

Children, Families & All Age Services (CFAA)

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Dear Parent/Carer

Your child is currently prescribed ADHD medication with medication reviews being provided by our service. We are contacting you due to the significant ADHD medication shortages and we understand this will be a worrying time. Unfortunately neither your child's GP nor your child's ADHD clinician can do anything to help with supply issues but we want to provide you with as much information as we can to try to help you during this time.

What is happening with ADHD medication shortages?

We have been alerted by NHS England to a significant shortage in a range of ADHD medication which affects different types, brands and strengths. You may already have experienced difficulty in obtaining medication and this is likely to become more difficult. At present the supply issues are expected to resolve at various dates over the coming months (depending on the type and strength of medication). The shortages include:

Methylphenidate:

Equasym XL 10, 20 and 30 mg capsules Xaggitin XL 18 and 36 mg prolonged-release tablets Concerta XL 54 mg prolonged-release tablets Xenidate XL 27 mg prolonged-release tablets

Lisdexamfetamine:

Elvanse 20, 30, 40, 50, 60 and 70 mg capsules

Guanfacine:

Intuniv 1, 2, 3 and 4 mg prolonged-release table

Atomoxetine:

There has been an ongoing shortage of all capsule strengths (particularly 40mg and 60mg) and also the liquid.

We expect these supply issues to affect most children and young people taking ADHD medication and to cause disruption to treatment. This will mean that:

- treatment is likely to be temporarily paused for many until the medications are back in stock
- some children and young people may have to take lower doses of their medication or may not be able to take it every day
- the national guidance is also not to start anyone on new ADHD treatment during this time

The shortages are caused by a combination of manufacturing issues and increased global demand and suppliers are working hard to resolve the issue.

We recommend that where possible your GP writes prescriptions for different strengths to make up a total daily dose. In some instances your GP may need to change the *brand* of medication (ie the same *type* of medication but made by a different manufacturer). We are working closely with GP practices to keep them informed of the situation, and also to advise on restarting medication once it becomes available again.

Is it safe to pause or stop ADHD medication?

Please be assured that there are no health risks if your child has an unplanned break in taking their ADHD medication **unless they are taking Guanfacine/Intuniv** (see below)

We understand that this may be difficult for your child but would like to reassure you that a temporary pause in taking ADHD medication won't cause them any physical harm. With <u>most</u> ADHD medication, your child can stop taking them, or take them on certain days and not others, without any ill effects. However there are some exceptions to this and advice is provided below for different types of medication

- *Guanfacine/Intuniv:* If your child is taking this medication it is very important to reduce slowly before stopping and this must be done under the guidance of your ADHD clinician. Please contact your child's clinician as soon as possible if you have not yet heard from them. If you do not have the number, email CAMHS.ADHD@berkshire.nhs.uk or call 0118 904 6401.You only need to call us if your child is taking Guanfacine/Intuniv. The CYP ADHD service cannot help with accessing medication.
- *Stimulant medication:* Stopping stimulant medication i.e. Equasym XL, Concerta XL, Xenidate XL, Xaggatin XL, Elvanse, will not cause any harm to your child. They can stop taking this or use it only on certain days without ill effects. Whilst supplies are limited, we recommend that your child takes their medication on school days, but not on weekends/half terms/holidays. You may also want to plan well in advance so that your child has some medication for any significant events such as mock exams.
- **Atomoxetine**: stopping this will not cause any harm to your child and they can stop taking this without ill effects. We find that taking atomoxetine some days and not others may not work well. It is usually best to either stop completely or to continue taking some every day.

What happens if my child has to pause or stop taking their ADHD medication?

Although stopping treatment is safe, if your child has to pause or reduce their ADHD medication, then their ADHD will of course have more impact on them at school and at home. The Berkshire ADHD Team will be contacting all schools to explain the need for additional understanding and support during this time as well as providing information on resources.

In most cases we don't recommend switching to another type of medication if your child's medication runs out. This is because:

- It may not be the best medication for your child.
- The time it would take to get the dose right for your child.
- We anticipate shortages will be resolved before your child gains the benefit from any new medication.
- Your child would then need to change back to the original medication once it becomes available.

What can I do to help my child?

- We recommend requesting prescriptions with as much notice as possible and ringing round pharmacies to check what they have available as supply of medications can vary from pharmacy to pharmacy. You may have more luck with smaller, independent pharmacies.
- You can use the Boots prescription stock checker online <u>www.boots.com/online/psc/</u> to look at stocks at nearby Boots stores. Please be aware that supplies are not guaranteed, or reserved, and will generally be very low currently. It's best to telephone in advance if possible, to avoid a wasted journey. Remember to take photo ID with you if you are going to a new pharmacy (this is needed due to ADHD medication being a controlled drug).
- Consider whether your child can manage a trial off medication this may be an option, particularly as this is recommended for some treatments. If your child has a break in taking their medication, keep in touch with school and make sure they are aware of this and are looking at how they can support.
- Keep in touch with school and make sure they are aware of any unplanned changes or pauses in ADHD medication and the impact of this on your child so they are aware and can look at the support they can provide in school (we will also be writing to all schools as well).

Some strategies that may help your child

- 1. Frequent movement break: Movement can help the brain to focus and reset. It may help to provide extra fidget toys or schedule extra breaks throughout the day.
- 2. Schedule time for calming activities: ADHD can make it tricky to switch off. Schedule time into the day for calming activities like art, going for a walk, playing football, etc
- 3. Try to stick to a routine: This can be hard for children and young people with ADHD, but it helps the brain to know what's happening. This includes getting enough sleep.

ADHD can make it harder to regulate emotions, so encourage your child to talk if they are struggling.

Where can I access support?

If you are not already a member, we invite you to join our online support network (SHaRON) where you can connect with other parents and with the Neurodiversity Service. If you would like to join please email your name, your child's name, and your contact details to: sharon.jupiter@berkshire.nhs.uk

You can access support from the NHS commissioned ADHD support services:

- **East Berkshire** (if your GP is in Bracknell, Slough Windsor or Maidenhead <u>https://www.gems4health.com</u>
- West Berkshire (if your GP is in Newbury, Reading or Wokingham)
- https://www.autismberkshire.org.uk/berkshire-west-autism-adhd-support-service/

See also ADHD Service - PSC (parentingspecialchildren.co.uk)

Here are some suggestions for other resources that might help:

Understanding and supporting my child's ADHD

www.adhdfoundation.org.uk/wp-content/uploads/2022/05/ADHD_FOUND_Takeda_ParentBooklet_May22_2.pdf

A teenager's guide to ADHD

www.adhdfoundation.org.uk/wp-content/uploads/2023/07/ADHD_Found_Takeda_TeenagerBooklet_July2023_STANDARD.pdf

ADHD for children

www.adhdfoundation.org.uk/wp-content/uploads/2022/05/ADHD FOUND Takeda KidsBooklet May22 2.pdf

What if I have urgent mental health concerns about my child?

For **urgent mental health concerns** please visit the Berkshire Healthcare website for advice or call 0300 365 1234, **8am-8pm Monday-Friday** (calls charged at local rate). Outside of these hours, call freephone **0800 129 9999** <u>https://cypf.berkshirehealthcare.nhs.uk/contact-us/i-need-urgent-help-now/</u>

Please note this is for urgent mental health concerns only and will not be able to advise on accessing ADHD medication.

Yours sincerely

Michelle Walton Team Lead On behalf of the ADHD Team

ENCLOSED:

- ✓ Information on ADHD medication shortages for children and young people
- ✓ Getting Help Now: ADHD
- ✓ Letter for school (we will send this to all SENCOs but you can also take this in)