

SHARED CARE PROTOCOL FOR THE PRESCRIBING AND MONITORING OF MEDICINES FOR ATTENTION-DEFICIT HYPERACTIVITY DISORDER (ADHD)

1. Introduction

This protocol describes how patients prescribed medicines for ADHD can be managed safely in primary care, secondary care and across the interface. It sets out responsibilities for each party, to ensure that these medicines are initiated, prescribed, dispensed and monitored appropriately, and according to the BNF and NICE guidelines.

This document is mainly concerned with those patients who are initiated on ADHD medicines within EPUT, and in particular, child and adolescent mental health services. However once the patient is managed in the community, their secondary care treatment might come from a non-EPUT provider of child and adolescent mental health services. All parties involved should therefore be aware that such non-EPUT providers of CAMHS in Essex, e.g. NELFT <https://www.nelft.nhs.uk/> , have their own protocols, therefore this protocol should be read alongside the formulary and shared care protocol published by those providers, as their agreements and arrangements may be different.

Background

Medicines are not indicated in all patients with ADHD and the decision to use medicines is based on the consultant’s evaluation of the patient’s history, and the duration and severity of symptoms.

A comprehensive treatment programme typically includes psychological, educational and social measures to stabilise patients with a behavioural syndrome.

This protocol fulfils the recommendations from NHS England¹ and NICE² Guideline NG87 to “*establish a shared care protocol*” with the patient’s GP for the prescribing and monitoring of medicines for ADHD.

All prescribers should be familiar with the requirements of controlled drug legislation governing the prescription and supply of stimulants.

2. Responsibilities

Secondary Care Prescriber Responsibilities

1. Contact the GP if the patient is referred for assessment by an alternative route other than GP referral.

2. Assess the patient, determine and document a diagnosis. If medicines for ADHD are to be prescribed they should only be initiated by a healthcare professional with training and expertise in diagnosing and managing ADHD.
3. If medicines are appropriate, before starting medicines for ADHD, complete and document a full pre-treatment baseline assessment, using the checklists in paragraph 6.3 in section 6 of the EPUT Formulary and Prescribing guideline, covering diagnostic criteria/ social/ neurodevelopmental/ educational/ employment/ substance misuse/ care needs, and a baseline physical health review. The physical health parameters to be reviewed at baseline are shown in Table 1 below.
4. Discuss information about ADHD, the anticipated benefits, harms and side effects of medicines, and the monitoring programme for ADHD, with patient and parents/carers. Provide patient information booklets/ leaflets relating to the prescribed medicines. Document these actions, and the patient's preferences and concerns.
5. Advise patient / parents/ carers that the treatment programme will be discontinued by the secondary care prescriber if the monitoring programme is not adhered to. Inform the GP in writing if appointments are not kept, speak to parents/carers if patient is not an adult, and send patient a letter asking them to make another appointment as soon as possible. Encourage parents and carers to oversee ADHD medication for children and young people.
6. Explain what this SCP arrangement means for the patient and why it might be an option in their case. The patient / parents/ carers should have the opportunity to ask questions and explore other options if they don't feel confident that shared care will work for them. They should be fully involved in, and in agreement with, the decision to move to a shared care model for their ongoing care. The patient/ parents/ carers will not be used as a conduit for informing the GP that prescribing is to be transferred.
7. Obtain the patient's/parent's/carer's agreement to be involved in a shared care model. As part of the consent process, patients/parents/carers must be made fully aware of all monitoring requirements, in line with national guidance on consent. Document the patient's/parent's/carer's agreement.
8. Prescribe the medicine for ADHD and monitor until the initial titration is complete (usually a 3 - 6 month trial of treatment, including regular reviews until a stable dose level is reached).
9. For children and young people:
Offer medicine according to the recommendations in the section 6 of the EPUT Formulary and Prescribing guideline, i.e. methylphenidate / lisdexamfetamine / dexamfetamine / atomoxetine or guanfacine.
NOTE: Not all are licensed for all ages and indications.
10. For adults:
Offer medicine according to the recommendations in the section 6 of the EPUT Formulary and Prescribing guideline, i.e. lisdexamfetamine or methylphenidate / dexamfetamine / atomoxetine
NOTE: Not all are licensed for all ages and indications.
11. Review risk of drug interactions between patient's current medicines and the ADHD medicines.

12. Evaluate adverse events noted by the GP or the patient/ carer. Report severe side effects to MHRA.
13. Review patient's physical parameters and behaviour (height/ weight/ cardiovascular/ tics/ sexual dysfunction/ seizures/ sleep/ worsening behaviour) as described in paragraph 6.9 of section 6 of the EPUT Formulary and Prescribing guideline. Monitor heart rate and blood pressure at a dose change and 6 monthly.
14. GPs should only be asked to prescribe drugs which are used in accordance with their product licence. Section 6 of the EPUT Formulary and Prescribing guideline states which medicines are currently unlicensed. For reference this is shown in Annex 2.
15. Continue to prescribe the ADHD medicines until a final therapeutic dose is established, and benefit from treatment is established (usually after a 3 - 6 month trial of treatment). Parents/ teachers should be advised to record ADHD symptoms, and adverse effects of medicines at baseline, and at each dose change, on standard scales, and progress reviewed regularly (e.g. by weekly telephone contact) with the specialist.
16. Obtain a second opinion or refer to a tertiary service if ADHD symptoms in a child aged 5 years or over, a young person or adult are unresponsive to one or more stimulants and one non-stimulant. Do not offer any of the following medication for ADHD without advice from a tertiary ADHD service:
 - guanfacine for adults
 - clonidine for children with ADHD and sleep disturbance, rages or tics
 - atypical antipsychotics in addition to stimulants for people with ADHD and coexisting pervasive aggression, rages or irritability
 - medication not included in recommendations in paragraphs 6.4 (children aged 5 years and over and young people) and 6.5 (adults) of Section 6 of the EPUT Formulary and Prescribing guideline.
17. Inform the child's school when the child is on any medicine, and whether it involves a lunchtime dose or not. Consider modified-release once-daily preparations for patient convenience and adherence, and to avoid the need to take doses at school.
18. At an appropriate point ask the GP to participate in a shared care agreement, using letter in Appendix 1, and document this. Seek agreement for prescribing, and seek agreement for who will undertake monitoring, including physical health. If the ADHD treatment is initiated for children/young people, liaise with the appropriate service on discharge, if this is not EPUT.
19. If the GP chooses not to participate in a shared care agreement it is the responsibility of the secondary care prescriber to continue prescribing and monitoring. Document the arrangement.
20. If the GP agrees to participate in a shared care agreement, document this. When a final therapeutic dose is established, and benefit from treatment is established (in the opinion of the secondary care prescriber, usually after a 3 - 6 month trial of treatment), send a completed Appendix 2 to GP, requesting that they start the shared care prescribing of the ADHD medicine. The secondary care prescriber will supply one month of ADHD medicine to cover the transition period. The patient should then be informed to obtain further prescriptions from the GP.

21. When completing Appendix 2 include the following:
- Full details of diagnosis, ADHD medicine brand, formulation, dose, recent physical examination results, and next due dates.
 - Communicate what has been agreed as to which party will undertake routine monitoring.
 - Include details of the circumstances under which the patient should be referred to the secondary care prescriber.
 - Request GP to observe for side-effects.
22. Assess the patient's continuing response to treatment after the trial. This will usually be done at 3 - 6 monthly intervals, depending on the specific circumstances of the patient. For patients who take methylphenidate for more than one year, the secondary care prescriber should interrupt treatment at least once a year to determine whether continued treatment with methylphenidate is necessary.
- Review patient's physical parameters and behaviour (height/ weight/ cardiovascular/ tics/ sexual dysfunction/ seizures/ sleep/ worsening behaviour) as described in paragraph 6.9 of section 6 of the EPUT Formulary and Prescribing guideline.
23. If the patient is admitted/ readmitted to an EPUT hospital, undertake any routine monitoring due according to the information provided by the GP.
24. Fully communicate in writing to the GP all results of monitoring carried out.
25. Promptly review patient if necessary, at the request of the GP, when there are unmanageable side effects or deterioration in mental state. Inform GP of any changes through formal correspondence within 2 weeks and supply necessary prescription for 2 week duration if dose changed. Information may need to be shared by secure email or telephone if doses have been changed so necessary adjustments can be made to GP records.
26. Telephone details and secure email addresses of both parties (secondary care prescriber and GP) should be exchanged and recorded. This will enable the practice to access timely advice, guidance and information if problems arise, and also enable secondary care clinicians to easily contact the GP if necessary. This should include out-of-hours contact numbers, e.g. how to access the on-call duty doctor. Patients and their carers should also be provided with contact details for support and help if required; both in and out of hours.
27. A healthcare professional in secondary care (e.g. medical prescriber or non-medical prescriber) with training and expertise in managing ADHD should review ADHD medicines at least once a year, and discuss with the person with ADHD (and their families and carers as appropriate) whether the medicines should be continued. The assessment will be comprehensive as described in paragraph 6.11 of Section 6 of the EPUT Formulary and Prescribing guideline.
28. The secondary care prescriber will encourage people with ADHD to discuss any preferences to stop or change medication and to be involved in any decisions about stopping treatments.
29. The secondary care prescriber will consider trial periods of stopping

medication or reducing the dose when assessment of the overall balance of benefits and harms suggests this may be appropriate. If the decision is made to continue medication, the reasons for this should be documented.

30. The secondary care prescriber will retain responsibility for monitoring drug therapy and making dosage adjustments. The GP will be informed of any dose changes as soon as possible to avoid an incorrect dose being prescribed.

31. Transition of child/ adolescent into adulthood.

The CAMHS secondary care prescriber will inform, in writing:

- Adult Psychiatric services of the details and history of the patient (presentation, progress, compliance with medication, etc.) who is approaching their 18th birthday and who has been identified as someone who will require on-going support with ADHD.
- Adult Psychiatric services of the need for on-going ADHD medicines.
- the GP regarding any decision to stop or alter the treatment plan prior to transition to adult services.

Should on-going prescription of psychostimulants be considered necessary, the patient will be advised of the need for safe storage to prevent diversion and potential abuse.

The Adult Psychiatric Outpatient clinic will accept patients who are approaching their 18th birthday and require on-going support and medication to manage their ADHD. They will review the patient regularly (at least annually) and liaise with the GP should treatment be varied or discontinued.

Should medication no longer be considered necessary – it will, upon the advice of the clinic, be discontinued slowly and the patient's on-going needs assessed by the adult CMHT.

General Practitioner Responsibilities

If further information is required contact 0300 1230808 (EPUT contact centre).

1. Reply to the request for shared care within two weeks of the GP receiving the request, with agreement or non-agreement.
2. If not in agreement, document in the primary care record that this patient is not in a shared care arrangement for medicines for ADHD. GP should write to secondary care prescriber and patient with reasons, explaining to the patient further supplies will be from the secondary care prescriber.
3. If in agreement the GP will confirm the agreement and acceptance of the shared care prescribing and monitoring arrangement. On receipt of a comprehensive referral letter from the secondary care prescriber (Appendix 2), take over the routine prescribing of ADHD medicines once a final therapeutic dose is established, and benefit from treatment is established (in the opinion of the secondary care prescriber, usually after a 3 - 6 month trial of treatment),
4. Ensure the brand, formulation, dose, frequency, timing of ADHD medicines prescribed is the same as that communicated by the secondary care prescriber. If a brand switch is made at the decision of the GP prescribing, it is the

responsibility of the GP to check that the new brand is bioequivalent.

5. Prescribe using specific instructions. Avoid using prescribing instructions such as 'as directed'.
6. Adjust the dose of medicines following instructions from the secondary care prescriber.

Notify the secondary care prescriber of the patient's failure to attend appointments.

7. Inform the secondary care prescriber of any physical illness/ medicine that may affect the patient's treatment with ADHD medicines.
8. Observe the overall health and wellbeing of the patient, including side effects of ADHD medicines. Monitor heart rate and blood pressure at a dose change and 6 monthly. Report any concerns about side-effects/ weight/ cardiovascular health/ tics/ sexual dysfunction/ seizures/ sleep/ worsening behaviour to the secondary care prescriber. Report severe side effects to MHRA.

Provide appropriate ongoing verbal and written information to patient.

9. Act on instructions from the secondary care prescriber if informed that patient does not attend clinic appointments, as the treatment programme will be discontinued by the secondary care prescriber if the monitoring programme is not adhered to.

Inform the psychiatrist if there is suspicion of abuse of controlled drugs.

Liaise with the secondary care prescriber if there are issues of non-attendance with appointments, or non-concordance with treatment.

10. Act on any recommendations from the healthcare professional (in secondary care) with training and expertise in managing ADHD who has reviewed the patient's ADHD medicines at least once a year and discussed with the person with ADHD (and their families and carers as appropriate) whether ADHD medicines should be continued.
11. Telephone details and (if appropriate) secure email addresses of both parties (secondary care prescriber and GP) should be exchanged and recorded. This will enable the practice to access timely advice, guidance and information if problems arise, and also enable secondary care clinicians to easily contact the GP if necessary. This should include out-of-hours contact numbers, e.g. how to access the on-call duty doctor. Patients and their carers should also be provided with contact details for support and help if required; both in and out of hours.

Patient/ Carer Responsibilities

- Ensure that they have a clear understanding of their treatment.
- Take/ administer medicines as prescribed.
- Attend all appointments for review of ADHD.
- Report any adverse effects to their GP and/or secondary care prescriber.
- Report any changes in disease symptoms to GP and/or secondary care prescriber.
- Alert GP and/or secondary care prescriber of any changes of circumstance which could affect management of disease e.g. plans for pregnancy.

- Undertake any monitoring as requested by the GP and/or secondary care prescriber.
- Inform their GP in sufficient time to obtain repeat prescriptions.

3. Prescribing information

Indications and licensing

Refer to Summary of Product Characteristics SPC for each drug, available at www.medicines.org.uk

Administration

As per BNF and SPC.

Brand Prescribing

ADHD medicines should be prescribed by brand name due to the wide variety of medicines available for each drug. Brands are not always interchangeable. Consult product literature when switching from immediate-release preparations to modified-release preparations.

Monitoring Standards

If medicines are appropriate, before starting medicines for ADHD, complete and document a full pre-treatment baseline assessment, using the checklists in paragraph 6.3 in section 6 of the EPUT Formulary and Prescribing guideline, covering diagnostic criteria/ social/ neurodevelopmental/ educational/ employment/ substance misuse/ care needs, and a baseline physical health review. The physical health parameters to be reviewed at baseline are shown in Table 1 below.

Table 1 – Baseline review of physical health, before starting medicines for ADHD.

Baseline
Medical history
Current medicines
Height. Compare with normal range for age/ sex.
Weight. Compare with normal range for age/ sex.
Pulse and BP. Compare with normal range for age. Refer to a paediatric hypertension specialist before starting medicines for ADHD if blood pressure is consistently above the 95th centile for age and height for children and young people.
Cardiovascular assessment
ECG, if the treatment may affect the QT interval

If any of the following apply, refer for a cardiology opinion before starting medicines for ADHD:

- history of congenital heart disease or previous cardiac surgery
- history of sudden death in a first-degree relative under 40 years suggesting a cardiac disease
- shortness of breath on exertion compared with peers
- fainting on exertion or in response to fright or noise
- palpitations that are rapid, regular and start and stop suddenly (fleeting occasional bumps are usually ectopic and do not need investigation)
- chest pain suggesting cardiac origin
- signs of heart failure
- a murmur heard on cardiac examination
- blood pressure that is classified as hypertensive for adults (see NICE's guideline on hypertension in adults)

Monitoring

Height:

- Children and young people – every 6 months

Weight:

- Children ≤ 10 years old – every 3 months
- Children > 10 years old and young people – at 3 months and 6 months at the start of treatment then 6 months thereafter.
- Adults – every 6 months

Plot height and weight of children and young people on a growth chart and ensure review by the secondary care prescriber.

Consider monitoring BMI of adults with ADHD if there has been weight change as a result of their treatment, and changing the medication if weight change persists.

Cardiovascular

Heart rate and Blood pressure, at a dose change, and every 6 months.

- If patient has sustained resting tachycardia (more than 120 beats per minute), arrhythmia or systolic blood pressure greater than the 95th percentile (or a clinically significant increase) measured on 2 occasions, reduce their dose and refer them to a paediatric hypertension specialist or adult physician.
- If taking guanfacine has sustained orthostatic hypotension or fainting episodes, reduce their dose or switch to another ADHD medication.

Blood Pressure

Tables for Children and Young People⁴: See Annex 1.

Dosage and Administration/ Precautions and Warnings/ Contra-indications/ Interactions/ Side effects

- Refer to BNF and SPC.

References

1. Responsibility for prescribing between Primary & Secondary/Tertiary Care. NHS England. January 2018. <https://www.england.nhs.uk/wp-content/uploads/2018/03/responsibility-prescribing-between-primary-secondary-care-v2.pdf>
2. NICE NG87, published March 2018. Attention Deficit Hyperactivity Disorder: Diagnosis and management <https://www.nice.org.uk/guidance/ng87> (September 2018).
3. BNF on-line edition, accessed 28/9/2018.
4. Reference: Standards for Assessing, Measuring and Monitoring Vital Signs in Infants, Children and Young People. Royal College of Nursing. May 2017. Accessed 27/11/2018. <https://www.rcn.org.uk/-/media/royal-college-of-nursing/documents/publications/2017/may/pub-005942.pdf>

Normal ranges for children and young people: respiratory rate (RR), heart rate (HR) and blood pressure (BP) ⁴.

Age	Guide weight (kg)		RR At rest Breaths per minute 5th-95th centile	HR Beats per minute 5th-95th centile	BP Systolic		
	Boys	Girls			5th centile	50th centile	95th centile
Birth	3.5	3.5	25-50	120-170	65-75	80-90	105
1 month	4.5	4.5					
3 months	6.5	6	25-45	115-160	70-75	85-95	
6 months	8	7	20-40	110-160			
12 months	9.5	9					
18 months	11	10	20-35	100-155			
2 years	12	12	20-30	100-150	70-80	85-100	110
3 years	14	14		90-140			
4 years	16	16		80-135			
5 years	18	18			80-90	90-110	111-120
6 years	21	20		80-130			
7 years	23	22					
8 years	25	25	15-25	70-120			
9 years	28	28					
10 years	31	32					
11 years	35	35					
12 years	43	43	12-24	65-115	90-105	100-120	125-140
14 years	50	50		60-110			
Adult	70	70					

Note on prescribing unlicensed medicines. Taken from EPUT Formulary and Prescribing Guideline, Section 6 ADHD.

At the time of publication of NICE CG87 (March 2018), medicines used for the treatment of ADHD did not have a UK marketing authorisation for use in all indications. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

The recommendations update NICE's technology appraisal guidance on methylphenidate, atomoxetine and dexamfetamine for ADHD in children and adolescents (TA98).

At the time of publication (March 2018), medicines used for the treatment of ADHD did not have a UK marketing authorisation for use in children aged 5 years and under for this indication.

Offer methylphenidate (either short or long acting) as the first line pharmacological treatment for children aged 5 years and over and young people with ADHD.

At the time of publication (March 2018), methylphenidate did not have a UK marketing authorisation for this indication in children aged 5 years or under.

Consider switching to lisdexamfetamine for children aged 5 years and over and young people who have had a 6 week trial of methylphenidate at an adequate dose and not derived enough benefit in terms of reduced ADHD symptoms and associated impairment.

At the time of publication (March 2018), lisdexamfetamine did not have a UK marketing authorisation for this indication in children aged 5 years.

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.

At the time of publication (March 2018), dexamfetamine was only licensed for the treatment of ADHD in children and adolescents aged 6 to 17 years when response to previous methylphenidate treatment is considered clinically inadequate. Dexamfetamine is not licensed for the treatment of ADHD in children and adolescents aged 5 to 17 years who have responded to, but are intolerant to lisdexamfetamine.

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.

At the time of publication (March 2018), atomoxetine or guanfacine did not have a UK marketing authorisation for this indication in children aged 5 years.

APPENDIX 1 - INITIAL LETTER

[Address]

[Date]

Dear Dr [Name]

Re: Shared Care Protocol for ADHD medicines

Patient: [Name, address, NHS No.]

I have seen this patient in clinic and believe that [he / she] is suitable for treatment with medicines for ADHD.

I have initiated this patient on [ADHD medicine, brand name, form, dose, frequency, timing] and will be monitoring and prescribing for this patient at our clinics until such time that the patient is deemed stable, which is likely to be in the region of [No.] months.

I would like to seek your agreement for you to take over the prescribing of this patient's treatment after this stabilisation period as per agreed Shared Care Protocol for ADHD medicines. A copy of this protocol can be found at <https://eput.nhs.uk/our-services/pharmacy/formulary-prescribing-guidelines-mental-health/> and is also enclosed.

PAPER COPY OF THE PROTOCOL TO BE PRINTED AS ENCLOSURE.

Please complete the form below and scan and email it from a secure nhs.net account to our secure nhs.net account below.

I thank you in anticipation.

Yours sincerely

[Name]

[Job title]

Scan and email to: [EPUT prescriber secure nhs.net email address]

nhs.net email to: [Clinical Commissioning Group secure nhs.net email address]

*[*Delete as applicable]:*

Agreement to undertake prescribing

*I agree to take over the prescribing responsibility for this patient as per Shared Care Protocol for ADHD medicines from such date as the patient is deemed stable.

Or

*I am not willing to undertake Shared care for this patient because [reason].

[Patient name], [NHS No]

Yours sincerely,

[Dr], [Date], [Practice address]

APPENDIX 2 - SECOND LETTER TO START SHARED CARE

[Address], [Date]

Dear Dr [Name]

Re: Shared Care Protocol for ADHD medicines
Patient: [Name, address, NHS No.]

DIAGNOSIS:

Thank you for agreeing to Shared care for the above named patient as per my initial letter dated [date].

I have been monitoring and prescribing for this patient for [no.] months and the patient is deemed stable as per agreed **Shared Care Protocol for ADHD medicines.**

The dose has been stable for months, and benefit from treatment has been established.

The patient is currently prescribed:

ADHD DRUG NAME:.....

BRAND:.....

FORMULATION:.....

DOSE:.....

FREQUENCY:.....

TIMING:.....

DATE ADHD MEDICINE STARTED:..

Recent monitoring

Parameter	Baseline	Date	Recent	Date
Height. Compare with normal range for age/ sex.				
Weight. Compare with normal range for age/ sex.				
Pulse and BP. Compare with normal range for age. Refer to a paediatric hypertension specialist before starting medicines for ADHD if blood pressure is consistently above the 95th centile for age and height for children and young people.				
Cardiovascular assessment				
ECG, if the treatment may affect the QT interval				

Monitoring

We have agreed the following:

Secondary care prescriber to review patient's physical parameters and behaviour (height/ weight/ cardiovascular/ tics/ sexual dysfunction/ seizures/ sleep/ worsening behaviour) as described in paragraph 6.9 of section 6 of the EPUT Formulary and Prescribing guideline. Monitor heart rate and blood pressure at a dose change and 6 monthly. Retain responsibility for monitoring drug therapy (including physical health parameters) and making dosage adjustments.

GP to observe the overall health and wellbeing of the patient, including side effects of ADHD medicines. Monitor heart rate and blood pressure at a dose change and 6 monthly. Report any concerns about side-effects/ weight/ cardiovascular health/ tics/ sexual dysfunction/ seizures/ sleep/ worsening behaviour to the secondary care prescriber.

Referral back to secondary care

The patient should be referred to the secondary care prescriber if the patient experiences unmanageable side effects or deterioration in mental state.

Prescribing

If you are in agreement please would you start prescribing for this patient within the parameters of the Shared Care Protocol for ADHD medicines. Please observe for side-effects. I have prescribed for this patient for a further month. I will send a clinic letter so the GP practice will be in receipt of the clinic letter within ONE week of the prescription being issued.

Review

An annual review of this ADHD medicine will be undertaken by:
..... (healthcare professional with training and expertise in managing ADHD), and will discuss with the patient (and their families and carers as appropriate) whether the medicines should be continued.

Yours sincerely

[Name], [Job title], [Contact number], [Care coordinator & contact no.]
[Community team & contact no.]