

**Shared care guidance**  
**Attention Deficit Hyperactivity Disorder (ADHD) – Children and Adolescents**

**Principles of Shared Care Agreements**

**Introduction**

Good organisation of care across the interface between primary and secondary/tertiary care is crucial in ensuring that patients receive safe and high quality care – and in making the best use of clinical time and NHS resources in all care. Good professional practice requires care for patients to be seamless; patients should never be placed in a position where they are unable to obtain the medicines they need, when they need them. Lack of communication between primary and secondary/tertiary care and misunderstandings around the responsibilities of the professionals involved are often cited as reasons for patients not being able to get their medicines in a timely manner, despite effective collaborative working and communication being an important part of patient-centred professionalism.

**1. Criteria for Classifying Drugs as Suitable for Shared Care**

a. It is in the best interests of the patient for a primary care prescriber to take over prescribing, however, specialist involvement is required for:

- initiation of treatment
- on-going specialist monitoring and/or
- assessment to enable effectiveness and /or
- reducing risk of toxicity.

and/or

b. Medicines that are specifically suggested as suitable for shared care by the DH or NICE.

**2. Shared Care Agreements**

a. Treatment should be initiated by a specialist (which could include consultant, suitably trained specialist non-medical prescriber or GP with specialist interest within a secondary, tertiary, or primary care clinic). Clinical and prescribing responsibility should be transferred to primary care only when the patient's clinical condition is stable or predictable. This does not mean that the patient is discharged from specialist care.

NHSE guidance states that patients can be discharged, but need a fast track referral route in certain circumstances e.g. Adult ADHD.

As the CCG is not responsible for agreeing tertiary care shared care, there may be a need to consider treatment on a case by case basis.

The GP should agree in writing for each individual case and the secondary/tertiary provider must continue to provide prescriptions until successful transfer of responsibilities. Specialist advice should be available to primary care prescribers i.e. not requiring referral back to specialist as such.

b. The legal responsibility for prescribing lies with the doctor or health professional who signs the prescription and it is the responsibility of the individual prescriber to prescribe within their own level of competence. This includes responsibilities with supplying or administering the prescribed medicine and instructions to others.

- c. Patients should be at the centre of the shared care agreement however where patients do not have the mental capacity to make healthcare decisions involvement of carers and/or attorneys (holding the Lasting Power of Attorney for health and welfare) should be considered prior to decisions around shared care.
  
- d. Shared care must be in accordance to the Shared Care template (Appendix 1). Communication between the specialist and the primary care prescriber should include the letters of request and agreement/refusal (Appendix 2).
  
- e. For medicines which are prescribed under a share care arrangement, primary care prescribers should have sufficient knowledge and experience to monitor, stop, or alter the dosage of the medicine **in appropriate circumstances and have access to specialist advice to support them** (details should be made available within Share Care Agreements i.e. not requiring referral back to specialist as such). The degree of control, which they have over this prescribing, and 'a route of return' to specialist care will form part of the shared care agreement.
  
- f. Agreements for shared care must not be used nor declined for cost shifting purposes.
  
- g. It is the responsibility of the Joint Prescribing Committee (JPC) to ensure that adequate support, education and information is made available to primary care prescribers who "share care" of patients with a specialist in order for treatment to be managed safely in primary care.
  
- h. GP/Primary care prescribers must seek further support from the referring specialist or CCG rather than decline shared care on the basis of lack of competence as default.
  
- i. Explicit criteria for review need for monitoring and discontinuation of the medicine should be included; this should also be communicated to the patient.
  
- j. Patients should never be used as a conduit for informing the GP that prescribing is to be transferred nor to inform the specialist that shared care has been declined. They should never be placed in a position where they are unable to obtain the medicines they need because of lack of communication between primary and secondary/ tertiary care.

### **3. Circumstances where shared care is not appropriate**

In some situations the use of shared care is not appropriate and in these cases the hospital/specialist should retain responsibility for prescribing. Whilst the situations may be broad and diverse the following would be examples:

- a. Patients receiving the majority of ongoing care, including monitoring, from the specialist service.
  
- b. Where the primary care prescriber does not feel competent in taking on clinical responsibility for the prescribing of the medicine despite taking steps (as stated in point 2e above) to seek further support from the specialist.
  
- c. Where a drug requires specialist intervention, stabilisation and monitoring on an ongoing basis.
  
- d. Where patients have declined the shared care option following informed discussions with the specialist prescriber.
  
- e. Where insufficient information has been provided to proceed with shared care and/or no

Shared Care Agreement or protocol exists.

- f. Unlicensed medicines unsuitable for use in primary care or being used 'off-label' for an indication with no established evidence base.
- g. Where drugs are being used as part of a hospital-initiated clinical trial.
- h. Where the drug is new, only available through hospitals or has not been approved for addition to the current primary care formulary.
- i. The indication for prescribing is contrary to NICE guidance and the use of the drug has not been approved on an 'exceptional basis'.
- j. A medicine for which the JPC considers there to be poor evidence base or lack of cost effectiveness compared to alternative commissioned treatments.
- k. Black Triangle Medicines (unless there is a large body of evidence supporting use e.g. BNF, NICE).
- l. There is a NICE recommendation that the medicine should not be prescribed on the NHS for the condition specified.
- m. Medicines subject to High-tech Hospital at Home guidance (EL (95)5).
- n. All other treatments funded by NHS England unless specifically agreed to be provided through a shared care prescribing agreement, or other process as agreed by the JPC.
- o. There is a clear NHSE/I Specialised Commissioning or JPC decision to not routinely fund usage of the medicine or NHSE considers the drug not suitable for shared care.
- p. Shared care should not be approved with non-NHS funded providers as no guarantee patients will continue to fund themselves.

#### 4. Funding Issues

- a. Each shared care protocol submission must include an estimate of the number of patients affected.
- b. Commissioners should take account of the operational and resource implications of shared care, and of the fact that this should also extend to the requirements and sustainability of hospitals in situations where shared care is not accepted.
- c. If the treatment is likely to produce significant cost pressures (i.e. it cannot be managed within the existing prescribing budget), then agreement needs to be reached with JPC and if supported, appropriate funds identified.
- d. All appropriate monitoring requirements (e.g. phlebotomy, ECG, height/weight checks) must be fulfilled. The person delivering that aspect of the shared care agreement should ensure that the resources to do this are in place in the clinical setting in which they are delivered (for example within a Primary Care Network (PCN)).
- e. The requirement for the appropriate resource will need to be considered by

commissioners, based on the likely workload implications of the transfer of care i.e. from secondary/tertiary to primary care.

## 5. Approval and Review of Shared Care protocols

- a. Consultation with primary/secondary/tertiary care prescribers must be sought when developing or reviewing a shared care protocol or supporting prescribing guideline.
- b. The JPC must recommend the approval of all shared care protocols before they can be distributed for use between primary and secondary care.
- c. A shared care protocol or supporting prescribing guideline will usually be approved for two years after which time an up-dated version should be submitted by the author for re-approval. Any major changes in national guidance or any significant issue that arises should prompt a review of the shared care protocol or supporting prescribing guideline at an earlier date.

### References

- Responsibility for Prescribing between Primary and Secondary/Tertiary Care. NHS England. Jan 2018.
- SPS - Shared Care Guidance - A Standard Approach - Regional Medicines Optimisation Committee (RMOC) October 2019 V2
- Good Practice in Prescribing and Managing Medicines and Medical Devices. General Medical Council Guidance. 2013.

## Appendix 1

### Shared Care Protocol

#### Attention Deficit Hyperactivity Disorder (ADHD) – Children and Adolescents

#### AREAS OF RESPONSIBILITY FOR SHARED CARE

This shared care agreement outlines suggested ways in which the responsibilities for managing the prescribing of **Methylphenidate, Lisdexamfetamine, Dexamfetamine, Atomoxetine and Guanfacine** can be shared between the specialist and general practitioner (GP). GPs are invited to participate. If the GP is not confident to undertake these roles, then he or she is under no obligation to do so (*please refer to Principles of Shared Care Agreements in point 2h*). In such an event, the total clinical responsibility for the patient for the diagnosed condition remains with the specialist. Refer to Principles of Shared Care document for full details, in summary:

- Transfer of monitoring and prescribing to Primary care is normally after the patient is on regular dose and with satisfactory investigation results for at least 4 weeks
- The duration of treatment will be determined by the specialist based on clinical response and tolerability.
- All dose or formulation adjustments will be the responsibility of the initiating specialist unless directions have been discussed and agreed with the GP/primary care clinician
- Termination of treatment will be the responsibility of the specialist.

#### PRESCRIBING INFORMATION

##### 1. Background

ADHD is defined as a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development. The definition requires that symptoms:

- Start before 12 years of age.
- Occur in two or more setting such as at home and school.
- Have been present for at least 6 months.
- Interfere with, or reduce the quality of social, academic or occupational functioning.
- Do not occur exclusively during the course of a psychotic disorder and are not better explained by another mental disorder.

The prevalence of attention deficit hyperactivity disorder (ADHD) varies among studies and is estimated to be around 2.4% of children in the UK. It is more commonly diagnosed in boys than girls (depending on the population studied, the ratio ranges vary from 9:1 to 2.5:1).

Drug treatment is not indicated as the first-line treatment for all school-age children and young people with ADHD. It should be reserved for those with severe symptoms and impairment or for those with moderate levels of impairment who have refused non-drug interventions, or whose symptoms have not responded sufficiently to parent-training/education programs or group psychological treatment.<sup>2</sup>

## 2. Indications (Please state whether licensed or unlicensed)

### Scope

Children and adolescents (from 6 years old to their 18th birthday) with a diagnosis of ADHD.

Drug treatment should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD and should be based on a comprehensive assessment and diagnosis.

The time taken to achieve a therapeutic dose of medication usually takes approximately 8 – 12 weeks, though this can sometimes take longer especially in patients with complex co-morbid conditions. Once the patient is stable, a shared care arrangement will be requested with the primary care clinician.

**Stimulants – Methylphenidate, Lisdexamfetamine, Dexamfetamine** (immediate release and long acting), and **Non Stimulants - Atomoxetine, Guanfacine** are indicated for the treatment of Attention-Deficit Hyperactivity Disorder (ADHD) in children of 5 years and older and in adolescents as part of a comprehensive treatment programme when remedial measures alone prove insufficient. These medications are licensed for use in children from the age of 6 years, and do not have a UK marketing authorisation for ADHD in children aged 5 years or under. However, [NICE Guidance](#) does support the use of these medicines in this population however this shared care guidance does not cover children under the age of 6 years (as per exemptions). Children under the age of 6 years will remain the responsibility of the initiating specialist. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. **Unlicensed medication should not be used or recommended without consulting a Specialist.** Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

Please note the following:

1. NICE guidance recommends Methylphenidate (either short or long acting) as the first line pharmacological treatment for children aged 5 years and over and young people with ADHD. Methylphenidate should be prescribed by brand.
2. **Lisdexamfetamine** is indicated as part of a comprehensive treatment programme for attention deficit/hyperactivity disorder (ADHD) in children aged 5 years and over when response to previous methylphenidate treatment is considered clinically inadequate.  
Consider Dexamfetamine for children aged 5 years and over and young people whose ADHD symptoms are responding to Lisdexamfetamine but who cannot tolerate the longer effect profile.
3. **Dexamfetamine** - *NICE states that this is an off-label use for some people aged 6 to 17.*

***Amfexa 10mg Tablets SPC*** Dexamfetamine is not indicated in all children with ADHD and the decision to use dexamfetamine must be based on a very thorough assessment of the severity and chronicity of the child's symptoms in relation to the child's age and potential for abuse, misuse or diversion. Treatment should be under the supervision of a specialist in childhood and/or adolescent behavioural disorders.

4. NICE also states: Offer Atomoxetine or Guanfacine to children aged 5 years and over and young people if:
  - They cannot tolerate Methylphenidate or Lisdexamfetamine or their symptoms have not responded to separate 6-week trials of Lisdexamfetamine and Methylphenidate, having considered alternative preparations and adequate doses.

### 3. Pharmaceutical aspects

Refer to most current BNF for children <https://bnfc.nice.org.uk/>

For a full list, see manufacturer's Summary of Product Characteristics (SPC) (on [www.medicines.org.uk/emc](http://www.medicines.org.uk/emc))

Please note that the BNF for children supports higher than normal doses of some formulations (e.g. Equasym XL, Medikinet XL, Concerta XL etc.). In these instances, the Specialist must take responsibility of titrating the dose upward and stabilising the patient before considering transfer back to the primary care clinician.

### 4. Exclusions or contraindications

*Please note this does not replace the Summary of Product Characteristics (SPC) and should be read in conjunction with it.*

- Children under the age of 6 years.
- Patients not registered with a GP in the Kent and Medway CCG area
- Patients unwilling or likely to be unable to be compliant with the service
- Non-NHS patients
- Patients where a written request for shared care has not been received.

Refer to current BNFC and SPC for contraindications:

[www.medicines.org.uk/emc](http://www.medicines.org.uk/emc)

### 5. Initiation and ongoing dose regime (by specialist)

**Note -**

- *Transfer of monitoring and prescribing to Primary care is normally **after the patient is stable on a regular dose** and with satisfactory investigation results for period of time as agreed by the specialist.*
- *The duration of treatment will be determined by the specialist based on clinical response and tolerability.*
- *Specialist to specify the length of treatment supplied to the patient in order to indicate to primary care when new supply will be required for forward planning.*
- *All dose or formulation adjustments will be the responsibility of the initiating specialist unless directions have been discussed and agreed with the primary care clinician*
- *Termination of treatment will be the responsibility of the specialist.*

- All medication for ADHD should only be initiated by a healthcare professional with training and expertise in diagnosing and managing ADHD. Healthcare professionals initiating medication for ADHD should:
  - Be familiar with the pharmacokinetic profiles of all the short- and long-acting preparations available for ADHD
  - Ensure that treatment is tailored effectively to the individual needs of the child, young person.
  - Take account of variations in bioavailability or pharmacokinetic profiles of different preparations to avoid reduced effect or excessive adverse effects.
- Ensure that dose titration is slower and monitoring more frequent if any of the following are present:
  - Neurodevelopmental disorders, e.g. autism spectrum disorder, tic disorders, learning



- disability (intellectual disability).
- Mental health conditions e.g. anxiety disorders (including obsessive–compulsive disorder), schizophrenia or bipolar disorder, depression, personality disorder, eating disorder, post-traumatic stress disorder, substance misuse.
- Physical health conditions, e.g. cardiac disease, epilepsy or acquired brain injury.

Methylphenidate, Dexamfetamine and Lisdexamfetamine	<ul style="list-style-type: none"> <li>- Schedule 2 controlled drugs (CD) thus subject to prescription requirements. Prescriptions must include:               <ul style="list-style-type: none"> <li>• Name and address of patient</li> <li>• Form and strength of preparation (e.g. 20mg capsules)</li> <li>• The dose (e.g. 20mg three times a day) and total quantity or number of dose units in words AND figures (e.g. 420mg = Four hundred and twenty milligrams or 21 capsules = Twenty one capsules)</li> <li>• Signed by the prescribing clinician (either in indelible ink or advanced electronic signature)</li> </ul> </li> <li>- Prescriptions for schedule 2 CDs are valid for 28 days from the date stated on the prescription and prescriptions are limited to a supply of 30 days treatment.</li> <li>- <b>Cautions</b></li> <li>- <b>Methylphenidate:</b> co-existing cardiac disease or psychiatric disorder, anxiety/agitation/tension, tics or family history of Tourette or other movement disorders, risk of dependence/diversion/misuse of medication (both prior to initiation and ongoing during treatment), epilepsy, pregnancy, breast feeding; avoid abrupt withdrawal.</li> <li>- <b>Dexamfetamine/Lisdexamfetamine:</b> Anorexia, mild hypertension, psychosis or bipolar disorder, renal impairment, history of epilepsy, tics or Tourette syndrome, risk of dependence/diversion/misuse of medication (both prior to initiation and ongoing during treatment), avoid abrupt withdrawal.</li> <li>- <b>Atomoxetine:</b> Cardiovascular disease, structural cardiac abnormalities, QT interval prolongation, psychosis/mania, history of seizures, aggressive behavior/hostility/emotional lability, hepatic impairment.</li> </ul> <p>For a full list of cautions, refer to the summary of product characteristics: <a href="http://www.medicines.org.uk">www.medicines.org.uk</a></p>
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## 6. Specialist responsibilities for monitoring (including frequency)

### At initiation:

- To confirm diagnosis and identification of suitable patients following full mental health and social assessment
- To take a complete history, documenting: concomitant medicines, past and present medical and psychiatric disorders or symptoms, family history of sudden cardiac death, unexplained death and malignant arrhythmia
- To assess baseline cardiovascular status, including blood pressure and heart rate before prescribing and get an electrocardiogram (ECG) and/or initiating specialist clinician cardiac advice if appropriate. See Appendix 1 for further information on monitoring blood pressure in children.
- The Specialist must also refer for a cardiology opinion in specific circumstances (or a paediatric hypertension initiating specialist clinician if blood pressure is consistently above the 95<sup>th</sup> centile for age/height) prior to medication initiation. A full list of cardiac related scenarios where this is necessary can be found in [NICE Guidance](#)



- Ensure baseline monitoring of height, weight, blood pressure and pulse has been performed, plus any additional relevant investigations (these must be shared with the primary care clinician).
- Conduct a risk assessment for drug abuse and diversion.
- To discuss the risks and benefits of medicines with patients and/or family, outlining possible side effects and explaining their roles.
- To initiate and titrate ADHD therapy
  
- Provide the patient (as appropriate), parent/carer and class teachers with **written information** about ADHD, its management, including, medical management, explaining the effects, side effects of medications and shared care arrangement. Document this discussion in the patients' clinical notes.
- Prescribe the medication until the dose is stabilized in terms of maximum effect and minimum/tolerable adverse effects. Doses should be gradually increased until there is no further clinical improvement in ADHD – That is, symptom reduction, behavior change, improvements in education and/or relationships and side effects are tolerable (usually a period of 3 months).
- To provide the primary care prescriber with clinical letter along with shared care criteria stating planned introduction, reviews, additional advice included in the treatment plan as appropriate and requesting shared care for the patient.
- Provide results of baseline tests and recommend frequency of monitoring to primary care clinician. The specialist must also explain what the recommended tests are and the reasons they are needed.
- When stimulant medication (methylphenidate, dexamfetamine or lisdexamfetamine) is being used, to look out for signs of diversion (transfer of medicine from the prescribed individual to one for whom it is not prescribed), misuse and abuse.
- If prescribing modified release methylphenidate this must be prescribed by brand to avoid the risk of the wrong formulation being dispensed. Please check the formulary for the cost effective/first line brand to prescribe.
- Evaluate adverse drug reactions reported by the primary care clinician, patient or the carer. Report events to [www.yellowcard.mhra.gov.uk](http://www.yellowcard.mhra.gov.uk)
- To provide outpatient reviews, set the review interval and criteria.
- Before shared care is put in place the patient must be fully informed of the plan and must be in agreement with it.

**At review:**

- Regular follow up should take place with a child and adolescent psychiatrist or paediatrician until the child is stabilized, monitoring therapy effectiveness and side effects.
- To review the patient and monitor the following (if relevant to specific drug) on an **annual basis (first review within 8 to 10 weeks** of initiation of medication), act on the results appropriately and communicate these results to the primary care clinician (see appendix 1 for more information):
  - Weight, appetite and height (plotted on a growth chart) recorded at baseline, following dosage adjustments and at reviews.
  - Blood pressure and pulse, recorded at baseline, following dosage adjustments (where possible) and at reviews.
  - Blood and platelet counts at discretion of supervising clinician(s) (e.g. if recurrent nose bleeds, bruising or infections occur). Baseline, then when clinically indicated. All blood results should be copied to the patient's primary care clinician.
  - Liver function tests if prescribing atomoxetine, if clinically indicated.
  - To refer patients who develop symptoms such as palpitations, exertional chest pain,

- unexplained syncope, dyspnoea, or other symptoms suggestive of heart disease for prompt specialist clinician cardiac evaluation.
- The development of new or worsening of pre-existing, psychiatric symptoms (also following dose adjustments and at every visit).
- Inform patients and patient’s carer that failure to attend annual review with specialist could result in the termination of the shared care agreement with their GP.
- Use appropriate tools to measure response as deemed necessary – SNAP, ADHD-RS rating scales and/or Qb testing.
- Undertake any necessary monitoring at clinic appointments: blood pressure, pulse rate, weight and height (on a growth chart and record centiles).
- To take responsibility for and advise when and how to stop the medication, including when drug holidays are recommended.
- Advise on the duration of continuation of the medication and if appropriate transition to adult services.
- Maintain good communication with the primary care clinician by:
  - Sending a letter after each clinic visit notifying the primary care clinician of changes in medication regime, adverse effects and results of the patients routine monitoring.
  - Periodically reviewing the patient’s condition and the need for on-going treatment and communicating promptly with the primary care clinician when treatment is changed.
  - Where blood tests are taken, results should be communicated to the primary care clinician, as well as actions to be taken in case of abnormal results, and advising the primary care clinician on when to adjust the dose, stop treatment or when to consult the initiating specialist.
- Counsel the patient and parent/carer on any dose changes that are made during clinic appointments.
- To notify the primary care clinician of patients failure to attend clinic appointments and give advice on suitable actions needed. Inform patient that further supply of their medication could be interrupted should they fail to attend review appointments. Patients should be encouraged to make arrangements for review as soon as possible.
- Ensure that clear arrangements exist for primary care clinicians to obtain advice and support.
- Respond to primary care clinician queries in a timely manner.
- To advise and support parents and teachers, liaising where appropriate with the child’s school.

## 7. GP responsibility

- Initial referral letter to CAMHS or specialist care for assessment of ADHD highlighting relevant history and impairments at home and school. The correct referral process to initiating specialist service should be followed.
- To provide prescriptions of the ADHD medications at the dose recommended by the initiating specialist once the patient is stabilised (not before at least initial three month stabilisation period).
- The term “as directed” **should not** be used when prescribing these medicines.
- A demonstrable system should be in place to ensure that prescribing is reviewed by the primary care clinician if there is no record of the fact that monitoring has taken place within the agreed time scales.
- Prescriptions for stimulants (methylphenidate, dexamfetamine and lisdexamfetamine) should be restricted to up to 30 days’ supply to comply with controlled drug prescription requirements.

- Ensure compatibility with concomitant medication and report adverse drug reactions to the initiating specialist and [www.yellowcard.mhra.gov.uk](http://www.yellowcard.mhra.gov.uk)
- If prescribing modified release methylphenidate this must be prescribed by brand to avoid the risk of the wrong formulation being dispensed.
- When stimulant medication (methylphenidate, dexamfetamine or lisdexamfetamine) is being used, to look out for signs of diversion (transfer of medicine from the prescribed individual to one for whom it is not prescribed), misuse and abuse.
- If care of the patient is transferred to another prescriber, the new prescriber should be made aware of the shared care agreement.
- To ensure all relevant staff within the practice are aware of each party's responsibilities.

#### **Monitoring (including frequency):**

- Monitor prescribing rate of ADHD medications for individual patients and report non-compliance to the initiating specialist where appropriate.
- Help with the monitoring of disease progression as stated in treatment plan and inform/refer to the initiating specialist team of any changes or deterioration in behavior (development of new or worsening of pre-existing, psychiatric symptoms).
- Monitor results at recommended frequencies as described in the share care agreement letter and clinic letter. Communicate any test results to the initiating specialist and inform them if abnormal.
- Stop treatment on the advice of the initiating specialist or immediately if an urgent need arises and inform the initiating specialist team.
- Monitor the patient as per the criteria suggested by the initiating specialist (e.g. patients pulse, appetite, blood pressure, height and weight – Plotted on growth chart).
- The following tests may be suggested by the initiating specialist to monitor in primary care. If suitable, a practice nurse may be able to complete these tests and escalate to the primary care clinician if there is cause for concern.
- **Height and weight**
  - Measure height every 6 months in children and young people
  - Measure weight every 3 months in children **10 years and under**. Measure at 3 and 6 months after starting treatment in children **over 10 years and young people**, and every 6 months thereafter, or more often if concerns arise.
  - Record height and weight of children and young people and plot on a growth chart (in lieu of a growth chart, record in the patients clinical notes the difference in growth centiles from the previous measurements/readings).
  - Initiating specialist may decide that physical observations may only be necessary once every six months (if patient has been stable on therapy for a significant amount of time and physical observations have also been stable). The initiating specialist should communicate this to the primary care clinician on every occasion.
  - If a trend of weight loss or growth retardation is observed in results over time, seek advice from the initiating specialist (psychiatrist or paediatrician) to consider stopping the medicine as an interim measure; in all instances the patient should be referred back to the initiating specialist.
- **Cardiovascular**
  - Monitor heart rate and blood pressure and compare with the normal range for age, before and after each dose change and every 6 months.
  - Routine blood tests (including liver function tests) or ECGs should not be done unless there is a clinical indication. Those patients who require routine blood tests or ECGs will be highlighted by the initiating specialist when prescribing responsibility is transferred to the primary care clinician.

#### **Review/follow up:**

- To record any changes in therapy in the patients clinical record on receipt of such communication from the initiating specialist and act upon these.
- Adjust the dose as advised by the initiating specialist.
- Counsel patient (and/or parent or carer) on any dose changes and ensure that the patient, parent or carer understands the dosing regimen.
- Ensure the patient, parent or carer understands that they must report any adverse effects to primary care clinician.
- All requests from the patient for repeat prescriptions should be reviewed individually prior to issuing.
- Report to and seek advice from the initiating specialist on any aspect of patient care that is of concern and may affect treatment.
- To refer patients who develop symptoms such as palpitations, exertional chest pain, unexplained syncope, dyspnoea, or other symptoms suggestive of heart disease for prompt specialist clinician cardiac evaluation.
- Seek advice from the initiating specialist when discontinuing medicines, including short-term discontinuations (i.e. drug holidays).

#### **8. Dose Management (by primary care)**

Seek initiating specialist advice.

Refer to current BNFC and SPC: [www.medicines.org.uk/emc](http://www.medicines.org.uk/emc)

#### **9. Significant medicine interactions – prescriber must consider interactions with any and all repeat medication the patient is taking at the time of initiation**

Refer to the current BNFC and SPC: [www.medicines.org.uk/emc](http://www.medicines.org.uk/emc)

#### **10. Adverse effect management**

*Specialist to detail action to be taken upon occurrence of a particular adverse event as appropriate. Most serious toxicity is seen with long-term use and may therefore present first to GPs.*

- If the patient has a sustained resting tachycardia (more than 120 beats per minute), arrhythmia or systolic blood pressure greater than the 95<sup>th</sup> percentile (or a clinical significant increase) measured on 2 occasions, contact the specialists for advice and guidance. A dose reduction and a referral to paediatric hypertension specialist may be required.
- For other severe adverse effects (e.g. new or worsening seizures, new emerging psychotic symptoms), it is recommended to stop the patients treatment and refer the patient back to the initiating specialist.
- For other mild/moderate adverse effects (e.g. dyspepsia) consider reducing the dose or stopping the medication and refer patient back to initiating specialist.
- Refer to current BNFC and SPC: [www.medicines.org.uk/emc](http://www.medicines.org.uk/emc)
- Report adverse drug reactions to [www.yellowcare.mhra.gov.uk](http://www.yellowcare.mhra.gov.uk)

#### **11. Advice to patients and carers**

*The specialist will counsel the patient with regard to the benefits and risks of treatment and will provide the patient with any relevant information and advice*

- Ask the initiating specialist or primary care clinician for information, if you do not have a clear understanding of the treatment.
- Attend review appointments with child and adolescent psychiatrist or paediatrician every 6-12 months or as advised, as continuing prescription may not be issued without regular

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review. Failure to attend review appointments could lead to termination of shared care agreement with GP.

- Attend review appointments at the primary care clinician (GP) practice for clinical monitoring as outlined in the original transfer of prescribing letter by the initiating specialist (e.g. blood pressure, pulse, height and weight).
- Arrange blood tests as per initiating specialist or primary care clinician request.
- Inform initiating specialist or primary care clinician of any medication being taken concomitantly (at the same time), including over-the-counter products.
- Take medicines as prescribed and agreed.
- Read the patient information leaflet included with your medication, be aware of side effects including palpitations, exertional chest pain, unexplained fainting, and shortness of breath, development of new or worsening of pre-existing psychiatric symptoms. Report any adverse effects, wanting symptoms or concerns to your primary care clinician or initiating specialist.
- Inform hospital and primary care clinician of any changes in address or telephone number/s
- Report any adverse effects to the primary care clinician or initiating specialist.

## 12. Pregnancy and breast feeding

*It is the responsibility of the specialist to provide advice on the need for contraception to male and female patients on initiation and at each review but the ongoing responsibility for providing this advice rests with both the GP and the specialist.*

Refer to the current BNFC and SPC: [www.medicines.org.uk/emc](http://www.medicines.org.uk/emc)

## 13. Specialist contact information

**This section has been redacted to maintain confidentiality.**

**Please contact your local medicines optimisation team for the full version.**

## 14. Additional information

Six-monthly reviews of symptom control and adverse effects are required for patients on licensed ADHD treatments. These reviews will be carried out every 6 months alternately by the initiating specialist clinician and by the primary care clinicians who have signed up to the community contract for ADHD treatment review (with the first review being undertaken by the initiating specialist clinician within 6 months of initiation and stabilisation of medication). This review is in addition to follow up appointments undertaken regularly by the specialist when treatment is being initiated and stabilised. See Appendix 2 for summary of monitoring requirements.

### Notes:

- Comprehensive treatment programme is defined to include psychological, education and social measures.
- Refer to the British National Formulary (BNF)<sup>3</sup>, BNF for Children (BNFC)<sup>4</sup> and individual drug's summary of product characteristics (<http://www.medicines.org.uk/emc/>) for further information.

Once prescribing is undertaken by the primary care clinician, some or all of the necessary clinical monitoring will take place in Primary Care. This is dependent on the facilities of the initiating specialist clinician clinic and the patients' geographical location. The Specialist will advise the primary care clinician on the clinical monitoring requirements (including test and frequency) that are required. The ADHD service will offer initiating specialist clinician advice and review any patient whose medication was started in the clinic at the request of the primary care clinician.

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If there is a need for initiating specialist clinician advice / interventions for patients who have an ADHD diagnosis / treatment, which was established elsewhere, a new referral to the service will be needed. primary care clinicians to refer to CAMHS if concerns with emotional health and well-being. Refer to initiating specialist clinician service if no concern with emotional health and well-being. If patient is currently on CAMHS caseload then initiating specialist clinician advice and intervention can be sought depending on patient's needs.

- **Risk of diversion**

- Healthcare professionals, parents and carers should monitor changes in the potential for stimulant misuse and diversion, which may come with changes in circumstances and age.

## 15. References

Acknowledgements: Adapted from shared care guidance written by North Central London joint formulary committee.

### References

1. NICE clinical knowledge summaries, May 2018. Attention deficit hyperactivity disorder. Available via <http://cks.nice.org.uk/attention-deficit-hyperactivity-disorder>
2. NICE guideline NG 87, September 2019. Attention deficit hyperactivity disorder: diagnosis and management. Available via <https://www.nice.org.uk/guidance/ng87>
3. British national formulary. Available via: [www.bnf.nice.org.uk](http://www.bnf.nice.org.uk)
4. British national formulary for children. Available via: [www.bnfc.nice.org.uk](http://www.bnfc.nice.org.uk)
5. Royal college of paediatrics and child health. Boys growth chart: [https://www.rcpch.ac.uk/sites/default/files/Boys\\_2-18\\_years\\_growth\\_chart.pdf](https://www.rcpch.ac.uk/sites/default/files/Boys_2-18_years_growth_chart.pdf)
6. Royal college of paediatrics and child health. Girls growth chart: [https://www.rcpch.ac.uk/sites/default/files/Girls\\_2-18\\_years\\_growth\\_chart.pdf](https://www.rcpch.ac.uk/sites/default/files/Girls_2-18_years_growth_chart.pdf)

## Appendix 2 – ADHD Monitoring Standards

Parameter	Frequency of monitoring	Monitoring responsibility	Action to be taken (by initiating specialist clinician or by prescribing primary care clinician)
<b>Efficacy</b>	At each appointment and when doses are changed.	Specialist / Prescribing primary care clinician.	Rating scales may be used.
<b>Non-specific side effects.</b>  <b>Concerns of substance misuse &amp; drug diversion.</b>	At each appointment.	Specialist / Prescribing primary care clinician / Monitoring primary care clinician.	Review and monitor for adverse effects, possible drug interactions, changes to medication regime, deteriorating behaviour.  Concerns about requests for unnecessarily frequent prescriptions should be communicated to ADHD initiating specialist clinician.
<b>Appetite, Weight &amp; height/ Growth development.</b>  Girls Growth Chart: <a href="https://www.rcpch.ac.uk/sites/default/files/Girls_2-18_years_growth_chart.pdf">https://www.rcpch.ac.uk/sites/default/files/Girls_2-18_years_growth_chart.pdf</a>  Boys Growth Chart: <a href="https://www.rcpch.ac.uk/sites/default/files/Boys_2-18_years_growth_chart.pdf">https://www.rcpch.ac.uk/sites/default/files/Boys_2-18_years_growth_chart.pdf</a>	At initiation of therapy, following each dose adjustment and at least every 6 months thereafter.	Specialist at initiation. Specialist & Monitoring primary care clinician alternately every 6 months.	Height and weight should be plotted on a growth chart, which should also be reviewed by the initiating specialist clinician team.  Failure to gain weight appropriately - may require dose reduction or withdrawal.  If growth is significantly affected by drug treatment, the option of a planned break in treatment over school holidays should be considered to allow 'catch-up' growth to occur.
<b>Pulse &amp; Blood Pressure</b> Further information on blood pressure monitoring and centile charts are available via <a href="https://www.nhlbi.nih.gov/files/docs/bp_child_pocket.pdf">https://www.nhlbi.nih.gov/files/docs/bp_child_pocket.pdf</a>	At initiation of therapy, following each dose adjustment and at least every 6 months thereafter.	Specialist at initiation. Specialist & Monitoring primary care clinician alternately every 6 months.	Plot on a centile chart if there is cause for concern. Monitor whilst taking medication to ensure within published range for age of child.  Seek initiating specialist clinician advice if drug treatment results in sustained resting tachycardia, arrhythmia, or systolic blood pressure greater than the 95th percentile (or a clinically significant increase) measured on two occasions or other significant adverse effects develop.
<b>Suicidal thinking and self-harming behavior.</b>	At initiation of therapy, following each dose adjustment and at least every 6 months thereafter.	Specialist / primary care clinician / parents or carers.	Parents and/or carers should be warned about the potential for suicidal thinking and self-harming behaviour.



<b>Full Blood Count.</b>	At initiation of therapy and only if clinically indicated (methylphenidate).	Specialist.	Low threshold for repeated investigation rather than schedule for routine testing e.g. if recurrent infections or purpuric rash occur, or if needed based on medical history.
<b>ECG &amp; thorough cardiac examination</b>	If there is past medical or family history of serious cardiac disease, a history of sudden death in young family members or abnormal findings on cardiac examination.	Specialist referral to paediatric cardiologist	Referral to initiating specialist.
<b>Liver function</b>	Duration of treatment (Atomoxetine)	Specialist/primary care clinician	Be vigilant for abdominal pain, unexplained nausea, malaise, darkening of the urine or jaundice. Routine testing of liver function not recommended.

**Appendix 3**  
**REQUEST TO SHARE CARE AND AGREEMENT FORM**

**Attention Deficit Hyperactivity Disorder (ADHD) – Children and Adolescents**

The expectation is that this information, along with the full shared care protocol, provides sufficient information to enable GP\* to be confident to take on clinical and legal responsibility for prescribing and monitoring. GP\* to review and must respond to provider trust request to share care within 2 weeks, using form provided.

*\*This may be any primary care prescribing clinician.*

<b>For completion by specialist (with shared care agreement form)</b>	
Patient name	
DOB	
NHS Number	
Patient height (cm)	
Centile	
Patient weight (kg)	
Centile	
Blood pressure	
Cardiac examination	
Pulse	
General health/medication conditions	
Cardiac history	
Risk drug abuse/diversion	
Baseline CGAS	
Drug (s) Dose, frequency, and route at handover	
Diagnosis (please indicate if unlicensed or "off-label")	
Date of first prescription by specialist	
Date of the next blood monitoring review date	
Estimated date for prescribing responsibility to be with GP* (at least 28 days after first prescribing)	
Special prescribing advice for this patient, to include any other medication patient is taking for same condition	
<b>KEY PRIMARY CARE INFORMATION (refer to full shared care guideline for full details)</b>	
GP* Responsibilities	

<b>MONITORING (as per Shared Care document unless stated below)</b>			
Frequency of GP* monitoring			
Frequency of specialist review			
TEST	NORMAL RANGE	Pre-Treatment Baseline Result (specialist responsibility)	Initiation of treatment Result (specialist responsibility)
<b>ACTION TO BE TAKEN IF ABNORMAL RESULT</b>			
TEST	RESULT	ACTION	

**Appendix 4**

**SHARED CARE AGREEMENT FORM**

**This form is used to agree shared care between specialist, patient and GP\*.**

**Specialist and patient agreement**

By signing below we accept:

- The Kent and Medway CCG shared care principles
- The requirements and responsibility defined in this drug specific shared care protocol
- To provide medication for the transition period (at least 28 days)

Specialist name:	Patient name:
Designation:	DOB:
Provider Trust:	NHS number:
Direct telephone number:	
Email:	
Specialist signature:	Patient signature:
Date:	Date:

**GP\* response to shared care request**

Please return to specialist within **2 weeks** of receipt of request to share.  
 This form is to be completed by the GP\* who is requested to share care.

I agree to accept shared care as set out in this shared care protocol and KMCCG shared care principles.

I have not received adequate support to take over prescribing therefore I do not accept shared care for this patient.

**My reasons for not accepting are:**

Please note that GP agreement is voluntary, with the right to decline to share care if for any reason you do not feel confident in accepting clinical responsibility.

GP* name	
Designation	
Direct telephone number	
Email	
Practice address	
GP* signature	
Date	

**Specialist to retain a copy in the patients' hospital notes**

**Copy to be given to patient**

**GP\* to retain a copy in primary care notes.**

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