

# A SURVEY OF ADHD in Irish Children



*Nationwide Survey of 150 Irish Parents of ADHD diagnosed children.*

This survey is supported by an unrestricted educational grant from Eli Lilly and Company (Ireland) Limited

Dear Parent,

In 2005, 150 parents of Attention Deficit Hyperactivity Disorder (ADHD) diagnosed children, took part in a survey designed to better understand how parents currently manage their child with ADHD and how the condition impacts on the family and normal daily living.

We also wanted to better understand the unmet needs in treatment options. Currently children tend to receive treatment that covers the school day only, leaving a great need for morning, evening and bedtime cover therefore increasing the strain on the child and immediate family.

Some of the most disconcerting findings of the research were the very low expectations that parents have for their child with ADHD. Completing school, making friends and growing up to have a 'normal' life were some of the hopes that parents had for their child highlighting the level of concern that most parents have about their child's ADHD. Early diagnosis and access to treatment is essential for these children so that the symptoms of this disorder can be treated as quickly as possible.

The survey, supported by Eli Lilly & Co (Ireland) Ltd, was commissioned by ADHD Action, a multi-disciplinary group that includes consultants in child and adult psychiatry, consultant paediatricians, a representative from National Educational Psychological Services (NEPS), Irish Primary Principals Network (IPPN) and from the Hyperactivity and Attention Deficit Disorder Family Support Group (HADD).

The group's principle aim is to educate the public and healthcare professionals about ADHD in order to improve disorder awareness levels and to dispel any myths and stigmas whilst offering support to parents and families living with the condition. Parents' hopes and aspirations for their children's future are encapsulated in this booklet also.

On behalf of ADHD Action, I would like to thank those parents who participated in the survey.

Lastly, I hope you find the survey results interesting and hopefully re-assuring on some level that other parents are dealing with similar issues in caring for a child with ADHD.

Professor Michael Fitzgerald  
Professor of Child Psychiatry,  
Trinity College Dublin & Chairman of ADHD Action

# The Core Symptoms of ADHD<sup>1</sup>

The following describes briefly the core symptoms of ADHD. Each child is unique so it is important to note that your child may suffer from some or all of these symptoms. There are also associated behaviours of ADHD which can be found on page nine of this booklet.

## **Inattentiveness**

Children with ADHD can be easily distracted, and will often flit from task to task. They do benefit from one-to-one supervision and when it comes to schoolwork they are very slow to complete it or they forget instructions. However, a child who is extremely inattentive while doing schoolwork may well be fully focused when playing video games or when being tested by a psychologist.

## **Impulsiveness**

Most children with ADHD talk over the top of others, they tend to be accident prone, and have very short fuses. They answer questions in class even before the question has been completed. Although they act without malice they also act without forethought, which can lead to problems in the playground and the child being labelled aggressive or even getting suspended.

## **Over-activity**

In primary school, children with ADHD are restless and fidgety, they have difficulty remaining seated and find it hard to stop talking. In the playground, they very often act like they have been released from captivity, and they find it even more difficult to settle back into class when they return. At secondary school, over-activity seems to have lessened. However, the children are generally still noisier and more talkative than their peers. Over-activity combined with impulsiveness can make managing these children very difficult.

# Parent Responses to the ADHD Survey<sup>2</sup>

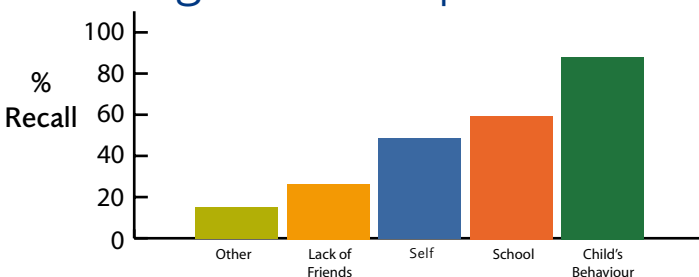
## The pathway to receiving a diagnosis

- On average, children included in the survey feedback, were 12 years of age
- The average age of diagnosis is eight years
- Although there are variances, on average there is a four year lag time between parents considering some difficulty to achieving actual diagnosis
- 87% of parents said their child's behaviour brought ADHD to their attention, with 60% mentioning schools
- 54% of parents had managed to achieve a diagnosis for their child locally, the remainder had to seek diagnosis outside of their area or they were referred to a central hospital
- Parents are more likely to go to their GP first, with 53% seeking a diagnosis from their GP. 100% of children were referred on for diagnosis
- From there the referral route varied greatly. 45% of children were referred to a psychiatrist, 52% were referred to a psychologist while 30% were referred to a paediatrician. (As percentages add up to more than 100%, it may indicate that a diagnosis was made by more than one healthcare professional.)
- Half of parents needed more than one visit to a healthcare professional in secondary care, with the average being five visits, before their child was diagnosed
- Access to private specialist care was achieved in less than four weeks for approximately 55% of those seeking it. Four-week access to public specialist care was only achieved in 13% of cases with 26% waiting one year or more for public access
- There was a great variance in approach and advice given to parents
- Additional research has show that 88% of children are diagnosed by a Child & Adolescent Psychiatrist, 24% by a Paediatrician, 24% by a Psychologist and 12% by a GP. 100% of Child & Adolescent Psychiatrists regarded themselves as being responsible for children with ADHD<sup>2</sup>.

*I hope my son can cope in school with education and with making and keeping friends*

Parent Quote

## What brought ADHD to parents' attention?



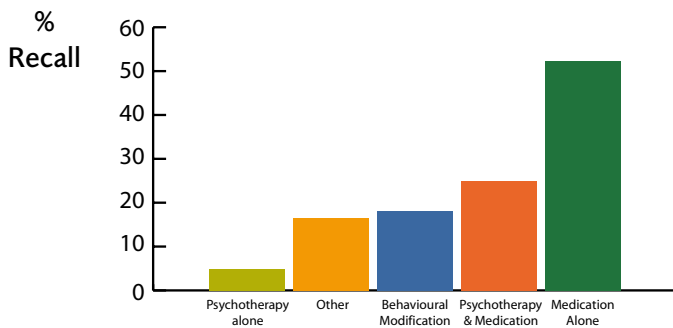
## Has your child been diagnosed with another condition?

- 75% of parents whose children had been diagnosed with ADHD stated that their child had been diagnosed with another condition
- Of those with a co-existing condition, 18% of ADHD children were diagnosed with a general learning disorder, 21% were diagnosed with a conduct disorder and 33% with Oppositional Defiant Disorder (ODD)
- Other conditions include anxiety, autism and Tourettes Syndrome

*We hope our child will grow up to be a normal happy adult*

Parent Quote

## ADHD Treatment



Current  
Treatment Plan  
for child with  
ADHD

- 38% of parents agree medication always calms their child, 47% saying it often helps the child pay attention
- 35% say medication always helps the child to be better at school while 43% maintain it often helps the child do better with the family
- 43% of parents of ADHD children state that their child never had a break from medication during school holidays and 44% state their child never had a break from medication at weekends
- When not on medication 79% of parents claim their child's symptoms often or always impact on family functioning and 71% said their child has difficulty playing with siblings or friends. *(As percentages vary, this may imply that medication is forgotten.)*
- 73% of parents agree medication offers control of symptoms throughout the day
- In contrast, our survey shows that there is a considerable difference when the child is on medication, facilitating more 'normal' daily functioning which allows the child to perform tasks and hence play and learn with family and friends
- 24% of parents said that psychotherapy and medication is part of their treatment plan

## Impact on Family

- 83% of parents stated they often or always got stressed with their child's condition
- Parent and advocacy groups were cited as the best source of information and the greatest help with 75% in agreement, the internet was next at 48%
- Education and life milestones are the most common cause for concern amongst parents. The child's unhappiness, lack of friends, aggressiveness and if they'll lead a normal life and be happy are all issues parents were worried about
- On reaction to a diagnosis of ADHD, responses ranged from relief to devastation for both parents and child

*We hope that our child will grow up to be fulfilled and will find appropriate employment*

Parent Quote

## Functioning for children with ADHD not on medication

- 69% had difficulty getting ready in morning
- 85% had difficulty with tasks late afternoon and/or early evening
- 58% had difficulty falling asleep
- 79% had symptoms which impacted on the family  
*(The above difficulties and symptoms occurred "Often or Always" as reported by parents in the survey)*

*We hope that our child will grow up to live his life to his full potential and have all the same opportunities as any person without ADHD*

Parent Quote

## Improved functioning for children with ADHD on medication

- 43% had difficulty getting ready in morning
- 42% had difficulty with tasks late afternoon and/or early evening
- 47% had difficulty falling asleep
- 38% had symptoms which impacted on the family  
*(The above difficulties and symptoms occurred "Often or Always" as reported by parents in the survey)*

*We're glad to know it wasn't bad parenting that was causing him to behave this way*

Parent Quote

## Side Effects

As with all medications, those available for the treatment of ADHD can cause side effects in some children. 61% of parents state that their child suffers side effects from their medication. Some of the more common side effects of ADHD medication include lack of appetite, insomnia and sleep disturbance.

*If my child has a bad day the family has a bad day*

Parent Quote

## Schools' Impact and Influence

- The survey shows a mixed response from parents on their views of school and its approach to ADHD
- Overall there is a view that with limited resources schools do what they can
- In conjunction with social and family functioning, education is of great concern for parents with ADHD children
- 75% of parents of ADHD diagnosed children state that medication has helped their child do better at school
- 47% of parents agree that teachers really help their child out
- 19% of parents feel that the school doesn't give the child the help that is needed

*(The above difficulties and symptoms occurred "Often or Always" as reported by parents in the survey)*

*I always knew something wasn't quite right. Aunts, uncles and grandparents always thought he was a bold child and they don't have much time for him.*

Parent Quote

# Associated Behaviours of ADHD<sup>1</sup>

In addition to the three core symptoms of ADHD, there is a cluster of associated behaviours which are listed below. Again, this list is intended as a guide and they are general behaviours that your child may or may not suffer from.

## **Persistence**

Persistence is generally considered the most irritating behaviour of children with ADHD. Frequent interrogation and inflammation of situations can generate immense tension. It is often the case that children's persistence (combined with impulsiveness) causes the most stress to teachers and parents.

## **Social clumsiness / poor social skills / relationship problems**

Social clumsiness causes children with ADHD to stand out in a crowd. They misread facial expressions, social cues and misinterpret the right behaviour required for a situation. They can act "silly" in a group and "come on" too strong, often exhibiting over-demanding and bossy behaviour in one-on-one situations with friends. Children with ADHD have the capacity to make friends, but have great difficulty keeping them.

## **Emotional over-arousal**

Children with ADHD tend to experience the extremities of the emotional spectrum – they do not tend to get a bit cross or a bit frustrated, nor merely like people or things. Instead they love intensely, and experience great anger or frustration.

## **Hypersensitivity**

Children with ADHD can be extremely sensitive to certain stimuli, showing strong aversions to certain fabrics, tastes, smells or textures. Some children react with discomfort to levels of sound and light that others find completely tolerable.

## **Variability**

Children with ADHD can have dramatic mood swings, which vary considerably from day to day, with no obvious cause. This also applies to performance in school.

## **Poor co-ordination**

Occasionally poor co-ordination presents a major motor clumsiness e.g. riding a bike, catching a ball; but more often it presents a subtle difficulty in performing two or more actions at the one time such as handwriting. Most children with ADHD have very untidy handwriting as a result of a combination of their difficulty with fine motor control, and with their impulsivity.

## **Disorganisation**

Children with ADHD are unaware of the mess they create. At school, they are disorganised, they do not structure their work, they may have difficulty in starting work, and may be confused as to what is required of them. Books and notes are not brought home for homework, schoolbags are left on the bus and gym bags are constantly getting lost. In secondary school, having the right books and being in the right classroom at the same time is a particular problem.

## **Poor time management**

Children with ADHD have a very poor sense of time. As a result, they regularly need support to help them achieve targets. They regularly procrastinate and find it hard to get tasks started. They have great difficulty in completing assignments in the time available. In exams, they spend too long on one question and do not have time to finish, and often do not even tackle the other questions.

## **Specific learning difficulties**

Many children with ADHD will have significant weaknesses in certain academic areas, such as reading, comprehension –oral and written, writing, spelling, language or mathematics.

## **Motivation difficulties**

Children with ADHD find it hard to focus on tasks which do not grab their attention. They simply do not have the self-regulation that other children have to apply themselves to tedious tasks. They may develop an antipathy to school and lack the motivation to try and overcome their difficulties.

## **Low self-esteem**

While children with ADHD can appear to have high self-esteem, many of them are exceptionally sensitive, and their self-esteem can suffer greatly. This is because they typically experience failure, and are at the receiving end of frequent negative feedback, despite putting effort into schoolwork. They want to be popular but are often treated like annoying outcasts and their co-ordination difficulties can leave them on the sidelines in team sports.

Low self-esteem can become a significant problem for the child as he/she gets older, and can have implications on the rest of their lives.

## **Stubbornness**

Children with ADHD frequently express opinions and views that are non-negotiable to them. If they believe black is white then nothing will change their opinion. Producing concrete evidence will often not sway them in their convictions. At another point in time, they may hold an opposing view just as firmly.

# International Parent Research – A global picture of ADHD<sup>3</sup>

Research undertaken by the World Federation for Mental Health (WFMH) in partnership with Dr Russell Barkley, Research Professor of Psychiatry, SUNY Upstate Medical University, USA, investigated the global effect of ADHD. This research was supported by an unrestricted educational grant from Eli Lilly. 938 parents of children with ADHD were interviewed across nine countries, revealing the following:

## ADHD Knows No Boundaries

- Global prevalence of ADHD is consistent across countries (3 – 7%)<sup>4,5</sup>
- ADHD impacts not only on the individual, but can also impact their family, friends and society.
- Symptoms of ADHD occur at all times of the day.
- ADHD remains under-recognised, under-diagnosed and under-treated in many countries.

## Diagnosis Experience

- The average length of time from when a parent first visited a healthcare professional to talk about their child's behaviour, to a diagnosis by a specialist, was approximately two years.
- Italy had the longest diagnosis time lag with average diagnoses taking just over three years. The US had the shortest diagnosis period, at just under one year. The average diagnosis in Ireland is 4 years, making Ireland above the global average<sup>2</sup>.
- 50% of parents felt that the diagnosis process took too long.
- 59% of parents believe that their child's primary care doctor did not seem to know much about ADHD.
- 31% of parents had difficulty getting a referral to a specialist.

## Perspectives on Treatment:

- 60% of children received psychosocial treatments including counselling, behavioural therapy, extra tutoring and family therapy.
- 89% of children received ADHD medication.
- 85% of parents agreed that treatment (including medication and/or psychological therapies) helped their child to concentrate and 75% agreed that it helped their child to interact socially. 79% of parents agreed that treatment helped to relieve pressure on the family and 82% agreed that overall, treatment had had a positive effect on their child.
- However, parents reported that the treatment their child receives provides little or no control of symptoms at critical times of the day, notably early morning (42%), mealtimes (32%), evening (41%) and bedtime (42%).
- 85% of parents agreed that ideal treatment would address symptoms throughout the day.

## Impact on Family:

- 88% of parents admitted to being stressed or worried about their child's ADHD.
- 43% of parents found it difficult to go places with their child. 32% felt uncomfortable inviting friends and family to their home because of their child's symptoms.
- Half of parents believed that their marriage had been negatively affected by their child's symptoms.

## Impact on Child:

- A majority of parents (87%) worried that their child's ADHD would threaten his or her academic success.
- 83% worried that their child's ADHD symptoms would limit his or her future career.
- 57% of parents claimed that their child had been excluded from social activities as a result of their ADHD symptoms.

# Parenting A Child With ADHD – Advice for Parents<sup>6</sup>

Parenting a child with ADHD, or any disability, can be overwhelming at times. All parents sometimes feel anger, fear, grief, frustration and fatigue while struggling to help their child. While no treatment can “cure” ADHD, the following tips can help you be the most effective parent possible for your child.

1. Seek up-to-date, scientifically supported information about ADHD. There is a great deal of information available on the diagnosis and treatment of ADHD. It is up to the parent, with the help of the physician to distinguish the “accurate” information from the “inaccurate”.
2. Seek an early referral from your primary care physician. Talk to your child's school or turn to patient groups for guidance on alternative points of entry.
3. Seek a professional evaluation and treatment. When first seeking advice, ask questions related to the diagnosis and treatment of ADHD. What methods will they use to evaluate the child? Are they able to evaluate for co-existing conditions that are common to ADHD? Effective treatment involves the use of several therapies including an appropriate educational programme, behaviour modification, parent, child and teacher education and sometimes counselling and medication. A thorough evaluation and assessment of your child's strengths and weaknesses will help you and members of your treatment team, your child's paediatrician, a psychologist and/or psychiatrist, and educators develop an appropriate and effective treatment plan.
4. Seek parent training from a qualified mental health professional experienced in ADHD. Being a parent of a child with ADHD can be frustrating and exhausting. You may find that approaches that work well with you other children do not work for their child with ADHD. Effective parent training will teach you strategies to change behaviours and improve your relationship with your child.

*Happy to know I wasn't the only parent in the same situation. Good to know there is medication available*

Parent Quote

5. Seek support for yourself. Parents can give each other information as well as support by attending local patient group meetings where available. The constant high level of parenting required can take a toll on even the very best parents. Seek marital counselling if necessary. Seek counselling if you begin to feel overwhelmed or defeated.
6. Insist on regular update meetings with your physician to ensure you and your child remain happy with the treatment plan and to allow medication and/or dosage to be monitored as your child grows. Keep a record of your child's behavioural patterns, a 'weekly diary' to support any concerns you may have when speaking with your physician about your child's progress. If you are unhappy with how your child's ADHD symptoms are being managed, seek a second opinion and turn to patient groups for advice. They will be able to guide you on when you should return to your child's physician/psychiatrist and are able to provide invaluable insight into alternative sources of information and support.
7. Tell your child that you love and support him or her unconditionally. There will be days when you may not believe this yourself. Those will be the days when it is even more important that you acknowledge the difficulties your child faces on a daily basis, and express your love. Let your child know that you will get through the smooth and rough times together.

*My child being diagnosed with ADHD was hard news, but glad there was an answer for his behaviour*

Parent Quote

*I finally knew what was wrong with my sons and could help them*

Parent Quote

## Local Support Groups

Group	Contact Name	Phone
HADD (All-Ireland support group)	Stephanie Mahony	01 8748 349 hadd@eircom.net
Attention Deficit Disorder Midwest Support Committee Limited (Limerick)	Betty Downes	061 312 621
ADHD Family Support Group Neighbourhood Youth Project (Blanchardstown)	Moira Hyland-Doyle	01 820 5253
Ballyfermot ADHD Support Group	Michelle Hayes	01 623 4829 087 962 5574
CLADDA (Clare)	Miriam Donnellan	065 683 9827 or 087 661 0534 or 086 080 7712
Drogheda ADHD	Geraldine Lennon	041 984 6614
Finglas/Cabra ADHD/ADD Support Group	Pauline Hazel	01 868 3806 or 087 970 0034
Galway ADHD Support Group	Rosemary Kavanagh	091 798 226
Irish National Council for ADHD Support Groups (INCADDS)	Ray Kavanagh	091 798 266
HADD Child & Family Support Group (Cork)	Joe Jeffers	021 451 5032
Mayo ADHD	Caroline Joyce	087 957 2311
Meath ADHD Parents Support Group	Anne O'Dwyer	086 156 8209
NIADD Support Centre (Belfast)	Sarah Salters	028 9020 0110
North Fingal ADHD Parents and Adults Support Group	Irene Donovan	087 644 9105
South Tipperary ADHD Support Group	Susan Long	052 29529
TRADDS (Kerry)	Michael Kelly	066 7128789

## Notes:

1. Research Company: Lewis Grant  
Cohort: Postal Survey of 150 parents of ADHD diagnosed children.  
Survey Date: Questionnaires were dispatched throughout November and December 2004. Replies were received up to February 2005
2. ADHD ACTION is a multi disciplinary group whose principle aim is to educate the public and health professionals about ADHD. It hopes to dispel myths and stigmas attached to ADHD and offer support to parents and families living with the condition. The group is chaired by Professor Michael Fitzgerald, Professor of Child Psychiatry, Trinity College Dublin and includes the following members:
  - Dr Amanda Burke, Child Psychiatrist, Child Guidance, Roscommon
  - Stephanie Mahony, Hyperactivity & Attention Deficit Disorder Family Support Group (HADD)
  - Siobhán Cartúir, Irish Primary Principals Network (IPPN)
  - Anne O'Leary, National Educational Psychological Service (NEPS)

## References:

- 1 Attention Deficit Hyperactivity Disorder ADHD and Education: A Resource for Teachers. HADD Family Support Group.
- 2 A Parent Survey of ADHD in Irish Children commissioned by ADHD Action and supported by Eli Lilly & Co (Ireland) Ltd. 2006
- 3 Without Boundaries Challenges and Hopes for Living with ADHD: An International Survey - 2005.
- 4 American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision, Washington, DC, American Psychiatric Association, 2000
- 5 Faraone SV, Sergeant J et al. The Worldwide Prevalence of ADHD : Is it an American condition? World Psychiatry 2003; 2 (2):104-113
- 6 Adapted with permission from 'Parenting a Child with AD/HD,' What We Know Sheet # 2, from the National Resource Center on AD/HD: A Program of CHADD (<http://www.help4adhd.org/en/living/parenting/WWK2>).



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