**Shared Care Protocol for the Management of Attention Deficit Hyperactivity Disorder (ADHD) for**
**DONCASTER: children, adolescents and adults**
**BASSETLAW: children and adolescents (upto age 17yrs 364 days)**

## 1.0 INTRODUCTION

The medical assessment and treatment of children with ADHD should be shared between Primary Care, Paediatrics and Psychiatry. This protocol sets out guidelines for assessment and treatment of children over 5 years with ADHD and delineated responsibilities when care is to be shared between Primary Care and Secondary Care and includes the transitional arrangements between Paediatrics and Adult Psychiatry.

Shared Care Protocols are intended to provide clear guidance to General Practitioners (GPs) and hospital prescribers regarding the procedures to be adopted when clinical (and therefore prescribing and financial) responsibility for a patient's treatment is transferred from secondary to primary care.

GPs, as independent contractors, have the right to decline to take clinical and prescribing responsibilities for a patient on their medical list who is being treated elsewhere. However the reason for this action must be documented. In the view of the Doncaster & Bassetlaw APC, it would be the exception for a GP to refuse to take clinical and prescribing responsibilities for an individual drug, where shared care guidelines for that drug have become common practice and where shared care guidelines include adequate support, education, and information as approved by the Doncaster & Bassetlaw APC.

If a specialist asks a GP to prescribe ADHD medication in relation to this disorder, the GP should reply to this request as soon as practicable.

The doctor who prescribes the medication legally assumes clinical responsibility for the drug and the consequence of its use.

| | Traffic light system classification | | |
|---|---|---|---|
| Drug Class | **Green[G]** | **Amber[A]** | **Red[R]** |
| Stimulant* | | Methylphenidate MR/ XL*<br>Lisdexamfetamine*<br>Dexamfetamine | |
| Non-Stimulant | | Atomoxetine<br>Guanfacine (5-17yrs) | Guanfacine (≥18yrs) |

G – Prescribing initiated and retained In Primary Care

**A – Prescribing initiated by specialist and passed to primary care after stabilisation – monitoring shared as specified in SCP**

R – Prescribing initiated and retained by specialist – Prescribing monitoring performed in secondary care

*MR/ XL formulation to be considered for patients who moved from another area and had been on long acting methylphenidate, children who have recurrence symptoms during the day, variable concentration during the day, are bullied at school and or refusal of administering the medication by schoolteacher or patient choice.

- **Methylphenidate MR and XL products should be prescribed by brand due to varying release profiles**
- Lisdexamfetamine is a prodrug of dexamfetamine and works in much the same way as a MR product.

## 2.0 DEFINITION

Attention deficit hyperactivity disorder (ADHD), also sometimes referred as hyperkinetic disorder (HKD), is a neurobiological disorder thought to be caused by an imbalance of some of the neurotransmitters found in the brain, principally called noradrenaline (norepinephrine) and dopamine.

## 3.0 BACKGROUND INFORMATION

ADHD is a common behavioural disorder occurring in children, adolescents and adults. The principal diagnostic features are inattention, hyperactivity, and impulsive behaviour that are often disruptive and may become defiant and aggressive. In adults with ADHD, symptoms of hyperactivity and impulsiveness that were present in childhood tend to decrease, but symptoms of inattention persist.

### 3.1 Prevalence

National Institute for Clinical Effectiveness (NICE) estimates that around 5% of school-aged children and adolescents would meet the DSM-IV diagnostic criteria for ADHD, equivalent to 366,000 children and adolescents in England and Wales, but not all of these children and adolescents would require treatment. Approximately 1% of school-aged children and adolescents would meet the diagnostic criteria for hyperkinetic disorder. A proportion of young people will continue with symptoms into adulthood. The prevalence of ADHD in adults is estimated to be about 2.5%.

### 3.2 NICE Guidance

When deciding which drug to use, prescribers should consider the following:

- whether the patient has other conditions such as epilepsy, tics or a cardiovascular history
- the side effects of each drug
- factors that might make it difficult for the person to take the medicine at the right time (for example, if it is difficult to take a dose during school hours)
- the possibility that the medicine might be misused, or passed on to another person for misuse
- the individual preference of the patient and/or their family or carer.

Where more than one of the medicines is considered to be appropriate for a child or adolescent, their doctor should choose the cheapest one.

ADHD medication is indicated for

- children and adolescents diagnosed with moderate and severe ADHD if
    - ADHD symptoms are still causing a persistent significant impairment in at least one domain after their parents have received ADHD-focused information,
    - group-based support has been offered and
    - environmental modifications have been implemented and reviewed
- adults diagnosed with moderate to severe ADHD if
    - ADHD symptoms are still causing a persistent impairment in at least one domain after having received ADHD-focused information and
    - environmental modifications have been implemented and reviewed

If treatment with medication for ADHD is required then methylphenidate, atomoxetine, dexamfetamine, lisdexamfetamine and guanfacine are all possible choices.

Pharmacological treatment should only be started after a specialist who is an expert in ADHD has thoroughly assessed the child or adolescent and confirmed the diagnosis. Once treatment has been started it can be continued and monitored by a GP.

### 3.3 Symptoms

Health care professionals recognise that there are 3 main combinations of symptoms:

- predominantly hyperactive- impulsive type.
- predominantly inattentive type (this is most common in adults)
- combined type (Inattentiveness, hyperactivity and impulsivity). This makes up the majority of cases for children and adolescents

Whilst most patients show these behaviours, the difference between ADHD and normal behaviour is the degree of impairment, and mainly how it affects the child at home, school and in the community children with ADHD show these behaviours to a significantly greater extent and severity.

In order to diagnose ADHD in an adult, symptoms should have been present in childhood and present in all areas of life.

### 3.4 Impact

Patients with ADHD might experience one or more of the following:

- Underachievement at school or work
- Problems with peers and adult relationships.
- Problems with finding and keeping a job.
- Alcohol and substance abuse.
- Criminal behaviour.
- Depression.

Early identification and treatment by a health professional is therefore very important to ensure that the child can fulfil their full potential.

### 3.5 Diagnosis

The World Health Organisation system (ICD- 10) is widely used in Europe. A diagnosis of hyperkinetic disorder (severe ADHD) requires three difficulties to be present- hyperactivity, impulsivity and inattention.

The DSM – V diagnostic criteria of the American Psychiatric Association has broader criteria: a diagnosis of ADHD can be made with either impulsivity-hyperactivity (the two problems are combined together) or inattention, as well as with both.

The health care professionals will look for alarm signals:

- The child who significantly under performs at school, despite having a normal intellect and no major specific learning difficulties.
- The child who has ADHD behaviour problems, which are considerably worse than, would be expected for the standard of parenting and home environment
- Adults presenting with potential ADHD symptoms

### 3.6 Differential diagnosis

(this does not exclude possible co-morbidity with ADHD)

- The normal active preschool child
- Intellectual disability
- Specific learning difficulties
- Autism Spectrum Disorder
- Epilepsy
- Depression
- Brain injury

- Family dysfunction
- hyperthyroidism
- Mania or bipolar affective disorder
- Substance misuse related diagnosis

They may also use some objective pointers towards diagnosis such as:

- Rating scales by parents and teachers e.g., Conners Teacher and Parent Rating Scales
- Tests which measure length and type of mental process (Psychometric tests and profiles)
- DIVA (Diagnostic Intervention in ADHD in adults)

## 4.0 TREATMENT

### 4.1 Non-Pharmacological Treatment

1. Parenting intervention is the first line treatment for mild to moderate ADHD in children and adolescents and should also be offered in severe ADHD (possibly in conjunction with medication)
2. Behavioural interventions **might include**:
    - Family therapy focusing on management strategies.
    - Individual therapy focusing on changing behaviours.
3. Non-pharmacological treatments should be considered for adults who have benefited from medication but whose symptoms are still causing significant impairment in at least one domain.

### 4.2 Pharmacological Treatment

Healthcare professionals initiating medication for ADHD should

- Be familiar with the pharmacokinetic profiles of all short and long acting preparations available for ADHD
- Ensure the treatment is tailored effectively to the individual needs of the patient
- Take account of variations in bioavailability or pharmacokinetic profiles of different preparations to avoid reduced effect or excessive side effects.

**Children under 5 years the age**

- All prescribing will stay with the specialist service and is not part of shared care arrangements

**Children 5 years and over and young people**

- Methylphenidate (short or long acting as appropriate) is first line treatment
- lisdexamfetamine and dexamfetamine being considered second and third line as per NICE guidance
- Non-stimulants atomoxetine or guanfacine will be considered where
    - The patient cannot tolerate methylphenidate or lisdexamfetamine

- Their symptoms have not responded to separate adequate trials of lisdexamfetamine and methylphenidate, having considered alternative preparations and adequate doses as per NICE guidance

**Adults**

Pharmacological treatment is the first line treatment option for adults with moderate to severe ADHD.

- methylphenidate (short or long acting as appropriate) and lisdexamfetamine will be considered first line as per NICE guidance
    - the alternative first line treatment should be considered where the initial choice has proven ineffective
    - dexamfetamine will be considered where the prolonged release profile of lisdexamfetamine is problematic
- atomoxetine will considered where
    - The patient cannot tolerate methylphenidate or lisdexamfetamine
    - Their symptoms have not responded to separate adequate trials of lisdexamfetamine and methylphenidate, having considered alternative preparations and adequate doses

It is accepted practice for shared care that initial dose stabilisation needs to be undertaken by the Consultant before prescribing can be passed to Primary Care. However, it is acknowledged that following a period of dose stabilisation that there may be an occasional requirement for the dosage of medication to be adjusted for some patients.

This Shared Care Protocol and Proforma allows for:

- Change of dosage within the same drug
- Change of form (i.e. tablet to modified release tablet) within the same drug without the need for completion of a new Proforma.

Any such changes must be initiated by the Consultant and communicated to the GP in writing.

Patients undergoing a dose or form change will be provided with a 1 month prescription from the Consultant to facilitate this change-over.

## 4.2 Drug treatment

For dose ranges and contraindications or further information for individual drugs please see

- the current BNF http://www.bnf.org.uk/bnf/bnf/current/index.htm or
- summary of product characteristics for the individual drug http://www.medicines.org.uk/

### Monitoring Schedule

| | | | MONITORING PARAMETER | | | |
|---|---|---|---|---|---|---|
| | **DRUG** | **SITE** | **Progression** | **Height** | **Weight** | **Pulse/ Blood pressure** |
| **CHILDREN (<18yrs)** | **Methylphenidate[1] Lisdexamfetamine Dexamfetamine Atomoxetine Guanfacine** | **Secondary care** | Baseline cardiovascular examination (including ECG if appropriate[2]) and assess for risk of substance misuse or diversion. Review adverse effects and effectiveness. ADHD reviewed at least annually against a standardised rating scale. | Baseline and then every 6 months. Recorded on a growth chart | Recorded on centile chart **5 to 10 years** Baseline and then every 6 months[3] **over 10 years** Baseline, 3 months then every 6 months | Baseline, after each dose change and then every 6 months[4]. Recorded on a centile chart. |
| | | **Primary care** | Symptom control and side-effect enquiry | | **5 to 10 years** 6 monthly – alternating with secondary care so that patient has weight check every 3 months | |
| **ADULTS** | **Methylphenidate[1] Lisdexamfetamine Dexamfetamine Atomoxetine** | **Secondary care** | Baseline cardiovascular examination (including ECG if appropriate[2]) and assess for risk of substance misuse or diversion. Review adverse effects and effectiveness. ADHD reviewed at least annually against a standardised rating scale. | Baseline | Baseline, then every 6 months | Baseline, after each dose change and then every 6 months[4]. |
| | | **Primary care** | Symptom control and side-effect enquiry | | | Following agreement with the secondary care physician (eg demonstrable hypertension or tachycardia) |

1. **Methylphenidate MR and XL products should be prescribed by brand due to varying release profiles**
2. **ECG's should be conducted by secondary care with GP's advised of incidental findings for consideration of cardiac referral**
3. **patients under 10 years of age need weight check every 3 months – these should be recorded in the patients RED book. If there is a drastic change in appetite or any other side-effects of the medication, parents should be advised to stop the medication and speak to the specialist service.**
4. **Elevated blood pressure monitoring should result in a clinician to clinician conversation regarding stopping the medication and managing the elevated blood pressure**

## 5.0 SHARED CARE ARRANGEMENTS

Once a stable medication regime has been established (usually 3 months), physical monitoring and prescribing of amber category drugs can be transferred to primary care with agreement.

### 5.1 Aspects of care for which Secondary Care Team is responsible

- Diagnosis and assessment
- Evaluation of cardiovascular status including baseline blood pressure and pulse. Provide the results of the cardiovascular assessment in the clinic letter and send to GP when medication is initiated.
- Support GPs in risk/benefit decision where patient is taking an ADHD medication and has
    - a sustained resting tachycardia (120 bpm)
    - arrhythmia
    - been a clinically significant increase in systolic blood pressure (or above 95$^{th}$ centile)
- Initiation and stabilisation of drug therapy, usually but not exceptionally, a period of 3 months.
- Patient/ family education
- Ensure patient/parent/carer is fully informed of potential benefits and side effects of treatment
- Ensure patient's guardian/carer is fully informed of the treatment.
- With consent, liaise with school (head / class teacher / SENCO / educational psychologist as appropriate) providing information about ADHD, drug therapy and storage.
- Provide a comprehensive treatment package in addition to stimulant and / or non-stimulant medications.
- Ensure that shared care arrangements are in place before transfer of treatment
    - That the patient/parent/carer is clear what is being monitored and by whom
    - That the patient/parent/carer knows what significant adverse effects/events to report urgently and to whom they should report (specialist or GP)
- Ensure the transition to adult services is as seamless as possible
- At regular intervals (2- 3 times in the first 6 months, then at least once yearly thereafter) to monitor mental state and behaviour, compliance problems and adverse effects.
- Write to the GP after every clinic visit detailing whether the stimulant or non-stimulant regime should remain the same or be changed. Specify any products / dose or frequency changes.
- Undertake dose changes where necessary in previously stabilised patients. Provide an interim medication supply of not less than 1 month duration.
- Monitor side effectiveness and adverse effects of medication as per table in 4.2 – recording weight monitoring appropriately in the patients RED book

- Record weight monitoring in the patient's RED book
- Report adverse events via the Yellow Card Scheme at www.yellowcard.gov.uk
- Expert clinicians suggest that additional blood tests should not be viewed as routine but only performed when clinically indicated. This will however be undertaken by the secondary care services where appropriate.
- Monitor height, weight, blood pressure and pulse every six months

## 5.2 Aspects of care for which Primary Care Team is responsible

- Ensure that shared care arrangements are in place before accepting treatment
    - That the patient/parent/carer is clear what is being monitored and by whom
    - That the patient/parent/carer knows what significant adverse effects/events to report urgently and to whom they should report (specialist or GP)
- If the specialist initiates treatment, **reply to the request for shared care as soon as practicable**
- Confirm that proposed therapy is not contra-indicated because of concurrent therapy for other conditions the patient may be suffering from e.g. check drug-drug and drug-interactions
- Ensure patient's guardian/carer is fully informed of the treatment
- Ensure clear arrangements are in place for back up, advice and support e.g. out of hours and/or when the consultant initiating therapy is not available
- Confirm with specialist which changes in these or other parameters should trigger urgent referral back to the specialist
- Seek specialist advice promptly as advised in the shared care protocol or if signs/symptoms of changes occur
- Amend prescription as per requests from secondary care for dose changes in patients on established treatment.
- Monitor side effectiveness and adverse effects of medication as per table in 4.2. - recording weight monitoring appropriately in the patient's RED book.
- Report adverse events via the Yellow Card Scheme at www.yellowcard.gov.uk
- If the drug has a black triangle status or is unlicensed, all events should be reported even if casual relationship is not known or if the adverse event is already known about
- Also report adverse events to the consultant sharing the care of the patient
- Stop treatment on advice of specialist, or immediately if intolerable side effects occur provided that it is safer to do so than to continue this therapy

## 5.3 Parent (or Carer's) Responsibilities

- Discuss potential benefits and side effects of treatment with the specialist and GP. Identify whether they have a clear picture of these from the specialist and to raise any outstanding queries.
- Check that where possible the specialists have provided a patient-held record or information sheet for monitoring and/or to alert other clinical staff to the treatment they are receiving.

- Share any concerns they have in relation to treatment with the medicine.
- Report any adverse effects to their specialist or GP whilst taking the medicine.
- Report to the specialist or GP if they do not have a clear understanding of their treatment.
- Participate in the monitoring of therapy and the assessment of outcomes, to assist health professionals to provide safe, appropriate treatment. Ensuring, where the patient is less than 10years of age or younger, that the patient's RED book is available for updating at each monitoring

## 6.0 PROCEDURE FOR ADOPTING SHARED CARE

### 6.1 General Procedure:

The specialist will send to the GP a diagnostic assessment report including cardiovascular assessment, a copy of the shared care protocol and a shared care referral specifying who is responsible for physical monitoring (height, weight, pulse and blood pressure). Both the specialist and GP should sign the proforma with a record kept in the GP and Hospital Records. Full details will be given of the prescribing regime (brand, form, strength and dose of medication) and follow-up plan.

The child and the responsible adult (parent or other carer) will be asked to make arrangements with their GP for continued supply.

### 6.2 Discharge Transfer

Paediatricians would generally provide outpatient care until the age of **17 years and 364** days for young people in full time education.
When a patient transitions to adults services

- the GP will be informed
- the existing shared care arrangements with CAMHs services will cease
- a new shared care arrangement will be invoked to reflect the sharing of care between GP service and adult mental health services.

## 8.0 REFERENCES


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## 8.0 SHARED CARE DEVELOPMENT

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