

August 2023.

Feedback from Parent Carers.

How the Prescription service works at Alder Hey Children's NHS Foundation Trust.

Introduction

We are the health and social care champion for people and communities across Sefton. We have the power to make sure leaders and other decision makers listen to feedback and improve standards of care. We also help people find reliable and trustworthy information and advice and have an independent Complaints Advocacy Service which supports residents who want to make a complaint about an NHS service.

What are our core beliefs?

- We believe that health and social care providers can best improve services by listening to people's experiences.
- We believe that everyone in society needs to be included in the conversation, especially those whose voices aren't being listened to.
- We believe that comparing lots of different experiences helps us to identify patterns and learn what is and isn't working.
- We believe that feedback has to lead to change, listening for listening's sake is not enough.

Feedback

We have been working with Sefton Parent Carers Forum, an active member of our steering group to gain feedback on how accessing prescriptions from Alder Hey Children's NHS Foundation Trust works. Problems with the service was an emerging theme. This report details the feedback which the forum helped us to gather and we would like the trust to review this feedback and provide us with a formal response to ensure that those accessing the prescription service in the future have a better experience.



Repeat prescription requests

"Ordered 2 weeks before we ran out, no prescription 3 weeks later. Called on telephone, no answer, left message no call back. Rang PALS. PALS team said the prescription team would send emergency prescription but one week later still nothing. When the prescription arrived, it was wrong."

"Put in a request 3 weeks ago and heard nothing."

"Why do they only issue 3 months at a time. Kids aren't having medication reviews for years at a time, so just issue 6 months worth and reduce the number of times we have to go through this!"

"Not allowed to order more than 2 weeks before we run out but the prescription is issued after 2 weeks and then we need to allow time for the courier to get it to Southport and then the chemist to order the drugs in. When we ring to complain, we are told "it's only ADHD they don't need it."

"Ordered prescription, nothing arrived. Chased up and told needed height, weight and blood pressure first. If they'd have just told me I would have arranged that 3 weeks ago!"

"Had text to say prescription would be 2 days but still waiting 3 weeks later!"

"It will be 4 weeks tomorrow since I ordered, still no prescription."



"Problem with local chemist getting 2 mg tablets when my child needs 4 mg. Prescription needs to be changed but cannot get anyone at Alder Hey to do this."

" Doctor said prescriptions only get couriered out on Monday, Wednesdays and Fridays."

"Been a nightmare, no meds for a week."

"After speaking to secretary ,turns out prescription has been stopped late last year but no reason in clinical notes and now need phone call with Pead to reinstate!"

"Put prescription on hold because I ordered 3 weeks early but didn't tell me and then they forgot, so no meds."

"Often get text to say prescription dispatched but 6 days later chemist doesn't have it ."

"Had to ask GP to issue emergency 1 week script so we didn't run out!"

"Saw the community Paed who increased dose to 2-3 tablets per night. Every time I ordered they wouldn't dispatch as said wasn't due but pharmacy hadn't been told of increase in dosage so still had use as 1 per night."

"Respite won't let my kid attend without her sleep meds so I have to keep some back."



"Had argument with local pharmacist as prescription advised Circadin to be crushed and pharmacist says it shouldn't be but they can't get hold of Alder Hey!"

"Anxiety meds for kids need to be prescribed through CAMHS not GP, but there is a 18 month waiting list to be seen."

"That melatonin service from Alder Hey – WTF?"

"Prescription lost between Alder Hey and local chemist."

"Used to order early to allow for delays but now get message back saying too early."

"Only had the system work properly twice in 18 months."

"It's an absolute joke how long we have to wait!"

"Service is an absolute joke!"

"Much smoother to order online."

"Service states no request received but we have an acknowledgement email."



Transition to Adult services and problems with prescriptions.

"Alder Hey told me my son is now under adult services and I was told meds will be prescribed through GP as shared care agreement. Spoke to my GP who said they can't prescribe Circadin or Melatonin."

"Intuniv is a hospital script only medication so can't get from GP now child is 18."

Ordering medication from other organisations/ borrowing from other parents.

"Chemist can't get Melatonin so I'm using stuff from the States!"

"You can buy liquid melatonin and gummies online as my son won't swallow the tablets."

"Issues with private diagnosis not being accepted so we are paying private clinic for private meds at £98 per month."

"I've borrowed meds off people as my son wasn't sleeping."



"The old Melatonin capsules were great then they stopped them and prescribed Circadin. My kids don't do well on it so we buy the Melatonin gummies from America."

"I buy spares of Melatonin from the states."

"Was so desperate, we put an appeal on Facebook and met another mum at an Asda car park. She lent me a pack and then I posted her a pack of ours when the prescription arrived. "

Summary and Next Steps.

From reviewing this feedback, this strengthens the emerging theme that there are issues for parent carers who access prescriptions from Alder Hey Children's NHS Foundation Trust.

Feedback shared has been themed and there are issues with access to repeat prescriptions, during transition to adult services and more concerning is the feedback in which parents are purchasing medication from other sources, whilst others are lending medication to others whilst they wait for theirs to become available!

We would encourage the Trust to review this feedback and provide assurances that the service will be reviewed particularly focusing on those issues we have identified with a formal response being shared back to Healthwatch Sefton in line with Healthwatch Statutory guidance, and welcome your response to this letter within the statutory 20 working day time frame (Health and Social Care Act, 2012).



Response from Alder Hey Children's NHS Foundation Trust.



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Private and Confidential

Diane Blair
Lead Officer / Manager
Healthwatch Sefton

5th September 2023

Dear Diane

On behalf of the Trust, thank you for sharing feedback on behalf of Sefton Parent Carers Forum with myself via email on 3rd August 2023 in regards to accessing prescriptions from the Developmental Paediatric Service at Alder Hey Children's Hospital.

Healthwatch Sefton identified three main themes from the 35 individual reviews which are:

1. Repeat prescription requests
2. Transition to Adult services and problems with prescriptions
3. Ordering medication from other organisations / borrowing from other parents

The investigation of your concerns has been co-ordinated by Jacqui Pointon Associate Chief Nurse Community and Mental Health Division and overseen by Paul Sanderson Interim Chief Pharmacist. I would like to address each theme in turn, with the aim of providing context and insight into the service that is provided to our patients, and I will share with you the improvement work that the teams are undertaking and planning. I hope that my letter helps to resolve the concerns of the Forum.

1. Repeat prescription requests

Parents and caregivers have brought to our attention that there have been delays in receiving their medication promptly. Our commitment is to process 100% of prescription requests within 14 calendar days in line with our service framework. Overall, the Trust has maintained a processing rate of 97-98% within this designated 14-day period in the last 12 months.

In the 2-3% of cases where this standard has not been met, it is routine practice for the Trust to temporarily put on hold the generation of prescriptions and/or supply of medication where clinically appropriate. Reasons why the prescription is put on hold temporarily include:

- Where parents or caregivers identify that the current dose of medication is not working or where there are side effects; in these examples a dose change may be required that cannot be accommodated through the repeat prescription service. A clinical review would be necessary.
- Where appointments have been missed for measurements or clinical reviews

However the Trust acknowledges that we experienced a significant decline in the processing rate down to 87% in May and July 2023. The decrease in service quality can be linked to a number of factors including:

- Neurodevelopmental services have experienced a significant surge in demand with the number of referrals to the ADHD team escalating by 190% from January 2022 (157) to January 2023 (456). A significant proportion of these referrals lead to diagnoses and subsequent initiation of medication, intensifying the pressure and demand on our services.
- Difficulties in staffing for both administrative and clinical roles. These challenges arise from factors such as unplanned and unexpected absence, and industrial action.

The Trust encourages the formal reporting of cases where issues have arisen so that we can conduct thorough investigations to determine the root causes and we have also identified the following key themes:

- Incorrect contact details: If updated contact details have not been provided, this affects our automated notification system which aims to inform parents/carers of the successful delivery of their prescription as the contact information is incorrect.
- Reliance on paper prescriptions which are not received by community pharmacies: The Alder Hey team rely on paper prescriptions. These are delivered by courier and there is an audit trail to record the safe delivery of these prescriptions to the patients designated community pharmacy. There are instances where community pharmacy teams state that these prescriptions have not been received. This leads to an investigation into the location of the lost/mislaid prescription and a delay in supply of medication as a duplicate prescription has to be sent to the community pharmacy.

A concern was raised that anxiety medication needs to be prescribed through CAMHS and not the GP however there is an 18 month waiting list to be seen. The Trust acknowledges that the Sefton CAMHS waiting times are longer than we would want them to be however I can confirm that no patient is waiting longer than 12 months and a child may be seen much sooner if the severity of the mental health condition needs a more urgent response.

2. Transition to Adult services and problems with prescriptions

You have received feedback from the Forum concerning transitional care. Our focus is on seamlessly transferring all children and young people to an appropriate adult healthcare provider in a timely manner. We also want to prevent any disruptions to the supply of medication. For ADHD cases in particular, we prioritise arranging appointments with the adult service before the discharge process can begin.

In cases where patients are solely prescribed melatonin, we work with GPs to assume responsibility for prescribing the patients' medication.

The team are keen to work with you and the families to understand what went wrong in the two cases where comments have been made within the feedback.

3. Ordering medication from other organisations / borrowing from other parents

Members of the Forum shared with you that they have sourced melatonin from alternative sources. There appears to be two main reasons why this may be happening related to:

- The timeliness of prescriptions as addressed above
- The perceived unsuitability of the prescribed / supplied melatonin preparations. In relation to this, the Trust are dedicated to ensuring that children and young people can comfortably take the medications we prescribe. This ensures that melatonin is taken as intended by the prescriber to ensure the best possible response to treatment.

We encourage our patients and parents/carers to communicate any concerns with us, so that our clinicians can address any issues together with our children and young people.

Without more information to understand each case it is difficult for the Trust to give a detailed response to this issue. I would like to highlight, however, that we offer four distinct formulations of melatonin for our children and young people. We believe these options do provide flexibility for our patients and cater to meet specific individual needs in how melatonin can be taken as intended by the clinician.

It is important to note that we are unable to offer 'unlicensed' melatonin preparations, such as 'gummies'. We strongly urge parents and caregivers to partner with us to find suitable licensed alternative melatonin preparations if needed and we do not endorse parents lending or borrowing medication or obtaining medication from other sources.

I would like to address a comment made regarding private diagnoses. It is standard practice for our team to review all letters and reports after a patient has undergone a private ADHD assessment. The aim of the review is to ensure that the assessment from the private provider aligns with diagnostic criteria as set out by NICE guidelines.

It has come to our attention that several private assessments have lacked a crucial component: a cardiovascular examination before initiating medication, in accordance with NICE guidelines. This examination requires an in-person evaluation of the child to perform these assessments before proceeding with or initiating medication.

Understandably this situation can create added pressure on families as they have to wait for our team to review the private assessment and carry out our in-person checks (in line with NICE guidelines) before medication can be supplied.

It is important to note that we are unable to prioritise families who opt for private assessments over NHS patients already on our waiting lists.

Service Improvements

I would like to inform you about several upcoming changes that are aimed at enhancing the experiences of our parents/carers. We are welcoming new administrative team members, which will restore our team to full capacity by the end of September 2023. Concurrently, we are undergoing a review of our prescription service's delivery approach from a prescribing standpoint.

We are collaborating with our digital teams to advance the implementation of an end-to-end electronic prescribing system. This system will transmit a digital prescription copy to our community pharmacy colleagues, with the goal of alleviating some of the challenges mentioned earlier. This advancement is also expected to lighten our administrative workload, thereby increasing our inherent capacity. Unfortunately there is no immediate solution available and as such this is a longer term aspiration, however we will continue to work toward this end.

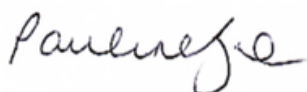
Recognising the importance of identifying areas that require improvement, we are committed to generating daily reports for any parent/carer whose case exceeds our 14-day turnaround time. This will enable us to pinpoint reasons for delays and address them

effectively. Pharmacy colleagues are working with the Business Intelligence team to develop this as quickly as possible.

Our dedication to continuous improvement drives us to use feedback as a catalyst for positive change. We are keen to continue to work in partnership with Healthwatch Sefton, gaining valuable insights into any challenges parent/carers may face, to achieve positive outcomes for children, young people and families and to enhance our services. I would therefore like to take this opportunity to once again express my sincere appreciation to Sefton Parent Carers Forum for providing the feedback to yourselves, and to Healthwatch Sefton for sharing with the Trust enabling us to investigate the concerns raised.

if you would welcome a meeting with the appropriate senior staff, or if we can be of any further assistance, please do not hesitate to contact myself again.

Yours sincerely



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