Australian Evidence-Based Clinical Practice Guideline For ADHD:

CONSUMER COMPANION GUIDE

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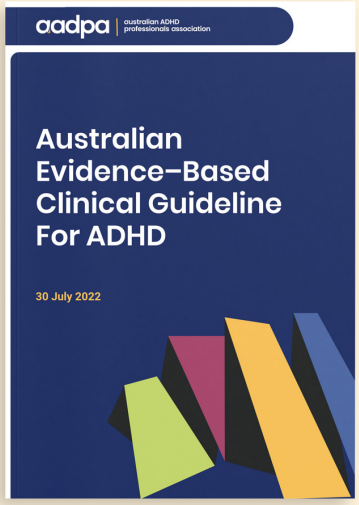
Introduction

In October 2022, the Australian ADHD Professionals Association (AADPA) published the Australian Evidence-Based Clinical Practice Guideline for ADHD. It was written for health professionals who diagnose, treat and support people with ADHD.



While the Guideline is the most up-to-date clinical practice manual in the world, it's not the easiest document to read. For this reason, AADPA set out to develop this Consumer Companion. We wanted to ensure the critical information contained in the Guideline could be easily understood and accessed by individuals with ADHD and their families, or by anyone searching for evidence-based credible information on ADHD.

Our Consumer Companion has been written by Louise Brown, a Doctor of Philosophy (Nursing) Candidate (Curtin University), Lived Experience Advocate and AADPA Appointed Board Director, and reviewed by the members of the original guideline development group who have a lived experience of ADHD, along with Prof David Coghill and Prof Mark Bellgrove.

We are always seeking feedback. Once you've had a chance to read our Consumer Companion, we would be grateful if you could please take some time to **complete this online survey**.

Louise Brown
AADPA Lived-Experience Appointed Director

Prof. David Coghill
AADPA President

Prof. Mark Bellgrove
AADPA Guideline Lead

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What is ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental condition characterised by differences in brain and cognitive development.

ADHD symptoms

Symptoms include greater difficulties with focusing and sustaining attention, hyperactivity, and impulsivity than would be expected for a person's age or developmental level. For many people, ADHD symptoms continue into adulthood and can be lifelong.

People with ADHD can struggle to:

- Focus and concentrate
- Control their impulses
- Stop and make decisions which take into account longer term consequences

They can also experience difficulties with:

- Planning and prioritising
- Getting organised
- Time management
- Emotional regulation

These difficulties can impact a persons's ability to study, work, manage responsibilities, develop and maintain social relationships, enjoy leisure time and relax. They can also negatively impact self-confidence and self-esteem.

Over 800,000 Australians have ADHD:

6-8% of Australian children

3-5% of Australian adults

What is the Guideline?

The Australian Evidence-Based Clinical Practice Guideline for ADHD provides a roadmap for ADHD clinical practice, research and policy.

Based on the best evidence available at the time of development, the Guideline promotes accurate and timely diagnosis of ADHD. It also provides clinicians, educators, consumers and policy makers with guidance on optimal assessment and treatment interventions.

The Guideline includes age-related recommendations on treatment options, and outlines how these options should be tailored to the needs and preferences of people living with ADHD.

What does the Guideline mean for you?

The Guideline was developed to improve the lives of all Australians living with ADHD. Adoption and implementation of the Guideline is intended to standardise ADHD care provision in all healthcare, educational, occupational, detention and general community settings.

This Consumer Companion of the Guideline is designed to ensure consumers with ADHD and their families are fully informed when being diagnosed, treated, and supported for their condition.

You can use the Guideline or this Consumer Companion to learn more about the type of care you, your child or loved one with ADHD should expect to receive. You can also use them to ensure you are making informed treatment decisions, and to advocate for appropriate care should you need to.

How was the Guideline developed?

Guideline development was led by the Australian ADHD Professionals Association (AADPA).

AADPA established a Guideline Development Group (GDG) to review the evidence around diagnosis, treatment and support of ADHD.

It found that the UK National Institute for Health and Care Excellence's Guideline for ADHD (NICE, 2018) was the most current and thorough guideline in existence. With permission, we have adapted and updated the evidence and recommendations in the NICE Guideline to fit the Australian setting.

When developing the Guideline, the GDG followed the very strict National Health and Medical Research Council of Australia (NHMRC) standards and procedures.

The development process:

- Identify and gain consensus on the clinical priorities and clinical questions about ADHD
- Update the evidence contained in the NICE Guideline and review new evidence using a systematic approach
- Determine the quality and certainty of evidence and develop actionable recommendations that balance potential benefits and harms, and fit the Australian context
- Integrate the best available evidence with multidisciplinary clinical expertise and consumer preferences
- Seek public consultation and integrate stakeholder feedback into the draft Guideline and recommendations
- Undergo an external review
- Finalise the Guideline and submit it to the National Health and Medical Research Council for approval

Approval of the Australian Evidence-Based Clinical Guideline for ADHD was given in July 2022.

During the development process:

The World Health Organisation's International Classification of Functioning, Disability and Health (ICF), was used as a framework for discussions and deliberations.

The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) framework was used to develop and present summaries of evidence and make clinical practice recommendations.

More information about the methodology used to develop the Guideline can be found here: https://adhdguideline.aadpa.com.au/about/methods/

About the Guideline Development Group (GDG)

The GDG comprised a broad range of people with experience of ADHD, including those with backgrounds in:

- Paediatrics
- Child and adolescent psychiatry
- Adult psychiatry
- General practice
- Psychology and neuropsychology
- Speech pathology
- Occupational therapy
- Pharmacology
- Nursing
- Education
- Academia and research

Four members of the GDG group identified as having a lived-experience of ADHD:

- Ms Edwina Birch
- Dr Madelyn Derrick
- Ms Ingrid Garner
- Ms Alyssa Weirman

Mr Michael Gathercole and Dr Cammi Murrup-Stewart provided perspectives from their experience in indigenous clinical practice, academic research and advocacy.

Special considerations

Consideration was given to the following groups during the Guideline development process:

- Aboriginal and Torres Strait Islander peoples
- People who are in the criminal justice system
- People with substance use disorders

Consideration was also given to:

- Culturally and linguistically diverse communities
- People with co-occurring neurodevelopmental and mental health conditions
- Women and girls
- People with low socioeconomic status
- Children in out-of-home care (ie: foster care)
- Older adults aged 65 years and above

More information about the members of the GDG can be found here:
https://adhdguideline.aadpa.com.au/about/introduction/

Conflicts of interest were managed by the Conflicts of Interest Management Group.
More information about the management of conflicts of interest can be found here:
https://adhdguideline.aadpa.com.au/about/introduction/

Guideline information and recommendations

To follow is a summary of the pertinent information and recommendations contained in Australian Evidence-Based Clinical Practice Guideline for ADHD.

These are categorised under the following headings:

- Identification
- Diagnosis
- Education and information
- Treatment and support
- Non-medication interventions
- Medication interventions
- Subgroups.

What are Guideline recommendations?

Guideline recommendations are clear and actionable statements that:

- Are based upon the best available research evidence and clinical practice experience
- Intend to optimise the care people living with ADHD receive

Guideline recommendations contain either the word '**should**' or '**could**'. These words refer to the quality of the evidence supporting a recommendation and/or the GDG's benefit verses risk assessment. It can be helpful to understand the meaning assigned to each of these words.

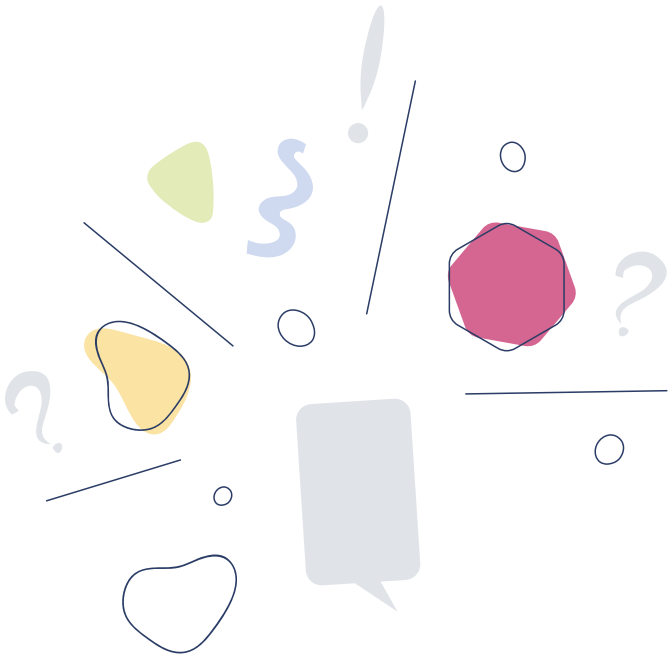
Definition of 'your family member'

In this Consumer Companion the term 'your family member' refers to your child, adolescent, spouse, partner or relative with ADHD.

Recommendation wording	
'should'	The recommendation is based on strong evidence **OR** The benefits of the recommendation were judged by GDG as exceeding any possible harms
'could'	Recommendations based on limited evidence **OR** Studies did not clearly demonstrate one approach was better than another **OR** The balance of benefits to harm is unclear

Identification

Early identification and intervention can reduce the impact of ADHD and maximise the outcomes of people living with the condition.



Risk of having ADHD

Some groups of people are at higher risk of having ADHD, having their ADHD diagnosis missed, or being diagnosed with ADHD later in life.

These include:

Children and adolescents

- Who are or have been in out-of-home care
- Diagnosed with oppositional defiant disorder or conduct disorder

People of all ages:

- With a close family member diagnosed with ADHD
- Born preterm or with a low birth weight
- Born with prenatal exposure to substances including alcohol and other drugs
- Diagnosed with another neurodevelopmental condition (e.g., autism spectrum disorder, intellectual disability, tic disorders, language disorders and specific learning disorders)
- Diagnosed with any mental health condition (e.g., anxiety, substance use disorders, borderline personality disorder, intermittent explosive disorder, internet addiction, psychotic disorders, binge eating disorder, gambling disorder)
- With a history of epilepsy, substance use or a sleep disorder
- Who experience suicidal behaviour or ideation
- With an acquired brain injury
- Who are in the criminal justice system or prison, or have been in the past

Women and girls with ADHD are at high risk of being missed or being diagnosed later in life.

If you or a family member meet one of these criteria **and** appear to be displaying any of the symptoms associated with ADHD (e.g., restlessness, difficulty maintaining routines, lack of time awareness, poor working memory, disorganisation, forgetfulness, and distraction), please consider speaking to your GP about screening for ADHD.

Please note: Screening everyone, including children, for ADHD is not recommended because the available ADHD screening tools do not meet acceptable levels of accuracy for universal screening.

Diagnosis

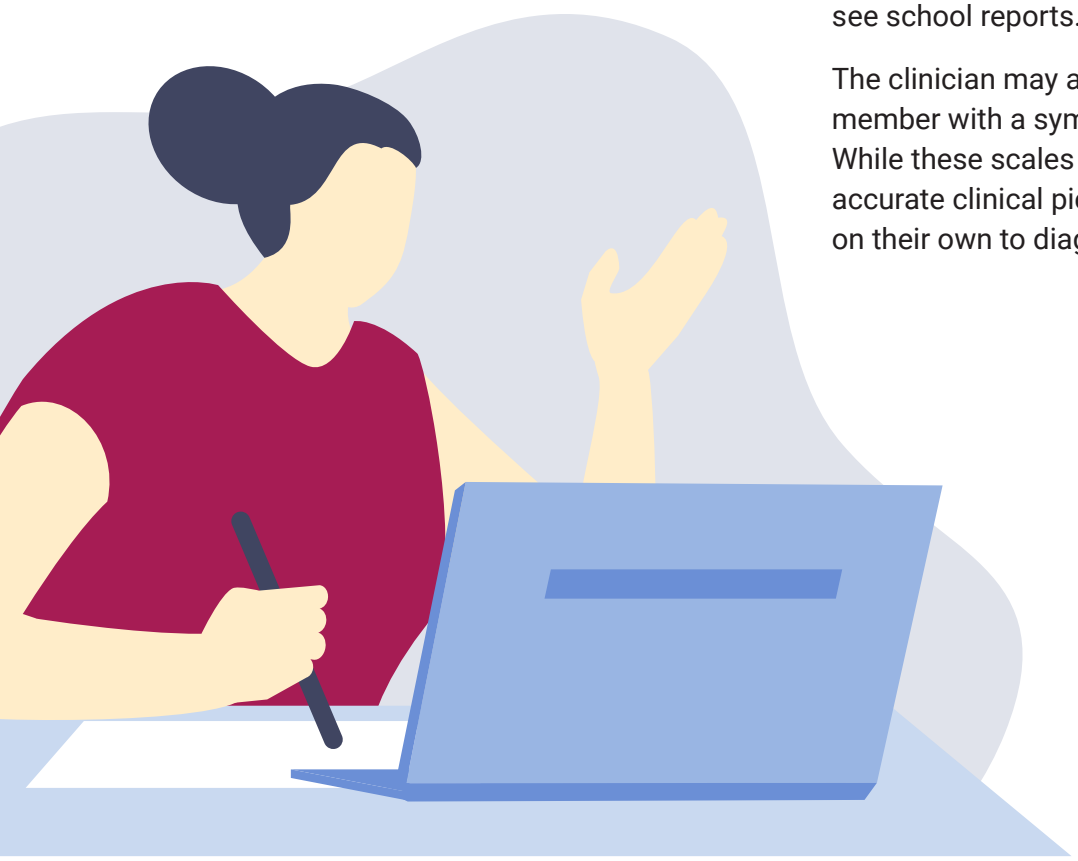
To be diagnosed with ADHD, you or your family member need to be assessed by a trained and credentialed clinician, such as a paediatrician, psychiatrist or psychologist, that is registered with the Australian Health Practitioner Regulation Agency (AHPRA).This clinician should be trained in diagnostic assessments and be experienced in the area of ADHD.

During the assessment, the clinician **should** seek to obtain a full developmental, mental health and medical history, as well as complete:

- A full clinical and psychosocial assessment that includes questions about ADHD symptoms and personal strengths, and how these present in different life settings. They will also ask questions about how much ADHD symptoms impact or disrupt everyday functioning.
- A medical assessment to exclude other causes of the symptoms and to identify if any associated conditions that also require investigation, intervention and support are present

The clinician **should** also obtain information from other people, such as teachers, parents, partners, friends or work colleagues, to ensure they gain an accurate picture of you or your family member's presentation. They may also ask whether ADHD runs in your family and request to see school reports.

The clinician may also provide you or your family member with a symptom rating scale to complete. While these scales can be helpful for obtaining an accurate clinical picture, they should not be used on their own to diagnose ADHD.



Important information to share

Some groups of people are at higher risk of having ADHD. Please inform the clinician completing the ADHD assessment if you or your family member fall into one of the at-risk groups listed on page 9 of this Consumer Companion.

There are also a number of co-occurring conditions that can present similarly to, or exacerbate, ADHD symptoms such as:

- Hearing or vision impairment
- Thyroid disease
- Anaemia

Some medications used to treat other health conditions can also cause side effects such as:

- Cognitive dulling (e.g., mood stabilisers)
- Psychomotor activation (e.g., decongestants, asthma medication, non-prescribed stimulants like caffeine)

If you or your family member has one of these conditions or takes any of the medications listed above, it is important that you inform the clinician undertaking the assessment.

Meeting the criteria for diagnosis

To be diagnosed with ADHD you or your family member must meet the diagnostic criteria set out in the Diagnostic and Statistical Manual of Mental Disorders (DSM)-5, or another authoritative diagnostic manual (e.g., the ICD-10 or ICD-11).

The DSM-5 diagnostic criteria states that:

- Children up to the age of 16 must display 6 or more inattentive and/or hyperactivity-impulsivity symptoms
- Adolescents and adults (17 years and over) must display 5 or more inattentive and/or hyperactivity-impulsivity symptoms

These symptoms must also be:

- Excessive for one's developmental age
- Present before the age of 12
- Persist for longer than 6 months
- Interfere with function or development in more than one setting (i.e., home, school, child care, university, work, relationships, etc.)
- Not better explained by another condition or disorder (i.e., co-occurring physical and mental health/neurodevelopmental disorders such as autism, conduct or other mental disorders or physical or cognitive differences)

Education and information

During the diagnostic process, and while receiving ongoing treatment and support, the clinician/s caring for you or your family member **should** provide education and information about ADHD and the evidence-based treatment options available, in a way that instils hope and motivation, and facilitates informed decision-making.

Some of the topics they **could** discuss with you or your family member include:

- ADHD symptoms
- Common challenges associated with ADHD, including the impact ADHD can have on relationships
- Factors that can influence the severity of ADHD symptoms and associated difficulties
- Ways of identifying and building on individual strengths
- Environmental modifications that can be made to assist with realistic goal attainment
- Potential educational and occupational challenges and the right to reasonable adjustments
- The risks that accompany untreated ADHD, such as the increased risk of self-medicating and substance misuse, and the increased risks associated with driving a vehicle unmedicated
- Co-occurring mental health or neurodevelopmental conditions that can accompany ADHD, and available treatment and support options
- The process of coming to terms with a diagnosis
- The potential to experience negative stigma and labelling after receiving an ADHD diagnosis and how to mitigate the risks

Questions you could ask a clinician caring for you or your family member

- What is ADHD?
- Why do you think I (or my family member) have ADHD?
- Is ADHD heritable?
- How do you diagnose ADHD?
- Could anything else cause ADHD-like symptoms?
- Do both inattentive and hyperactive-impulsive symptoms need to be present to have ADHD?
- What are the common challenges people with ADHD experience?
- Can ADHD affect relationships?
- What are the risks associated with not diagnosing ADHD?
- What are the risks associated with not treating ADHD?
- What can improve ADHD symptoms? What can make them worse?
- What treatment and support options are available?
- Are there environmental adjustments at home, school or work that can be made to support me (or my family member with ADHD)?
- How can I identify and build on my (or my family member's) strengths?
- What does the future look like for someone with ADHD?
- Do I (or my family member) have a co-occurring condition?
- Should I tell people I (or my family member) have ADHD?

Information sharing

Clinicians and educators may be able to better support you or your family member's education, employment, community activities or other roles, if they share relevant information with other professionals and service providers such as employers or sporting groups.

This information could include:

- ADHD symptoms and how they are likely to affect daily life, participation in different settings, and keeping up with treatment interventions
- The presence of other co-occurring conditions and identified special needs
- The treatment plan in place to support you or your child
- Advice on reasonable adjustments and environmental modifications (e.g., small groups or individualised learning)
- The value of open channels of communication between education/workplace/community settings and clinicians

Please note: Sharing information with others comes with both risks and benefits that need to be considered. Where appropriate, your consent **should** be obtained before any information is shared.

Advice for family members

If you are a family member of a person with ADHD (i.e., a parent, spouse, partner or relative) it is beneficial to:

- Monitor your own wellbeing
- Develop a support network
- Seek guidance and support if you are facing any challenges

Support available

To assist you and your family, the clinicians **should** provide information about:

- Local and national support groups and voluntary organisations (also known as consumer groups). A list of these organisations can be found on **Page 28** of this Consumer Companion
- Up-to-date, reliable, and reputable websites
- Support for education and employment
- Eligibility for disability support
- Eligibility for government benefits and allowances, including carer allowance provisions

Treatment and support

Multimodal treatment and support refers to the inclusion of both non-medication and medication interventions in a person with ADHD's treatment plan.

Medication treatment options are most effective at reducing core ADHD symptoms. Non-medication treatments provide additional support to minimise the daily impact of ADHD symptoms and associated difficulties.

You or your family member with ADHD **should** be:

- Offered multimodal treatment and support
- Provided with information about all available treatment options, including:
  - the typical benefits
  - possible adverse effects
  - likelihood of being effective
  - recommended treatment length (if known)
  - time taken before symptom or functional improvements are likely to be noticeable
- Involved in making all treatment decisions. This includes children and young people, as appropriate for their age and developmental stage

The components of the multimodal treatment plan and sequence of treatments agreed on, **should** accommodate you and/or your family member's preferences, unique needs, and individual goals, and take into consideration you or your family member's personal strengths and the impact of any co-occurring conditions.

Please note: Although people with ADHD tend to benefit most from combined medication and non-medication treatments, there are occasions when:

- A person's ADHD symptoms may be adequately supported by only one type of treatment intervention
- The severity of a person's ADHD symptoms requires medication be used as a first-line treatment intervention. ADHD medication reduces symptoms more quickly and can enable later engagement in non-medication treatment options.
- One type of treatment may be more accessible than another, based on cost, location, and service availability including waiting times to access services

Care coordination and care transition

When multiple clinicians and/or educators are involved in providing care, the clinicians caring for you or your family member **should** suggest that a care coordinator is appointed.

You or a family member can choose to take on this role. If this is not possible, support to arrange an appropriate care coordinator, maybe a clinician, **should** be provided.

If transition between services or tiers of the health system (e.g., from paediatric services to adolescent services, or between youth and young adult services to general adult services) is required, an appropriately trained person from your or your family member's health care team **should** be appointed to coordinate and provide education and support during the transition process.

Planning **should** commence at least 12 months prior to you or your family member's 18th birthday, be holistic in nature, and involve collaboration between you or your family member and all relevant care providers.

Non-medication interventions

Non-medication interventions can assist with skill development and improve a person with ADHD's well-being, quality of life, self-esteem, and social, adaptive and family functioning.

Information on all the non-medication treatment interventions available **should** be provided to you or your family member in a way that facilitates informed decision-making.

The information covered **should** include the:

- Potential benefits of an intervention and the likelihood of it being beneficial
- Recommended treatment length and time required before it is possible to assess for benefits
- Likely costs involved and funding considerations, such as Medicare rebates
- Options for changing intervention providers

You or your family member can choose whether or not to engage in any of the treatment interventions offered to you, or choose to change interventions or intervention providers if desired.

Lifestyle changes

Lifestyle factors, such as sleep patterns, diet, and engagement in physical activity, impact upon health and wellbeing.

You or your family member with ADHD **should** be offered guidance and/or a referral to a specialist who is qualified to assist with improving sleep, diet and/or engagement in physical activity, if required.

Parent/family training

Parent/family training refers to a broad range of approaches that aim to assist parents meet the additional needs of children and adolescents with ADHD.

If you are a parent of a child with ADHD, you **should** be offered parent/family training, especially if your child has co-occurring oppositional defiant disorder or conduct disorder.

Any parent/family training intervention/s offered to you **should**:

- Support the optimisation of parenting skills
- Be delivered in a sensitive and culturally appropriate manner
- Focus on the strengths and challenges associated with ADHD in a balanced way
- Include education and information on at least one of the following:
  - » ADHD symptoms and their impact on functioning
  - » recommendations for environmental modifications or ways of providing a positive, predictable and structured environment
  - » strategies to modify behaviour including positive parenting approaches

Please note: parent/family training does not imply one's parenting skills are deficient in any way, but rather that specific skill development is helpful for supporting children with ADHD.

Cognitive-behavioural interventions

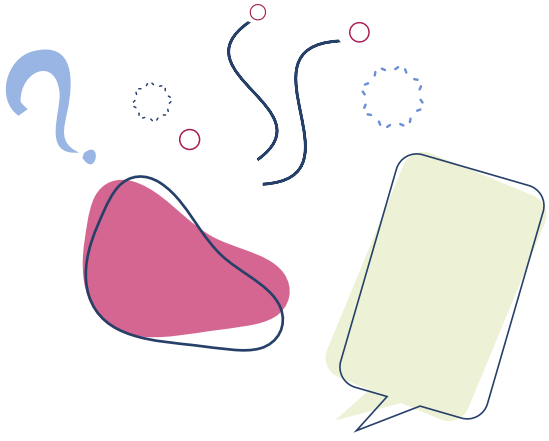
Cognitive behavioural interventions refer to a broad range of approaches that:

- Are delivered directly to the person with ADHD in an individual or group format
- Use cognitive and/or behavioural interventions to minimise the day-to-day impacts of ADHD symptoms

Cognitive behavioural interventions also play an important role in addressing co-occurring conditions, such as anxiety or depression.

The cognitive behavioural intervention/s offered to you or your family member **should** be specifically tailored to cater to the needs of people with ADHD, focus on the strengths and challenges associated with ADHD in a balanced way, and include one or more of the following:

- Education and information on:
  - » ADHD and its impact on functioning
  - » effective environmental modifications
  - » effective behaviour modification strategies
- Therapeutic interventions that assist with the processing of thoughts and feelings and facilitate skill development and healthy adjustment



Children and adolescents

Dependent upon their developmental capabilities, including their capacity to be self-aware, self-reflect and influence their own thinking processes:

- Younger children may benefit from cognitive behavioural interventions that focus on the development of:
  - » foundational skills such as emotional literacy, proactive help-seeking, and problem-solving
  - » healthy self-esteem
- Adolescents may benefit from cognitive behavioural interventions that focus on developing simple behavioural techniques

As a parent, you **could** be offered cognitive-behavioural interventions for your child or adolescent with ADHD.

Should you choose to access a cognitive-behavioural intervention for your child or adolescent with ADHD, the intervention **should** be provided alongside parent/family training. You **should** also be involved in the intervention to an extent that allows you to support its implementation.

Adults

Adults with ADHD **should** be offered cognitive-behavioural interventions. Examples include:

- Mindfulness-based cognitive therapy
- Dialectical behaviour therapy
- Broader cognitive behaviour therapy

Please note: people with ADHD and complex needs may feel more comfortable working one-on-one with the clinician providing the intervention, while people with ADHD seeking social support may prefer participating in group interventions.

ADHD coaching

ADHD coaching can potentially assist people with ADHD to identify and put in place environmental and behaviour modification strategies that can support their ADHD symptoms, executive functioning, self-esteem, wellbeing, and quality of life.

ADHD coaching **could** be offered to adolescents or adults with ADHD.

Please note: If you or your family member choose to participate in ADHD coaching, ensure your service provider is appropriately credentialled i.e., an ADHD coach who is a member of the International Coaching Federation or an allied health professional such as a psychologist.

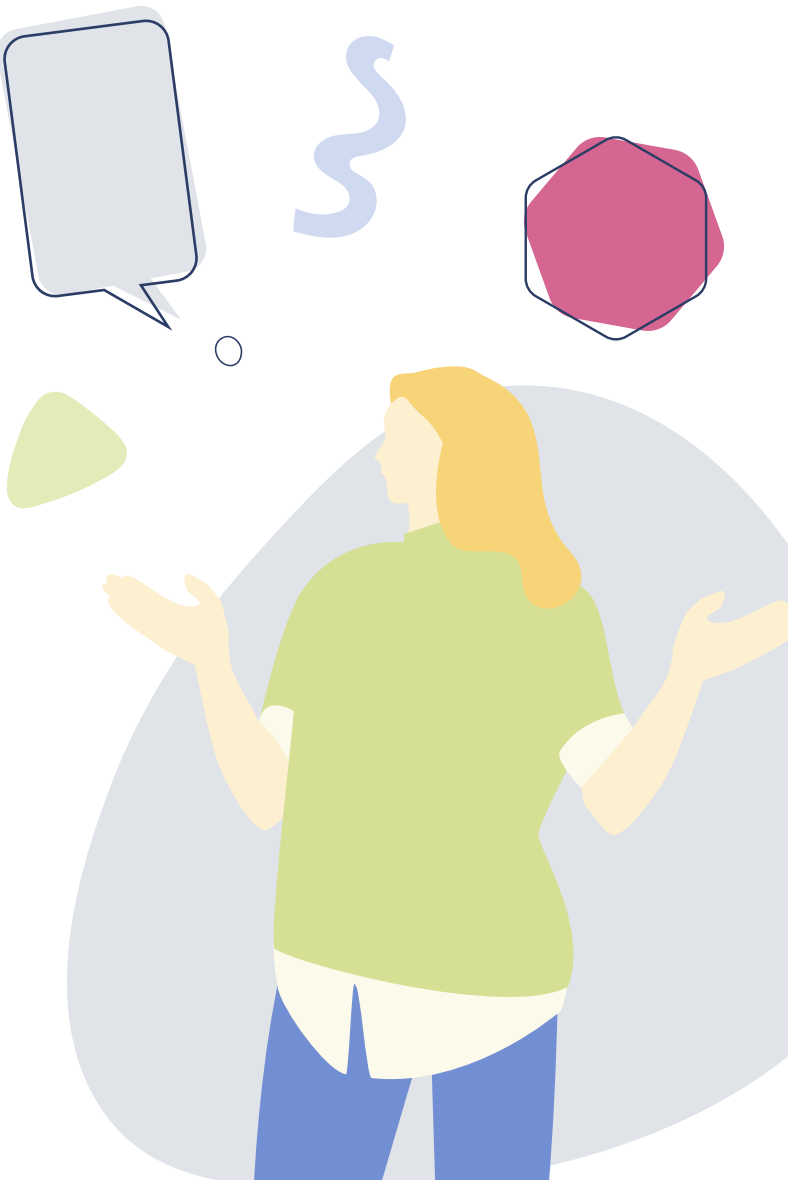
Interventions with insufficient evidence

Cognitive training

Cognitive training for ADHD refers largely to the use of computerised training programs to improve aspects of cognition such as attention and memory. Insufficient evidence was found to support a recommendation on cognitive training as a treatment for ADHD.

Neurofeedback

Neurofeedback refers to a type of brain training that aims to alter electrical brain activity via operant conditioning (rewards and punishment). Insufficient evidence was found to support a recommendation on Neurofeedback as a treatment for ADHD.



Questions you could ask a clinician about non-medication treatment options

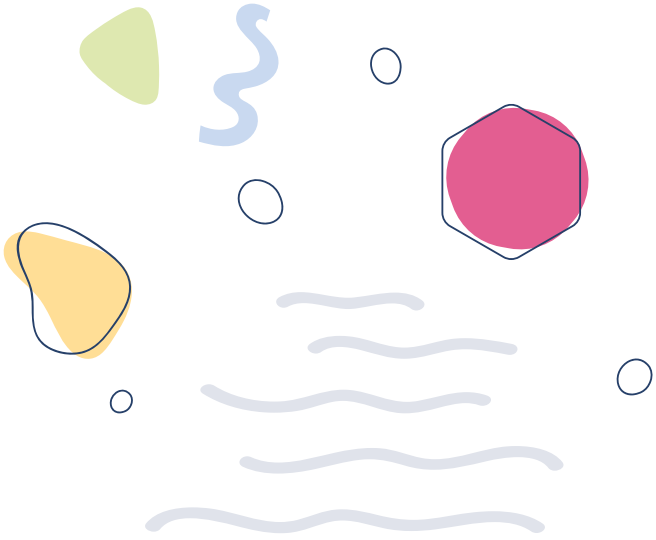
- Are there any treatment interventions that could help me come to terms with my (or my family member's) ADHD diagnosis?
- Are there any treatment interventions that could help me (or my family member) live more successfully with ADHD?
- Are there any treatment interventions that could help me to better scaffold and support my (or my family member's) ADHD traits?
- Are there any treatment interventions that could help improve my (or my family member's) self-esteem?
- Are there any non-medication treatment interventions that could help improve my (or my family member's) relationships with others?
- Can exercise, sleep and diet affect ADHD symptoms? What changes should I consider making? Are there any treatment interventions that might be helpful?
- Are there any treatment interventions that can help with skill development?
- What does the treatment intervention involve?
- Why do you think the treatment intervention would be helpful?
- How can I (or my family member) tell if the treatment intervention is making a difference?
- What if the treatment intervention doesn't appear to be helping?
- What if the treatment provider doesn't feel like the right fit for me (or my family member)?
- Do you know approximately how much treatment interventions cost and whether I can claim any money back on Medicare or private health insurance?

Medication interventions

Medications used to treat ADHD effectively reduce core ADHD symptoms.

Medication should form only one part of a person's treatment plan. Although ADHD medications reduce ADHD symptoms and improve self-control, used alone, they rarely reduce all ADHD-related difficulties. Furthermore, stimulant medication does not provide full coverage over the course of the day/evening.

There are two general types of medication that can be used to treat ADHD: **stimulants and non-stimulants**.



Stimulant medication

Three types of stimulant medication are available in Australia. Their generic names are:

- methylphenidate
- dexamfetamine
- lisdexamfetamine

All three are similar in effect and tolerability.

Methylphenidate is available in both short-acting and long-acting formulations, while dexamfetamine is available as a short-acting formulation and lisdexamfetamine as a long-acting formulation.

Short-acting formulations of stimulant medication exert their effect and wear off quickly (around 4 hours). Long-acting formulations exert their effect more slowly but provide longer lasting coverage (8 to 12 hours).

Short-acting and long-acting stimulants could be offered together to optimise effect (e.g., an 8-hour modified-release preparation of methylphenidate in the morning and an immediate-release preparation of methylphenidate later in the day to extend the duration of effect up to 12 hours).

Some short-acting formulations of stimulant medications contain gluten. Please inform the prescribing clinician if you or your family member are allergic to gluten.

Non-stimulant medication

Non-stimulant medications are recommended for use when stimulant medication is not tolerated, is ineffective or contraindicated (i.e., there is a possibility they could cause harm).

The generic names of the two non-stimulant medications approved for use in Australia are:

- atomoxetine
- guanfacine

Clonidine is another non-stimulant often used to help manage ADHD in Australia.

Medication Choice

Evidence shows that treatment of ADHD in children and adolescents (aged 5-17 years) and adults (aged 18 years and over) with stimulant medication is associated with clinically important benefits, in comparison to placebo and other medications. Therefore:

- Children and adolescents with ADHD (aged 5-17 years) **should** be offered stimulant medication as the first-line medication treatment where symptoms are causing significant impairment
- Adults with ADHD (18 years and over) **should** be offered stimulant medication as the first-line medication treatment where symptoms are causing significant impairment

People with ADHD can respond differently to each type of stimulant medication. If the first stimulant medication you or your family member tries doesn't produce the desired effect, the opportunity to trial another **should** be offered.

If stimulant medications cannot be tolerated or are ineffective, a non-stimulant medication **should** be offered.

Children under 5 years

Insufficient evidence on the effectiveness of medication use in children under 5 years was found.

If a child under the age of 5 is displaying ADHD symptoms that are causing significant problems in more than one setting, a specialist with expertise in child development and treatment of ADHD in young children (either a paediatrician or a child psychiatrist) **should** assess the child to identify suitable treatment options.

Medication **should** be used cautiously and monitored closely in children under the age of 5.

Adults over the age of 65

Unless contraindicated, adults over the age of 65 **should** be offered ADHD medication and carefully monitored for side effects.

Before starting medication

Before taking medication for ADHD, if you or your family member have a history of any of the following, it is important to inform the prescribing clinician:

- Congenital heart disease
- Previous cardiac surgery
- A family history of sudden death in a relative under the age of 40
- Shortness of breath or fainting on exertion
- Heart palpitations, chest pain, a heart murmur or hypertension
- A gluten allergy

Questions you could ask a prescribing clinician about medication

- What type of medication is this?
- Is it a stimulant or a non-stimulant medication?
- How does this medication work?
- How long will it take to start working?
- How can you tell if the medication is working?
- What side effects could someone taking this medication experience? How common are these?
- What can be done to help these side effects?
- Will you have to adjust the dose to work out what the most effective dose will be?
- When should this medication be taken?
- Who do I talk to at the school if my child needs to have a dose of medication at lunch time?
- Is this medication taken with food or without food?
- Are there any medications, supplements, foods or drinks that could affect this medication?
- Does this medication need to be taken every day?
- What would happen if someone suddenly stopped taking this medication?

Commencing medication

ADHD medication **should** be started at a low dose and increased or decreased until the optimal dose has been identified (i.e., the dose at which symptoms are reduced and functional outcomes are optimally improved, with minimal adverse side effects). The prescribing clinician **should** monitor your or your family member's progress closely during this time.

It can be helpful to monitor and record any positive and/or negative effects experienced and share this information with the prescribing clinician. Some specific things to look out for include:

- Weight loss
- An increase in tics
- Poorer sleep quality
- Worsening mood or irritability
- Increased anxiety

Sometimes when a person starts taking ADHD medication, they become aware of how severe their untreated symptoms were, and require psychological support to adjust to this awareness.

Although very rare, there is a chance stimulant medication may cause psychotic or manic episodes in some people. If you or your family member experience one of these adverse effects, immediately stop the medication and contact the prescribing clinician.

Ongoing management

Once medication is optimised and stabilised, you or your family member **should** continue to be monitored by the prescribing clinician as required. At least once a year they **should** also review and discuss your medication with you or your family member.

You or your family member's preferences for continuing, stopping or changing medication **should** be considered during the medication review, and you or your family member **should** actively participate in making all treatment decisions.

If you have a child or adolescent with ADHD, the prescribing clinician **should**:

- Measure their height every 6 months
- Measure their weight 3 and 6 months after starting treatment and monthly thereafter, or more often if concerns arise
- Plot their height and weight on a monthly growth chart
- Monitor their heart rate and blood pressure after any change in medication or medication dosage and every 6 months

If you or your family member are an adult with ADHD, the prescribing clinician **should** monitor your heart rate and blood pressure after any change in medication or medication dosage and 6 monthly. They **should** also measure your or your family member's weight if indicated.

If weight loss is identified as an issue, it can be helpful to:

- Take medication either with or after food, rather than before meals
- Increase food consumption by adding meals or snacks early in the morning or late evening once medication has worn off
- Consume high-calorie foods of good nutritional value
- Seek dietary advice
- Consider a planned break in treatment or consider changing or stopping medication, in consultation with the prescribing clinician

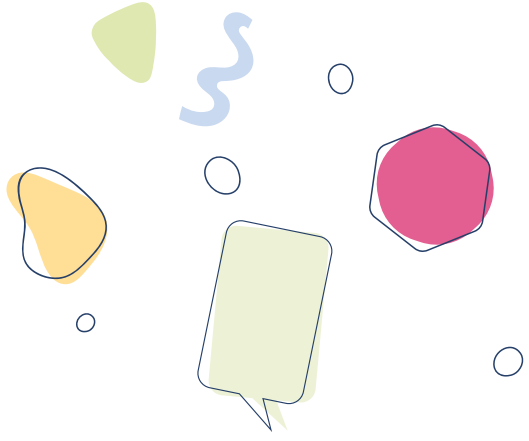
Remembering to take medication

If you or your adult family member has problems remembering to take medication, it can be helpful to:

- Use visual reminders (e.g., apps, alarms, clocks, pill dispensers, or notes on calendars or fridges)
- Imbed taking medication into your daily routine (e.g., with/after meals or after brushing teeth)

If you are a parent of a child or adolescent with ADHD it is best to supervise your child's ADHD medication usage.

Please note: People receiving treatment for ADHD **should** be reviewed regularly according to the severity of their condition, regardless of whether or not they are taking medication.



Additional recommendations

There are several groups that may benefit from individual consideration.

People in the criminal justice system

The percentage of youth and adults in the criminal justice system with ADHD is much higher than the percentage of youth and adults in the general population. In comparison to youth and adults in the general population, youth in prison are estimated to be five times more likely to have ADHD, while adults in prison are ten times more likely to have ADHD. [1-5]

When unidentified and untreated ADHD has been shown to increase the likelihood:

- Offending
- Being arrested and incarcerated
- Being involved with aggressive disturbances, violence or critical incidents in prison
- Re-offending following release from custody.

Males, young people and First Nations People appear to be most at risk [2]

There also appears to be an association between ADHD and:

- The development of conduct disorder in children
- Anti-social behaviour later in life
- Socio-economic disadvantage
- Co-occurring conditions linked to offending such as substance use [6]

Diagnosing and treating people within the criminal justice system is difficult, but the potential benefits are likely to be substantial.

Medication treatment interventions for ADHD reduce ADHD symptoms, improve frustration intolerance, and decrease restlessness and mood liability. They may also:

- Reduce the rate of violent and critical incidents in prisons and make them safer places to live and work
- Reduce the rate of reoffending and violence following release [5,7,8]
- Assist in the treatment of other conditions (such as personality disorders, substance use disorders, and anxiety disorders)

Screening and assessment processes should be established to identify the presence of ADHD and co-occurring conditions among people entering the criminal justice system.

Custodial staff and people working in the criminal justice system such as police, lawyers, administrators and members of the judiciary should receive ADHD awareness training.

If you or your family member enters the criminal justice system, they should be screened for ADHD and for other co-occurring conditions such as substance use disorders.

If diagnosed with ADHD, that person should be provided with:

- A comprehensive multi-agency integrated and coordinated care plan
- Education and occupational programs that aim to increase engagement and skill development
- Medication and non-medication interventions in line with those offered to people with ADHD in the community
- Assistance and support when transitioning into the community

Please note: Women in the criminal justice system with ADHD are less likely to be identified and receive effective treatment. ADHD in women is under recognised and symptoms are often masked when they have other conditions such as anxiety, depression, PTSD, substance use disorders, self-harm, and borderline personality disorder. [4]

Aboriginal and Torres Strait Islander peoples

There is very little research focused on understanding, identifying, assessing and treating ADHD in Aboriginal and Torres Strait Islander People.[9] **The Guideline highlights the urgent need for more research and investment aimed at optimising the outcomes of First Nations People living with ADHD.**

Some cultures view mental health holistically, meaning that mental health is not just about their symptoms or functional impairment. Many cultures also view ADHD symptoms differently.

Most of Australia's indigenous population view health as encompassing spiritual, environmental, community, cultural, political, social-emotional and physical wellbeing. [9, 10]

First Nations People are at risk of misidentifying or misinterpreting ADHD symptoms. Lack of research and poor healthcare provider understanding of indigenous values and beliefs, may also put indigenous people at risk of:

- Being over or underdiagnosed with ADHD
- Receiving culturally inappropriate care

More research examining the prevalence of ADHD in Aboriginal and Torres Strait People is also needed. At present, the limited research available indicates:

- Indigenous children are at higher risk of experiencing clinically significant hyperactivity problems in comparison to non-indigenous children [11]
- Aboriginal and Torres Strait Islanders may view hyperactivity or high levels of activity as appropriate in some settings (e.g., a playground) and problematic in others (e.g., the classroom, when shopping)
- ADHD is more common in indigenous boys than girls [11]
- A higher proportion of adult indigenous prisoners have ADHD in comparison to adult non-indigenous prisoners [12]

The Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice report [10] emphasises **nine guiding principles** that should inform the care provided to all Aboriginal and Torres Strait Islander people.

These nine principles are listed on the following page.

If you or your family member are Aboriginal or a Torres Strait Islander and are being screened for or treated for ADHD, your clinician **should** ensure:

- Access to a cultural interpreter or an Aboriginal and Torres Strait Islander health worker is provided during consultations, if required
- Care is culturally appropriate and strengths focused
- Consideration is given to the relevant cultural and social meaning and significance of ADHD symptoms
- Input into care planning is sought from you or your family member and other people considered important (e.g., parents, family members, the community, Elders)
- You or your family member's wishes are prioritised, along with the wishes of other people considered significant.
- Any medication and treatment interventions offered are tailored to Aboriginal and Torres Strait Islander peoples and you or your family member's local culture, and offered in a culturally sensitive manner

The nine guiding principles that should inform the care provided to all Aboriginal and Torres Strait Islander people [10]

1

Aboriginal and Torres Strait Islander health is viewed in a holistic context that encompasses mental health and physical, cultural and spiritual health. Land is central to wellbeing. Crucially, it must be understood that while the harmony of these interrelations is disrupted, Aboriginal and Torres Strait Islander ill health will persist.

2

Self-determination is central to the provision of Aboriginal and Torres Strait Islander health services.

3

Culturally valid understandings must shape the provision of services and must guide assessment, care and management of Aboriginal and Torres Strait Islander peoples' health problems generally and mental health problems in particular.

4

It must be recognised that the experience of trauma and loss, present since European invasion, are a direct outcome of the disruption to cultural wellbeing. Trauma and loss of this magnitude continue to have intergenerational effects.

5

The human rights of Aboriginal and Torres Strait Islander peoples must be recognised and respected. Failure to respect these human rights constitutes continuous disruption to mental health (as against mental ill health). Human rights relevant to mental illness must be specifically addressed.

6

Racism, stigma, environmental adversity and social disadvantage constitute ongoing stressors and have negative impacts on Aboriginal and Torres Straits Islander peoples' mental health and wellbeing.

7

The centrality of Aboriginal and Torres Straits Islander kinship must be recognised as well as the broader concepts of family and the bonds of reciprocal affection, responsibility and sharing.

8

There is no single Aboriginal or Torres Strait Islander culture or group, but numerous groupings, languages, kinships and tribes, as well as ways of living. Furthermore, Aboriginal and Torres Strait Islander peoples may currently live in urban, rural or remote settings, in urbanised, traditional or other lifestyles, and frequently move between these ways of living.

9

It must be recognised that Aboriginal and Torres Strait Islander peoples have great strengths, creativity and endurance and a deep understanding of the relationships between human beings and their environment.

(National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Well Being 2004-2009, page 6)

People with substance use disorders

ADHD is a risk factor for the development of substance use disorders in adolescence and adulthood [12,14]. Research indicates that in comparison to those without ADHD, people with ADHD are:

- Two to three times more likely to become nicotine dependent
- Fifty percent more likely to develop a drug or alcohol disorder [13]
- At higher risk of hospitalisation due to having a substance abuse disorder
- At higher risk of relapsing following addiction treatment [14]

Similarly, people presenting with substance use disorders are at increased risk of having ADHD. [13, 14]

If you or your family member have problematic substance-use or a substance use disorder and seek care from a mental health setting, the treating clinician **should** routinely screen for ADHD. Screening **should** take place when you or your family member's substance use is sufficiently stabilised.

If you or your family member have ADHD and problematic substance-use or a substance use disorder, you **should** be offered multimodal treatment for both disorders.

If you or your family member have ADHD and seek care from a mental health setting, the treating clinician **should** screen for problematic substance use or substance use disorders.

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Support groups and consumer organisations

National ADHD Consumer Organisations

The ADHD Foundation Australia

PO Box 22, Epping NSW 1710
Website: **www.adhdfoundation.org.au**
National Support Line
Phone: 1300 393 919
Email: **support@adhdfoundation.org.au**

ADHD Australia

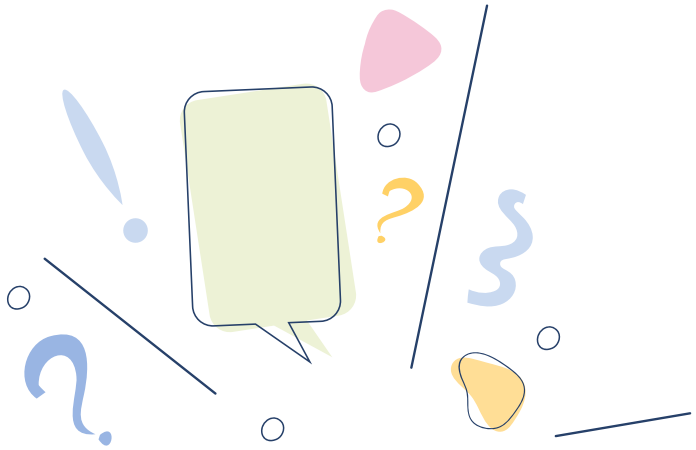
PO Box 164, Westmead NSW 2145
Website: **http://www.adhdaustralia.org.au/**
Email: **info@adhdaustralia.org.au**

Parents for ADHD Australia

Website: **https://parentsforadhdadvocacy.com.au**

Facebook: **https://www.facebook.com/Parents4ADHDadvocacyAu**

Email: **info@parentsforadhdadvocacy.com.au**



ADHD Support Groups

New South Wales

ADDults with ADHD
National Support Line
Website: **https://www.adultadhd.org.au/**
Email: **info@adultadhd.org.au**

Macquarie ADHD Parent Support Group
Website: **http://www.macquarieadhd.org.au/**
Facebook: **https://www.facebook.com/macqadhd.org.au**
Email: **info@macquarieadhd.org.au**

ADHD Illawarra Support Group
Website: **http://www.adhdillawarra.org/**
Email: amy.williamson@citylife.org.au or jill@citylife.org.au

Western Australia

ADHD WA
The Niche, QEII Health Campus, 11 Aberdare Road, Nedlands WA. 6009
Website: **www.adhdwa.org**
Facebook: **https://www.facebook.com/adhdwa.org**
Telephone: (08) 6457 7544
Email: **hello@adhdwa.org**

Victoria

Adult ADHD Melbourne
Website: **http://www.adhdsupport.org.au/**
Facebook: **www.facebook.com/AdultADHDMelbourne**
Email: **adultadhdmelbourne@gmail.com**

ADHD Melbourne

Facebook: **https://www.facebook.com/ADHDMelbournePage/**

Australian Capital Territory

Canberra & Queanbeyan ADD Support Group (ADDACT)
Website: **www.addact.org.au**
Facebook: **https://www.facebook.com/Canberra-and-Queanbeyan-ADD-Support-Group-Inc-ADDACT-162648903792487/**
Email: **admin@addact.org.au**

A message from AADPA

Our hope is that this **Consumer Companion** to the Australian Evidence-Based Clinical Practice Guideline for ADHD, enables individuals with ADHD and their families to learn more about the type of care they should expect to receive, make informed care decisions, and advocate for appropriate care should they need to.

We recognise that there are areas where greater knowledge and evidence on ADHD is required, as well as further opportunities to work towards enhancing the lifetime outcomes of people with the condition. The Australian ADHD Professionals Association (AADPA) is committed to working with people with lived experience of ADHD to address these needs.

Our vision

To optimise outcomes for people living with ADHD across the lifespan, by promoting research and enabling the uptake of best-practice evidence-based clinical care.

Our values are:

Credibility

We pride ourselves on our ability to collaborate across disciplines. We have demonstrated transparency and a successful track record for achieving our objectives.

Commitment

We are committed to delivering outcomes that will improve the lives of those living with ADHD and facilitate thriving, by ensuring the membership has a diversity of voices, knowledge, and lived experience that can inform our decision-making and priority-setting.

Authority

Our diverse membership includes national and international leaders in their respective disciplines, consumers and community stakeholders, as well as the next generation of clinicians and researchers.

Insight

We are committed to increasing the involvement of people with lived experience in all our activities.

We are:

Independent

We place a high value on being an 'honest broker' which is made possible by our strong network relationships and our united purpose.

Effective

We have and will continue to provide an authoritative evidence-based voice that influences and develops policy initiatives that are consumer-focused, affordable, equitable, and importantly, deliverable.

Inclusive

We understand the needs and priorities of clinicians, researchers and the community and will expand AADPA member involvement in future initiatives. We are committed to including the often-overlooked voices of Indigenous and CALD communities in our policy development.

Innovative

We seek opportunities that will empower professionals to provide best-practice ADHD assessment, treatment and supports and enable consumers to make their own decisions about how to best manage their ADHD symptoms.

Our purpose

- Ensure the successful and widespread uptake of the Australian ADHD Guideline, and manage and implement future reviews and updates.
- To be a unifying and inclusive agent that fosters cooperation, collaboration and the exchange of ideas and information to advance better clinical care and support pathways and help inform research priorities.
- Provide decision and policymakers, in government and non-government agencies, with accessible and relevant information and advice to inform effective decision-making and inclusive policy.
- Foster the next generation of clinicians and researchers specialising in ADHD and promote participatory practices.
- Produce reliable and credible information and resources, with the aim of promoting acceptance and understanding of ADHD.

The full Australian Evidence-Based Clinical Practice Guideline for ADHD has been endorsed by the following organisations:

aadpa

APS Australian Psychological Society

The Royal Australian & New Zealand College of Psychiatrists

RACP Specialists. Together
EDUCATE ADVOCATE INNOVATE

Your Health in Mind

Occupational Therapy AUSTRALIA

acpa The Australian Clinical Psychology Association

ADHD Foundation

RACGP

Speech Pathology Australia

adhdWA

Australian Government
National Health and Medical Research Council

WORLD FEDERATION ADHD

AAPi
AUSTRALIAN ASSOCIATION of PSYCHOLOGISTS INC

ADHD Australia

aadpa.com.au

Contact us via the **contact form** on the website

Feedback

We would be grateful if you would provide us with feedback on this Consumer Companion. To do so, please **complete this online survey**.

aadpa | australian ADHD professionals association