realise they have to be sociable. But there are other expressions of the disorder, and a classic one is a restlessness, an inability to settle physically in a chair, or restless in the need for new stimulation in jobs or even in their relationships,” he said.

The impact on people’s lives in the short and long term

The impact for each person is quite different and ADHD often masquerades as other conditions; so sorting this out can be difficult. Ernst Eiselen identified late diagnosis as one of the many problems. “Early diagnosis can make things easier, especially with learning because there are aids available. But it is not a popular diagnosis. It’s genetic in many cases, so the first issue is to get parents to accept that the child has the condition and that it is probably inherited. If they made a critical analysis of their own lives, they may find they also have the disorder,” he said.

Dr Eiselen also explained that adults with ADHD experience discomfort that differs according to the nature of the condition; some are more impulsive and some are inattentive or disorganised and that makes it difficult. “But on the positive side – which I always point out – one of the strengths for ADHD sufferers is the ability to think laterally because they can switch between ideas and string ideas together, thereby producing inventive and novel solutions,” he said. Acceptance in successful people with undiagnosed ADHD is also an issue. “They may have the idea that if it’s treated, they will lose it. But when they realise that they won’t lose their creative edge, but a lot of the discomfort will go away, then there is more acceptance,” he added. The fact that it is not a single condition, like mumps or measles, adds to the difficulty of treating ADHD.

“ It is a shame that there is a group of really bright kids that can get overlooked ” Michele Toner

Shane Langsford agreed that in children also, the impact of ADHD depends on the subtype. “The children who are the predominantly inattentive presentation subtype are not absorbing information in the classroom as well as other children. For the hyperactive-impulsive individuals, they are often not paying attention because they are busy doing something else,” he said.

ADHD may also be associated with comorbidities, such as anxiety and depression as well as the more complex conditions, like schizophrenia and bipolar disorder. “In terms of lived experience that is untreated, there is certainly depression, anxiety and poor self-esteem,” said Mr Steele. “Having been unsuccessful at school, university or TAFE for a long time is very demoralising. Not being able to achieve and seeing their friends with apparently equivalent situation and intelligence doing well; they feel they are useless or a failure.”



Section 2: ADHD in the community

The panellists provided insights into the impact of the media's stereotyping of ADHD on those with the condition and how this affects their diagnosis and management.

The impact of stereotyping in the media and community on those affected

Dr Toner considered stereotyping to be a huge problem. People with ADHD find themselves in a hostile society which has no understanding of ADHD. "People think it's badly behaved children who come from dysfunctional families," she said. "So people with ADHD don't disclose their diagnosis. I often advise people not to disclose the diagnosis unless they know they will get meaningful support. Others don't seek out a diagnosis because they don't wish to be labelled by society. So the media plays a huge part in that." There is a need for education about ADHD, and health departments need to educate the public in the same way they do with anxiety and depression she added.

“People think it's badly behaved children who come from dysfunctional families” Michele Toner

Shelley Blakers agreed that ADHD is often linked to poor parenting or over emotion due to the lack of a clear scientific way of diagnosing. "The children who are hyperactive or impulsive stick out in a classroom. It is the inattentive kids with the associated learning difficulties who are the most misunderstood. They are lost because they are quiet and overshadowed," she said.

Ms Maughan noted that she personally didn't have a problem saying she has ADHD at her stage in life, because she has had a successful career and "so what if I've got ADHD." Ms Blake also said that her diagnosis did not change things, other than having a label. "I was very fortunate in that I am a confident person and had other achievements, sporting in particular. So there was no reason, and I was never given any reason, to think it was something I should be ashamed about. When I tell people, some dislocation registers when they match me up with their beliefs about ADHD – it isn't what they thought it would be." For her, humour is one of the coping mechanisms. "I'm super ADHD – people laugh along with you and they realise it is okay to laugh and isn't something I'm ashamed of. I definitely believe in the strength that my ADHD has given me and I like sharing that with other people," she said.

Mr Steele explained that admitting ADHD in the workplace is an issue, not so much for older adults, but for a lot of middle-aged people who are still trying to develop a career. For those who are aware of their weaknesses admitting a diagnosis of ADHD is really problematic. "There is so much misinformation about ADHD and, because they can't trust that their managers and co-workers will interpret it in an evidence-based way or won't pass it on to someone, they really fear being overlooked for advancement or being ostracised in the organisation. Also there is potential for systemic discrimination in the set-up of offices and the way that work is organised. Small strategies and changes can make a spectacular difference for those affected and for the benefit of the workplace," he said.

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Ray Steele

The impact of stereotyping on how ADHD is managed

Dr Eiselen observed that the community tends to isolate people with ADHD, because often as children they are disruptive and disorganised, and in general make things more difficult for others – simple things like being late, forgetting things and jumping between different subjects. Consequently, there may be resistance to the diagnosis.

Mr Steele agreed that stigma plays a big part in people's willingness to go ahead and be appropriately diagnosed. It impacts their willingness to come forward. "For many people with ADHD this is already an issue; thinking without acting is one of the characteristics of ADHD – so implementing an idea like getting a diagnosis can take years for some. So anything, like stigma or misinformation, gets in the way," he said.

Section 3: Helping people manage their condition

Perhaps the first challenge is achieving the diagnosis. Dr Langsford explained that the diagnosis is not easy to make and is clouded by many things, such as the frequent presence of comorbid disorders. Only medical practitioners can make the diagnosis. GPs must refer to medical specialists and clinical psychologists (though they can't prescribe medication) who may make the diagnosis over one or more sessions, or if more information is needed, they may seek a more global comprehensive assessment to establish that the primary issue is indeed ADHD. Psychologists perform these assessments and specialists, such as paediatricians or child psychiatrists, interpret the results together with information already garnered from the parents or person to make the formal diagnostic decision. With ADHD, the possibility of comorbid learning disorders, depression and/or anxiety is high, and as such, necessitates this formal, comprehensive assessment. "This assessment tries to weed out whether there is one overarching condition causing the symptomology of others, or if there are in fact multiple coexisting conditions present in their own right," Dr Langsford said. "Really you are trying to isolate what is the underlying primary condition. By treating the primary cause, some of the secondary issues will disappear as a result."

Access to information and support

The panellists emphasised the need for greater support of people with ADHD. Dr Toner advocated greater nurturing of consumer support organisations. "I think it is important to assist groups, such as LADS in WA and ADDults in NSW, and for support groups in other States to grow stronger. There is no government funding provided, although there are constant calls for referrals from government departments," she said. "

Ms Maughan explained that people come to support groups, like LADS, at many stages of their journey. When teachers suggest to parents that their child may have ADHD, the families come to these organisations or they may seek other forms of information. She said that, "there needs to be much more support for the many people, who for whatever reason don't understand they have ADHD or don't want to know." Mr Steele added that there was also a need for greater access through the public health system to the diagnosis and treatment options for the whole potential population. For many adults, treatment is primarily through a private practitioner. "In addition to the cost, there are a limited number of professionals who are trained and prepared to treat ADHD," he said. "There are a large number of professionals who are not trained and are not able to diagnose the initial presentation, not only GPs, but also psychologists and psychiatrists. That is a major issue for adults. We have people ringing all the time looking for referrals to professionals, particularly from country areas."

Although the Internet was identified as being potentially helpful in providing support for ADHD, there are misinformation problems and other limitations. Dr Toner observed that there was a vast virtual ADHD community where people are connecting and supporting each other and passing on information, including evidence-based information.

Dr Eiselen agreed that the internet can be helpful for patients, but the information needs to be put into context by doctors and other health professionals. "Information that people read themselves from different sources put into context by health professionals is often the best way to acceptance rather than hearing it from one person," he said. Ms Blake added that she found internet chat rooms convoluted and it would be great to see this happening face-to-face. "There are no groups, or they are hard to find, and there are limited options for someone who is not medicated and who needs skill sets to help them function. There are younger people who may not want to see a psychiatrist or psychologist one-on-one," she said.

“There needs to be much more support for the many people, who for whatever reason don't understand they have ADHD or don't want to know”

Marion Maughan

Are the health and education systems coping?

The panellists expressed concerns about the inconsistencies in the services provided to people with ADHD. "There are pockets of excellence and if people can afford private treatment, then they will get excellent treatment. There are also pockets of excellence in the public health sector. There are wonderful child development centres doing outstanding work; however, by the time they get to be seen in such centres many have been on a waiting list for 6 months, and not everyone gets to these centres," said Dr Toner. "For adults, with few exceptions, there is no treatment in the public sector so they have to pay for private practitioners and there is a financial burden on the family. Many of the medications on the PBS for children are not on the PBS for adults, adding to that burden."

Dr Eiselen pointed out that probably no system in the world is coping with ADHD and that the published figures probably underestimate the true prevalence of ADHD. "In some people it is very subtle and eventually you ask where does it begin and where does it end," he said. "The more subtle ones that do need help may be missed. The system is ideally suited in the way it is structured to be able to cope but it needs to be steered in the right direction." He added that it is an unpopular diagnosis and a difficult one to make. It is a spectrum, and the complexity means that it's hard to gauge in precise terms.

Ms Blakers added that some professionals have been targeted by campaigns. "So they may be wary about building a practice around something like ADHD," she said. "Campaigns, both political and probably religious, have targeted the whole notion of ADHD. If you're prescribing medication for ADHD, your prescription rates are in the headlights."



Section 4: Helping those with ADHD

Reasons for change

The media's stereotyping and consequent stigma linked to ADHD have created barriers to seeking both diagnosis and support for parents of children with ADHD and for adults with the condition. For adults, the lack of public health services and the expense of treatment are further disincentives. "Stigma is a barrier and prevents and makes people hesitant about receiving assessments, diagnosis and ongoing treatment," said Ms Maughan. The socioeconomic impacts are also an issue – what happens to families and the whole community. "Are Australians prepared to ignore 3% of the population? An anti-stigma campaign is very important and there needs to be a concerted effort," she said. Ms Blake agreed that tackling the stigma surrounding ADHD was of utmost importance. "For people with ADHD to flourish there is a certain dependence on the behaviour and actions of those around them," she said. "It's all about recognising and addressing strengths and weaknesses and perhaps boosting the strength side of it – showing more of that. My lack of impulse control is what makes me a good skier." "The negative and positive aspects of ADHD can be balanced with appropriate support, but part of the misinformation is a tendency to go down one track or the other," Mr Steele added.

“I would like everyone to have the same outlook as I have. We are all familiar with Tigger from Winnie-the-Pooh – adorable and funny although probably a nightmare in the classroom”

Annabel Blake

a consequence disease outcomes have improved with early diagnosis and advances in sciences. The same could be done for ADHD, channelled through role models of successful people – of which there are many, to change the public's perception. If support services are to be successful, the first thing to change is public perception," he said.

Dr Toner also recommended improving support for the family as a unit. "Because of the genetic component, often these children come from very chaotic families," she said. Ms Blaker suggested that building services for the families of children with ADHD should involve all the allied services, and that these must be better funded and done in a coordinated way. "It is such a multifaceted issue that you can't look at services in isolation. Somehow it needs to be integrated, so that families are not going to a hundred different people who give them slightly different messages," she said. She went on to say that more meaningful support and education in the workplace is also needed, "ADHD may be trivialised because the boss doesn't understand the difficulties," Dr Toner said. Another important problem is the lack of meaningful ADHD accommodation for year 12 exams similar to that which exists in the tertiary sector. "Special exam arrangements across the country in year 12 are draconian and inequitable".

“... for policy makers to recognise that there is probably an economic benefit in dealing with this condition. If we don't, like many other situations, we are buying into a much bigger lifelong cost”

Ray Steele

Changing the system to help people with ADHD

Providing more comprehensive access for adults with ADHD to services in the public sector, better education across the healthcare professions, targeting the media with more balanced evidence-based information, providing broader support and producing Australian guidelines for the management of ADHD were among some of the changes panellists advocated. "It is only recently that ADHD has become part of the formal education of GPs, psychiatrists and psychologists, so there needs to be targeted education to increase awareness. Also needed is increased awareness in teaching, especially at the tertiary level," said Mr Steele.

Dr Toner added the better education of the public would also help and Dr Eiselen suggested adopting a breast cancer model to address this. "Breast cancer has been 'popularised' and as

Changes that would have the most positive impact

Dr D'Arcy asked the panellists to nominate changes that could have the most positive impact. Ms Maughan nominated a multimodal treatment approach to ADHD. Often the treatment of ADHD is talked of in terms of medication. Medication is an important part, but it isn't the only part, and it is the part that people do not take to readily. Some parents are often reluctant to medicate their children. They will seek many different avenues of information before they will consider medication. Telling them what to do is not helpful. "There are many different options, psychology, coaching, relationship and educational aspects, joining support groups and accessing other therapists, such as speech and occupational therapists. This needs to be available across the States and for people in remote and rural areas. There is so much to be done for so many," she said.

Mr Steele had three suggestions: “Firstly, normalising ADHD in communications and conversations. Secondly, I’d like to see a national group being more effective in coordinating the good efforts that exist and filling the holes,” he said. “Finally, for policy makers to recognise that there is probably an economic benefit in dealing with this condition. If we don’t, like many other situations, we are buying into a much bigger lifelong cost. If it is dealt with during childhood, there is economic benefit.”

Dr Toner indicated that she would like to see ADHD included in the brief of StigmaWatch which has done such a good job around depression and anxiety. “I’d like to see an anti-stigma campaign. Also better education, so that people with ADHD can disclose their condition and they not be embarrassed about having it. Finally I’d like to see a lot more teamwork between medical, allied health and education with processes in place to work as a team and support whole families,” she said.

Dr Langsford advocated overcoming the bottleneck in obtaining a diagnosis. “There is a bottleneck in getting to a diagnosis made by a medical specialist, and this could be helped if deemed appropriate by the medical profession, by relaxing the requirements, for example by allowing GPs who have done extra training and education to diagnose and treat ADHD,” he said. Also the media portrayal of ADHD needs to be corrected. This tends to focus on hyperactivity and impulsive behaviour and almost always presents ADHD individuals who also have comorbid behavioural conditions, such as Conduct Disorder or Oppositional Disorder, because this makes good viewing. “Often parents have expressed that they feel insulted and bemused when their child’s assessment results indicate possible ADHD, because their child is not badly behaved, and the only knowledge of ADHD they have at this point is what they have seen on the television.”

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Shane Langsford

Dr Eiselen said he would like to see the diagnosis de-stigmatised and greater acceptance of it by colleagues, and at least the ability for a short trial of treatment to assist in making the diagnosis and as a part of creating acceptance of the diagnosis. He also suggested a better perspective on medical treatment – “does the patient need medication as part of the overall treatment? The overall treatment should not be just medication – that is an important message,” he said.

Ms Blake also nominated the ‘acceptance’ of ADHD. “I’ve found that humour is a great tool and people respond well to it. Also, successful people with ADHD could not only talk about their successes but also their difficulties. This contrast may help people, who are sceptical about the existence of ADHD, have a better understanding.”

Ms Blakers suggested the need for more conversation about the impact of inattention on learning. There are critical windows to learning that are missed if there is inattention. Trouble attending, difficulty learning and language problems have a multiplying, not an additive, effect. “You cannot learn if you cannot attend to the task. This gets lost in the behavioural focus, which is relatively easy to address by getting children to attend and sustaining that attention. The impact of inattention on learning at critical times can do a lot of damage and set people up for ongoing failure throughout childhood and adolescence. We have to make learning successful, we have to provide the avenue for learning and see attention problems early. Attention and learning are intertwined,” she said.

“A young man with ADHD told me ‘I wear failure like my favourite T-shirt’. He went on to say that throughout his schooling ‘not one day or one thing was a success’. It is not okay that we have children go through the school system and say that failure is so comfortable it’s like putting on my favourite T-shirt”

Shelley Blakers

Where to from here?

A discussion is needed regarding ADHD in the community to address the stigma attached to the condition and to ensure those with ADHD and their families get the support they require.



For further information about ADHD consult your healthcare professional. The *A snapshot of ADHD: a consumer and community discussion* took place in Sydney on 15 March 2014. The professionals quoted in this report all participated in the discussion. The panel discussion was sponsored by Shire. The panellists were provided sponsorship to allow them to participate. Dr D'Arcy was paid a fee to facilitate the discussion. The opinions expressed are that of the invited panellists and do not necessarily reflect those of the sponsor. Please consult cited references for more information. Medicines Australia's Code of Conduct sets the standards for the ethical marketing and promotion of prescription products in Australia. As a member company of Medicines Australia, Shire endorses the Medicines Australia Code of Conduct. (www.medicinesaustralia.com.au)



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