‘I am unsure on where to go and who to talk to’: The impact of the end to Shared Care for ADHD

October 2025

Joe Pearce

healthwatch Essex

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Key findings

Since late 2024, many GPs in Essex have withdrawn from Shared Care agreements for ADHD medication. Our survey on this topic evaluated the impact of this change on people with ADHD in Essex. 70 people responded from across Essex, distributed across our three ICB areas: Hertfordshire and West Essex (HWE), Suffolk and North East Essex (SNEE), and Mid and South Essex (MSE). This included 58 people who had been prescribed medication.

- **57%** of people previously prescribed medication told us their GP was ending prescribing and monitoring of ADHD medication.
- **63% of adults** previously prescribed medication were affected, compared to **40% of children.**
- **Suffolk and North East Essex** was worst affected, with **two thirds** of those on medication affected. All respondents who had previously been on Shared Care in SNEE were affected.
- **78%** of those on Shared Care with **private specialists** were affected.
    - These respondents told us they now faced costs of up to **£300 a month** to return to the private provider for prescriptions, and those who could not afford these costs faced long waits for new assessments with Right to Choose or NHS providers.
- **88%** of those affected told us they had experienced **increased stress or anxiety** due to uncertainty about care.
    - Respondents told us that the stress, uncertainty, and difficulty navigating care was negatively affecting their mental health, wellbeing, and relationships.
- **76%** of those affected told us they had **run out of medication.**
    - This was affecting people's ability to study for exams and performance at work.
- Those affected told us about lack of notice and poor communication about the changes from providers: **Over half were given one month's notice or less**, and **39%** told us that told us **no arrangements had been made for their ongoing care.**

Acknowledgements

We would like to express our heartfelt thanks and gratitude to everyone who contributed to this project, in particular:

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Contents

Glossary

ADHD – Attention Deficit Hyperactivity Disorder

BMA – British Medical Association

CAMHS – Child and Adolescent Mental Health Services

EPUT – Essex Partnership University NHS Foundation Trust

GP – General Practice/Practitioner

HWE – Hertfordshire and West Essex

ICB – Integrated Care Board

LMC – Local Medical Committees

MSE– Mid and South Essex

NICE – National Institute for Health and Care Excellence

PALS – Patient Advice and Liaison Service

SEN – Special Educational Needs

SEND – Special Educational Needs and Disabilities

SNEE – Suffolk and North East Essex

1. Introduction

1.1 Introduction

Since late 2024, many GPs in Essex have withdrawn from Shared Care agreements for ADHD medication, leading to disruption in access to prescriptions and ongoing care for ADHD for many patients. This report considers how patients have been impacted by GPs withdrawing from care for ADHD medication in Essex. We conducted a survey of people with ADHD using medication in Essex to gather people's experiences. This work was conducted in collaboration with Healthwatch Suffolk, who ran a parallel survey in Suffolk and produced a report have produced a report highlighting the impact of the situation on people with ADHD living in Suffolk.

1.2 ADHD and Shared Care

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by inattention and/or hyperactivity-impulsivity that negatively impacts academic, occupational, or social functioning (World Health Organization (WHO), 2025: 6A05). People with ADHD describe the experience of hyperactivity and inattention as having a mind that is 'racing and tumbling' (Watters et al. 2017: 175) and as contributing to feelings of chaos in their lives (Toner et al. 2006). Children with ADHD describe feeling out of control and having difficulties with learning, feeling different to others, and experiencing stigma (Ringer 2019: 220). Many people with ADHD experience difficulties with school and work which contribute to issues with self-esteem (Ginapp et al. 2022: 9). Many people with ADHD also emphasise positive aspects to it, for example describing it as a 'superpower' that gives them energy and drive (Healthwatch Essex 2024).

Support for people with ADHD can be non-medical, such as from environmental modifications to promote focus, parent-training programmes, and cognitive-behavioural therapy (NICE 2018: 1.5). However, people with ADHD may also be prescribed stimulant medication such as methylphenidate and lisdexamfetamin (NICE 2018: 1.7.7, 1.7.11). A hospital or specialist clinic will usually be responsible for ADHD assessment, followed by initiation and stabilisation of medication. However, specialists can seek agreement for a patient's GP to take over subsequent prescribing and monitoring of medication under an arrangement known as Shared Care. Under a Shared Care agreement, clinical responsibility for prescribing and monitoring is then transferred to a GP or other primary care prescriber (NHS England 2018: 10), with the exact arrangements for this depending on the particular case and being agreed between the specialist and Primary Care.

In the early to mid-1990s in the UK, ADHD diagnosis was mainly restricted to children, and predominantly treated in specialist tertiary clinics, where pharmacological intervention was rare. It gradually came to be diagnosed by a wider range of specialists (e.g. in Child and Adolescent Mental Health Services), before a change in NICE guidelines in 2008 led to recognition that ADHD may continue into adulthood, followed by more investment into Adult ADHD Services (Asherson 2022: 4). In 2018, NICE Guidelines were updated again to recommend that, in cases where medication is prescribed to treat ADHD, prescribing and monitoring of ADHD medication should be carried out under Shared Care Protocol arrangements with Primary Care, following titration and dose stabilisation (NICE 2018: 1.7.29).

Shared Care agreements are not part of GPs' core contracts, meaning that it is voluntary for GPs to enter into them. GPs may refuse to enter a Shared Care agreement for any reason, including lack of capacity within a GP practice or lack of specialist knowledge of the condition or medication (BMA 2025).

A number of known challenges exist for implementing Shared Care. Crowe et al. (2010) considered the challenges that GPs faced when adhering to Shared Care protocols, through semi-structured interviews with 47 practice staff. They found that GPs voiced concerns over the sharing of test results between the specialist and Primary Care, with reports of tests being duplicated by specialists, or being omitted where both parties believed the other to be responsible for tests. GPs also shared doubts about whether specialists were complying with monitoring responsibilities. They also expressed reluctance to accept Shared Care agreements where patients were able to see different GPs in the same practice, as they worried that other professionals in their practice may not share the same level of expertise.

With regards to ADHD medication specifically, Carrington et al. (2018) considered why GPs may refuse Shared Care agreements for ADHD through a survey and semi-structured interviews. They found that GPs expressed concerns about Shared Care for ADHD medication, including:

- Doubts about the robustness of diagnosis

- Concerns over communication from secondary care
- Concerns over the monitoring of medication by secondary care
- A perception that medication was misused, or prescribed when non-pharmacological support had not been offered to the patient.

Asherson et al. (2022: 12) also highlight that GPs may be concerned about increasing workload, with GPs raising worries about workload shifting from secondary care to primary care (Croxson et al. 2017).

1.3 Waiting times and assessment pathways

In recent years, waiting times for NHS services in England have increased dramatically, reaching 4+ years for children and 8+ years for adults (NHS England 2025: 6). A 2023 Freedom of Information Request found that the average waiting time for the children's service at Essex Partnership University NHS Foundation Trust (EPUT) was 31 weeks, with longest waiting times reaching 95 (EPUT 2023). Meanwhile, a 2025 Freedom of Information (FOI) request to EPUT found that in 2024-25, the average waiting time from referral to initial assessment for adults was 115 weeks, up from 13 weeks in 2021-22. The same FOI request revealed that there were 12,790 people waiting for an assessment in 2024-25 with the EPUT Adult ADHD Service, but that only 402 people received an assessment that year (EPUT 2025). If the service continues to see people at this rate, the projected wait time for new referrals to this service would be 31.8 years. NHS England (2025: 6) attributes the increase in referrals to greater awareness of ADHD, changes to diagnostic criteria, previous misdiagnosis and missed diagnosis (especially among female patients), more scientific evidence that ADHD persists into adulthood, and the perceived need for a diagnosis to access support in work and education.

This increase in waiting times has contributed to many people seeking a diagnosis privately, often with the intention of seeking a Shared Care agreement with their NHS GP for medication and monitoring, following initial assessment and titration of medication. Under the Right to Choose scheme, patients in England are also able to choose to be seen by private services contracted by the NHS to provide care for ADHD. Patients can therefore ask to be referred to a Right to Choose provider with a shorter waiting list if their local service is too long. However, Right to Choose services also have increasing waiting lists, and not all services are able to prescribe medication (ADHD UK, 2025).

1.4 End to GP prescribing and Shared Care for ADHD medication

On the 1st of August 2024, GPs voted to take industrial action as part of a dispute between the British Medical Association (BMA) and NHS England around changes to their contracts for 2024/2025 that had started in April 2024. As part of this industrial action, the BMA released a published a list of nine possible actions that GP practices could take to support general practice that were permissible within their contracts. Individual practices, under the guidance of Local Medical Committees (LMCs), were left to decide which of these actions to implement. One of these actions was as follows:

> *Stop supporting the system at the expense of your business and staff - serve notice on any voluntary services currently undertaken that plug local commissioning gaps.*
>
> British Medical Association, 2024

Shared Care agreements for ADHD fall into this category of voluntary services for GPs, meaning that GPs were free to withdraw from them at any time.

In June 2024, Local Medical Committees in Essex received a draft Local Enhanced Service specification from Mid and South Essex (MSE) Integrated Care Board (ICB) and a Shared Care Protocol from EPUT for ADHD for consideration (North Essex Local Medical Committee, June 2024: 2; South Essex Local Medical Committee, June 2024: 4). Minutes from the June 2024 Local Medical Committee meetings for North Essex and South Essex show that members of the LMCs raised concerns about underfunding of the proposals. They also highlighted concerns around the shift of work from secondary to primary care and an increase in ADHD diagnoses originating from private providers. Over the next nine months, the ICBs and LMCs negotiated potential changes and further proposals. In October 2024, the LMCs wrote to practices advising them of their right to withdraw from Shared Care agreements for ADHD medication and refuse to take on any new patients. They provided practices with a template to withdraw care and served notice to their respective ICBs (North Essex Local Medical Committee, October 2024; South Essex Local Medical Committee, October 2024). The North Essex LMC voted to withdraw from provision of adult ADHD services in North East Essex in November 2024 (North

Essex Local Medical Committee, November 2024), followed by child services in December 2024 (North & South Essex Local Medical Committees, December 2024). Following these votes, the South Essex LMC also wrote to MSE practices to recommend that they withdraw provision for children (North & South Essex Local Medical Committees, December 2024).

In early 2025, MSE provided the LMC with an enhanced offer for Shared Care agreements. The LMC left the choice of whether to accept this up to individual practices. At the same time, SNEE ICB planned for GP federations to take over ADHD care for adults and children in North East Essex. No arrangements were made for those who had previously been under Shared Care with private providers.

1.5 Purpose

This report considers the impact that changes to GP prescribing have had on patients in Essex. We conducted a survey aimed at people with experience with ADHD medication living in Essex to ask them about the impact that these changes were having on them. In particular, we aim to consider:

- How have people with ADHD living in Essex been affected by GPs ending prescription and monitoring of GP medication?
- How have the changes affected different groups of people, particularly:
  - Different demographic groups
  - Adults and children
  - People's whose assessment and initiation of medication were managed through different pathways (e.g. Right to Choose, Private and local NHS services)

2. Findings

2.1 Who responded?

76 people responded to the survey. Of these, 6 respondents were filtered out of the survey due to not having any experience of ADHD medication and not being interested in accessing it. All descriptive statistics from this point forward are based on the remaining 70 respondents.

Responding for self or child/cared-for

There were two pathways through the survey: One for those responding for themselves, and one for people responding on behalf of a child or other person they care for. As shown in Table 2-1, 60% of respondents responded for themselves, and 40% responded on behalf of their child or someone else they care for.

Table 2-1: Breakdown of respondents by who responded for themselves, or on behalf of their child/cared-for

Responding for:	Count	Percent
Myself	42	60%
For my child or someone else I care for	28	40%

For the purposes of this report, 'respondent' from this point forward refers to the person affected by the issue – this refers to the child or cared-for person rather than the parent or carer who responded on their behalf.

Geographic distribution

The survey was advertised as being open to residents across Essex. To estimate the geographic distribution of survey respondents, respondents were asked to share the GP surgery they were registered with. 64 respondents shared their GP surgery, and 62 of these were located in Essex, with one respondent's GP located in Suffolk within SNEE close to the border with Essex, and one located out of the area of interest in Kent. Table 2-2 and Figure 2-1 summarise the distribution of respondents by ICB area across Essex.

Table 2-2: Breakdown of respondents by ICB area

ICB area	Count	Percentage
Herts & West Essex	7	9%
Mid & South Essex	34	45%
Suffolk & North East Essex	22	29%
No response	7	10%

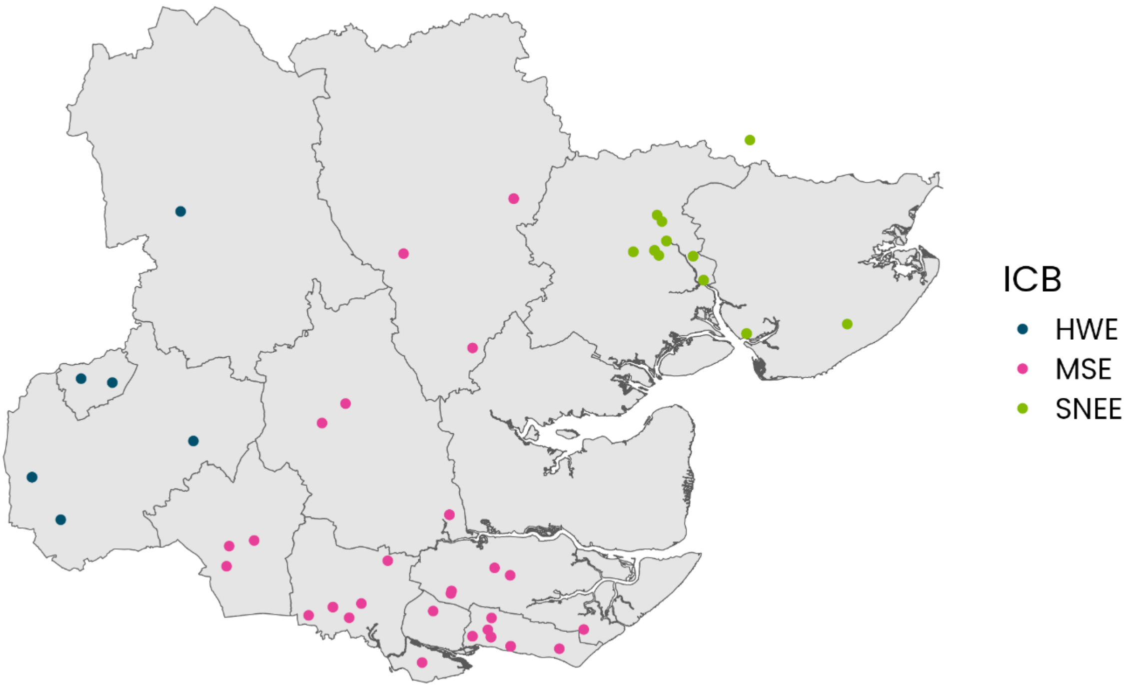


Figure 2-1: Map showing the distribution of respondents across Essex, based on the approximate location of their GP surgery. The colour of each dot shows which ICB area their GP falls under.

Gender

48 responses (69%) came from female respondents and those answering on behalf of a female child or cared-for person, while 22 (31%) came from male respondents and those answering on behalf of a male child or cared-for person. No respondents gave a response other than male or female for gender.

As shown in Figure 2-2, the proportion of female respondents was greater among those responding for themselves (n = 33, 79% of all those responding for themselves), compared with those responding on behalf of a child or cared-for person (n = 15, 54% of all those responding for child/cared-for).

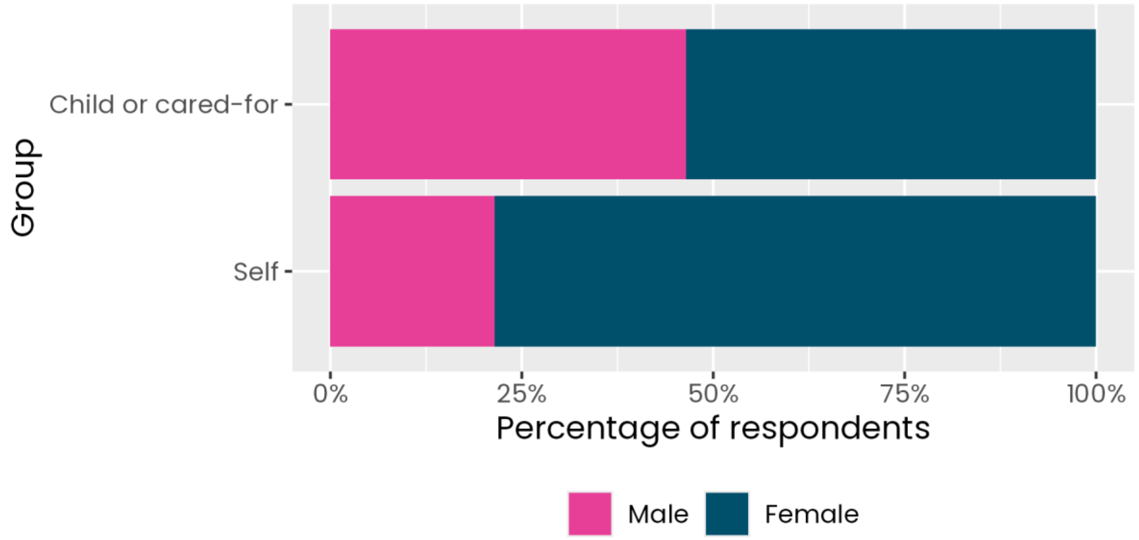


Figure 2-2: Proportion of respondents by gender and group

Ethnicity

83% of respondents (n = 58) were White: British/English/Northern Irish/Scottish/Welsh, or White: Irish. 5 respondents were White: Any other White background. One respondent was recorded in each of the following categories:

- Asian/Asian British: Pakistani
- Latin American
- Mixed/multiple ethnic groups: Black Caribbean and White
- Mixed/multiple ethnic groups: Asian and White

- Mixed/multiple ethnic groups: Black African and White
- Asian/Asian British: Indian
- Prefer not to say

Age

Table 2-4 Age of respondents responding on behalf of themselves

Age	Count	Percentage
18 - 24 years	10	23.8%
25 - 49 years	27	64.3%
50 - 64 years	5	11.9%

Table 2-3 Age of child or cared-for person that survey was completed on behalf of

Age	Count	Percent
12 or younger	5	17.9%
13 - 15 years	8	28.6%
16 - 17 years	6	21.4%
18 - 24 years	8	28.6%
25 - 49 years	1	3.6%
50 - 64 years	0	0.0%

Age at diagnosis

Table 2-5: Age at diagnosis of respondents

Group	12 or younger	13 to 15 years	16 - 17 years	18 - 24 years	25 - 49 years	50 - 64 years	N/A
Self	4.8% (2)	4.8% (2)	9.5% (4)	9.5% (4)	61.9% (26)	4.8% (2)	4.8% (2)
Child or cared-for	60.7% (17)	25.0% (7)	3.6% (1)	3.6% (1)	3.6% (1)	0.0% (0)	3.6% (1)
Total	27.1% (19)	12.9% (9)	7.1% (5)	7.1% (5)	38.6% (27)	2.9% (2)	4.3% (3)

2.2 Who was impacted by the changes?

Overall proportion of those affected

This section considers the 58 respondents who had been prescribed medication. Of these, 45 (77.6%) were currently or had previously been prescribed medication by their GP, while the remaining 27.6% (16) were prescribed medication solely through a specialist provider, with no GP involvement. Of these 58 respondents, 60.3% (35) had been prescribed medication under a Shared Care agreement, while 12.1% (7) had been under their GP's sole care with no specialist involvement.

Of the 45 participants who had previously been prescribed medication by their GP, 33 (73.3%) were affected by changes to GP prescribing. 25 reported that their GP had already stopped prescribing their medication, and a further 8 had been informed that their GP would stop prescribing in the future. Participants who responded for themselves were affected at a slightly higher rate (80.8%, n = 21)

Table 2-6 Proportion of those on medication affected by GPs ceasing prescribing of ADHD medication

Group	Already stopped	Informed that GP will stop	Not informed of any changes	No GP involvement
Self	45.7% (16)	14.3% (5)	14.3% (5)	25.7% (9)
Child or cared-for	39.1% (9)	13.0% (3)	17.4% (4)	30.4% (7)
Total	43.1% (25)	13.8% (8)	15.5% (9)	27.6% (16)

than those whose responses came from a parent or carer (63%, n = 12). Table 2-6 gives a breakdown of the percentage of those affected out of all 58 respondents who were on medication.

Table 2-7 Proportion of those affected by current age

Age	Already stopped	Informed that GP will stop	Not informed of any changes	No GP involvement
Over 18	46.5% (20)	16.3% (7)	14.0% (6)	23.3% (10)
Under 18	33.3% (5)	6.7% (1)	20.0% (3)	40.0% (6)
Total	43.1% (25)	13.8% (8)	15.5% (9)	27.6% (16)

Age and diagnosis age

As shown in Figure 2-3 and Table 2-7, adults were more likely to have found that their GP had ceased prescribing and monitoring, and more likely to have been told that their GP would cease prescribing in the future. 63% (n=27) of adults were affected by the change. Those affected were comprised of 20 adults whose GPs had stopped prescribing, and a further 7 who reported that their GP had informed them they would stop. This is compared to 33.3% (n=5) of under-18s reporting their GP had already stopped prescribing, with only one additional respondent reporting that their GP had informed them they would stop. This may be driven by the fact that a smaller proportion of adults (23.3%, n=10) had previously had no GP involvement in prescribing than the under-18s (40.0%, n=6).

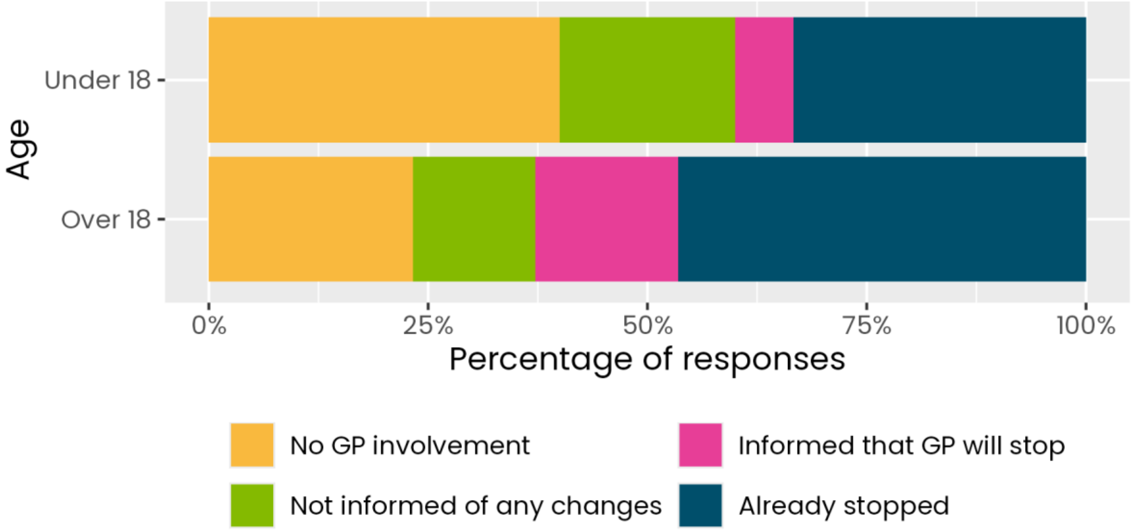
Similarly, as shown in Figure 2-4 Proportion of people affected by a higher proportion of respondents diagnosed as adults (44.8%, n=13) were affected compared to those diagnosed under 18 (33.3%, n=8). This does not appear to be explained by differences in the number of people with GP involvement, as these

Table 2-8: Proportion of those affected by age at diagnosis

Age at diagnosis	Already stopped	Informed that GP will stop	Not informed of any changes	No GP involvement
18 or older	44.8% (13)	13.8% (4)	13.8% (4)	27.6% (8)
Under 18	33.3% (8)	16.7% (4)	20.8% (5)	29.2% (7)
Total	39.6% (21)	15.1% (8)	17.0% (9)	28.3% (15)

are roughly similar in terms of raw numbers and proportions between those diagnosed as adults and as children.

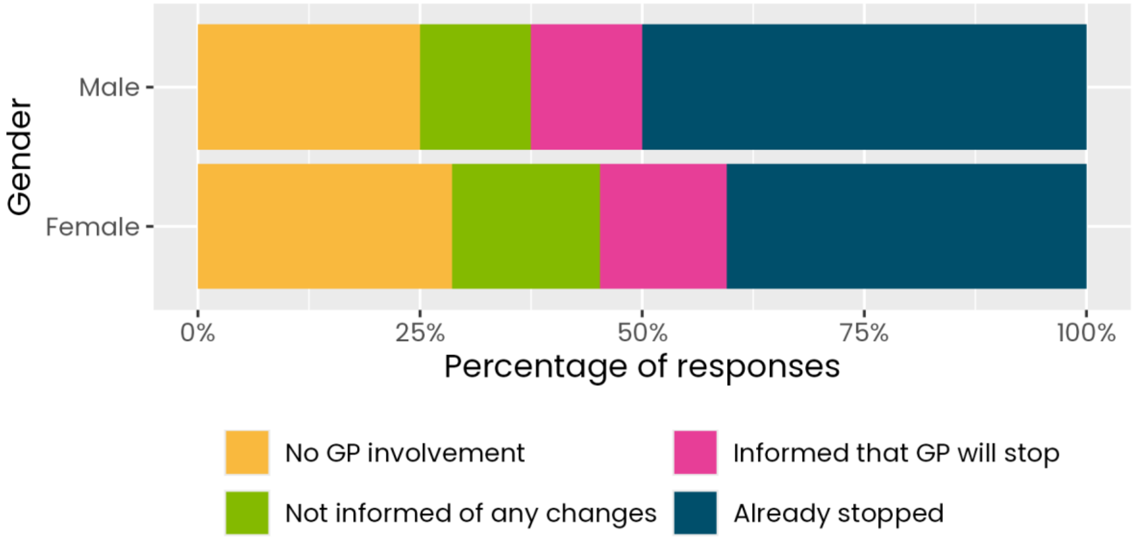
Figure 2-3 Proportion of over 18s and under 18s on medication affected by GPs ceasing prescribing of ADHD medication



Gender

The proportion of people affected by gender was roughly similar, with a slightly higher proportion of male respondents (50.0%, n = 8) reporting their GP had stopped prescribing, compared to 40.5% (n=17) of female respondents, as shown

Figure 2-4 Proportion of people affected by gender



in Figure 2-4. However, it is worth noting there were considerably more female respondents, despite ADHD diagnoses being more common among males, so this sample does not represent the wider population of those affected in terms of gender.

Comparison by ICB area

Table 2-9 Proportion of those on medication affected by the changes, by ICB area

ICB	Already stopped	Informed that GP will stop	Not informed of any changes	No GP involvement
HWE	0.0% (0)	0.0% (0)	66.7% (4)	33.3% (2)
MSE	44.8% (13)	6.9% (2)	24.1% (7)	24.1% (7)
SNEE	47.6% (10)	19.0% (4)	0.0% (0)	33.3% (7)
Total	41.1% (23)	10.7% (6)	19.6% (11)	28.6% (16)

As shown in Table 2-2, most respondents were registered with GP surgeries in SNEE or MSE, with only 7 (9%) registered in Hertfordshire and West Essex. However, as shown in Figure 2-5, none of the respondents who came under the Hertfordshire and West Essex ICB were affected by the change. Two of the respondents from this area were not affected due to not receiving prescriptions or monitoring from their GP in the first place. The remaining four did not report

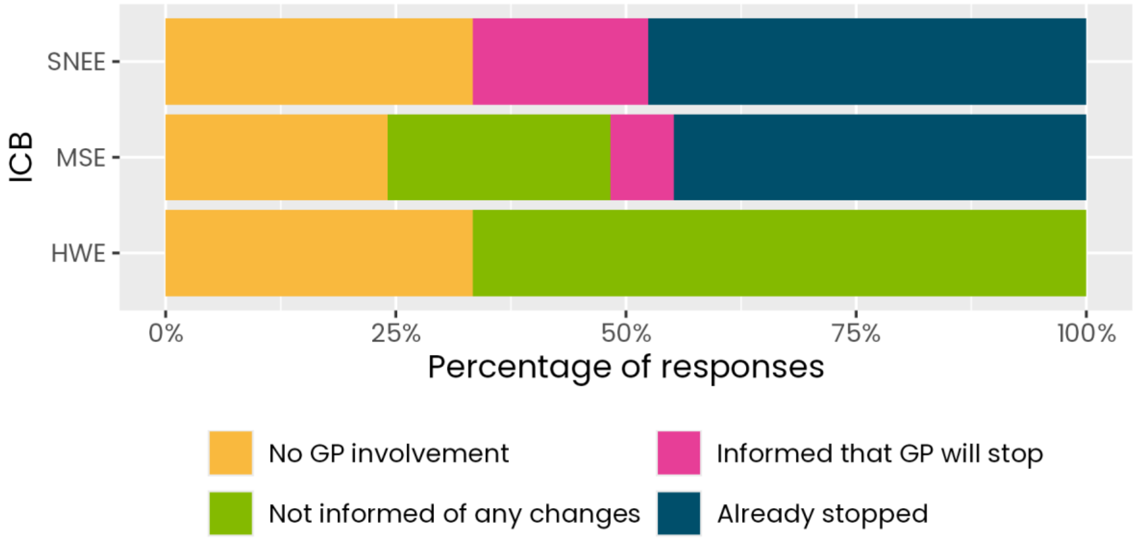


Figure 2-5: Proportion of people who previously received their prescription from their GP affected by changes by ICB area of GP surgery

having been informed of any changes. In contrast, all respondents from SNEE and a majority of respondents from MSE who had previously been prescribed medication by their GP were affected by the changes. These findings are broken down in detail in Table 2-9.

Comparison between assessment pathways

Table 2-10 Proportion of people affected by assessment pathway

Assessment pathway	Already stopped	Informed that GP will stop	Not informed of any changes	No GP involvement
Abroad	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (3)
Multiple	20.0% (1)	20.0% (1)	0.0% (0)	60.0% (3)
NHS	40.7% (11)	14.8% (4)	22.2% (6)	22.2% (6)
Private	61.1% (11)	16.7% (3)	16.7% (3)	5.6% (1)
RTC	40.0% (2)	0.0% (0)	0.0% (0)	60.0% (3)
Total	43.1% (25)	13.8% (8)	15.5% (9)	27.6% (16)

As shown in Figure 2-5, people who had been assessed through a private route, either through a specialist or private GP, were affected at a slightly higher rate than those who had been assessed through the NHS. All respondents who received prescriptions from their GP and had been assessed through Right to

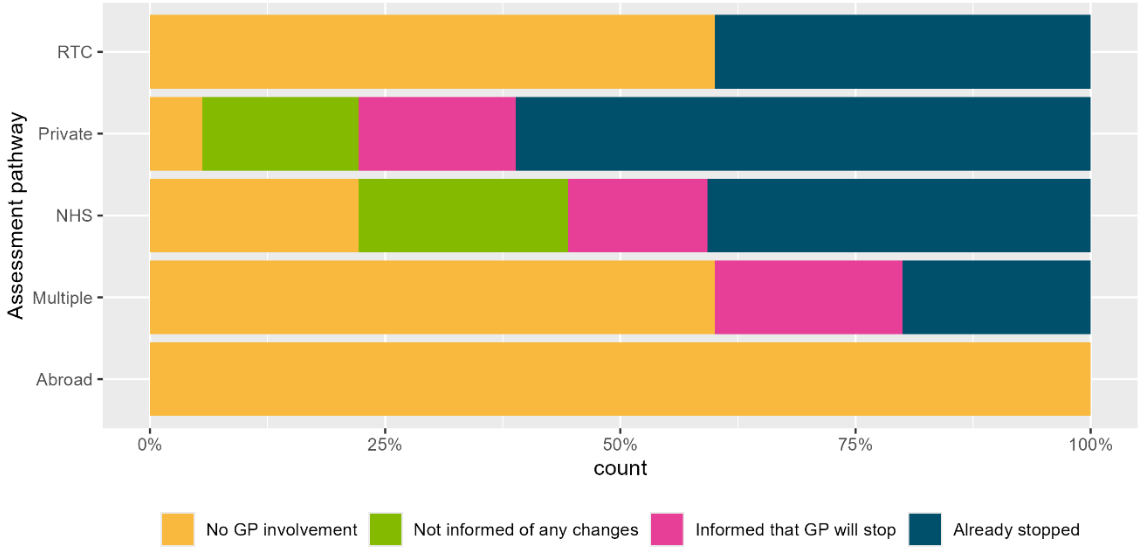


Figure 2-6 Proportion of people affected by assessment pathway

Choose, or had been assessed multiple times through different pathways, had had been affected by the changes. However, these respondents tended to have their prescriptions managed by their specialist provider rather than their GP, so were less likely to be affected.

The high rate of withdrawal from Shared Care with private providers may explain why those diagnosed as adults have been affected at higher rates. 15 respondents diagnosed as adults (44.1%) were assessed privately, compared to just one who was diagnosed before the age of 18.

2.3 How were people impacted by the changes?

33 respondents who had previously been on Shared Care agreements or under sole care of their GP told us that their GPs had already stopped or informed them they would stop prescribing ADHD medication. These respondents were asked questions about the impact this was having on their ability to access medication, notice given, arrangements made going forward, and the qualitative impact that these issues had on their life and wellbeing.

Notice given

As shown in Figure 2-7, over half of respondents whose GPs had withdrawn from prescribing reported that they had received less than a month's notice of the change, with 6 respondents (18%) reporting that they had received no notice, with their prescription being withdrawn with immediate effect.

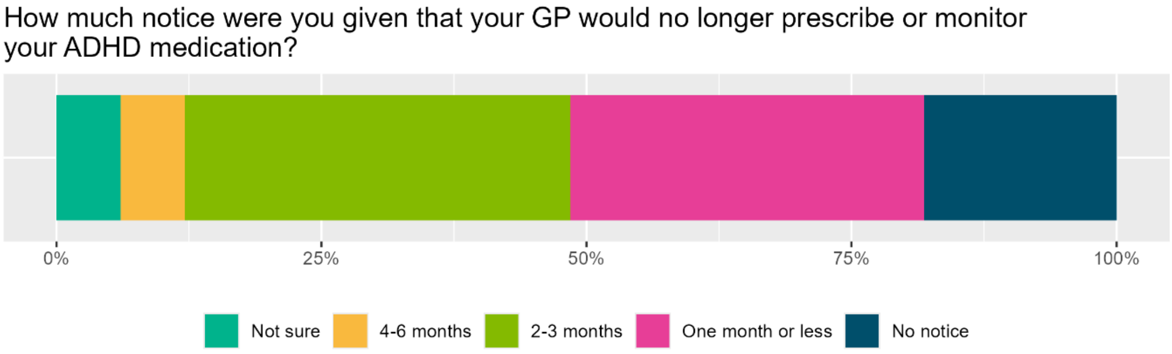


Figure 2-7 Notice given for withdrawal of prescriptions and monitoring

Arrangements going forward

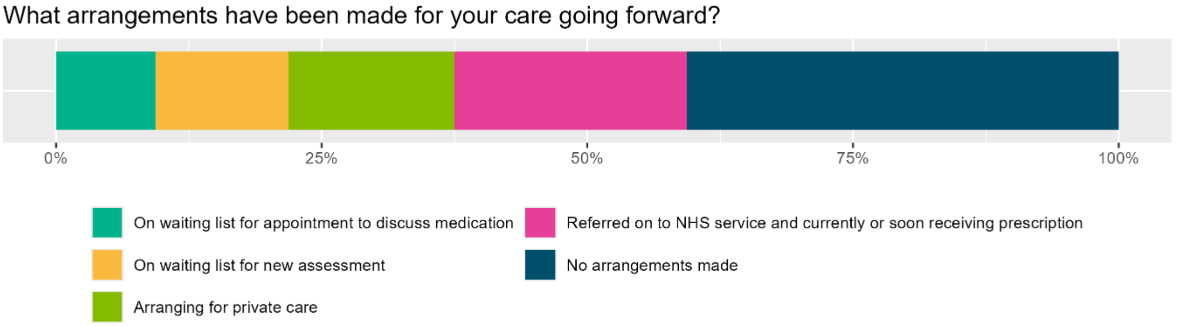


Figure 2-8 Arrangements made going forward

As shown in Figure 2-8, 13 respondents (39.4%) told us that no arrangements had been made for their ongoing care following withdrawal of GP prescribing. Only seven (21.2%) had been successfully referred on to an NHS service (e.g. GP federations) which had taken over care, although a further four were waiting for an appointment to discuss medication (e.g. a medication review). Four were now waiting for a new assessment despite already having received a diagnosis, and five were arranging for their care to be managed privately.

Proportion of those negatively affected

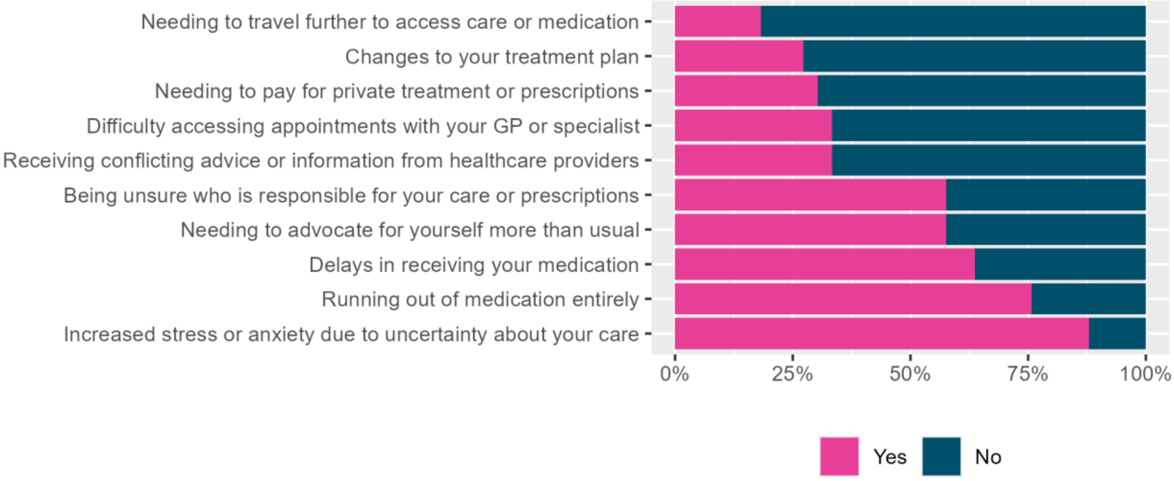


Figure 2-9 Proportion of respondents affected by various issues cause by withdrawal of GP prescribing

Figure 2-9 shows a number of issues people encountered as a results of their GP withdrawing from ADHD prescribing and Shared Care. The most common of these was 'Increased stress or anxiety due to uncertainty about care', experienced by 29 (88%) of those affected. 25 (76%) of respondents affected had run out of medication entirely, while 21 (64%) had experienced delays. More than half reported they were unsure who was responsible for their care or prescriptions, and more than half felt they needed to advocate for themselves more than usual.

Communication: 'I still haven't heard anything'

Respondents told us they had faced problems with communication from their GP and specialist services and had encountered problems with communication between services. 11 respondents (33% of those affected by the change) told us that they had received conflicting advice or information from their healthcare providers as a result of the changes.

Although some respondents told us they felt they had been appropriately informed about the changes, many told us that they were not given enough notice, information or told with appropriate care and consideration. One respondent said:

> *The way I was informed was nonchalantly during an appointment for something unrelated. The GP was quite defensive when I expressed shock and concern and said that GPs weren't "being paid" to deal with ADHD. In my mind, my ADHD is like any other illness the GP might prescribe medication for - Menopause, depression - I don't understand why ADHD is different? They never even monitored me and only ever prescribed medication.*

Multiple respondents reported that although they had been referred on to a new provider, for example a Right to Choose provider, they hadn't received any communication from them. For example, one said:

> *My NHS GP did (eventually, after I complained to PALS about the lack of information regarding future support and my impending financial issues) tell me that I could put in a Right to Choose request for a referral to an ADHD clinic which would be covered by the NHS and doesn't have a super long waiting list, but I gave them this paperwork over a month ago and I still haven't heard anything from them.*

One respondent shared their experience of communication issues between different providers:

> *I received a letter from my GP informing me that they wouldn't be prescribing my medication in a few months' time. The letter said that I would hear from whoever was taking on my prescribing. I received no such letter […] They later rang me back and said that there was some kind of issue and that Psychiatry UK was going to be prescribing for me again. It took forever through an online chat portal to actually speak to a person at Psychiatry UK, they then told me that my GP surgery hadn't contacted them and they weren't prescribing for me and they gave me an email address to give to the surgery. I rang the surgery, and they informed me that they definitely had contacted Psychiatry UK and that I would need to contact Psychiatry UK again to let them know. […] The whole thing as usual*

> *has been a complete nightmare, so many barriers which my brain struggles with.*

Another described similar issues, being told by their GP that they would be contacted by another organisation, but never receiving any further information from them:

> *I was very concerned when I heard my daughter was being moved out from GP care for her ADHD. At the time I had no idea how Shared Care worked, all I knew was that the GP would no longer be providing the medication that enables her to stay at university, and that I should wait for more information […] Nothing happened, and continued to happen after this, as the deadline crept closer. I was not contacted by any other organisation. The GP was unable to provide any information. There was clearly dispute between the GP and the local care body. I contacted PALS, but they gave me the same information as the GP and referred me to the same websites which explained the change, but only in terms of the bureaucracy behind it. Eventually I spoke to the GP pharmacist at a medication review - he was wonderful - he explained the change, where the process had got to, and reassured that my daughter would not have problems accessing the medication. I have still not had any further information about the change after the initial letter.*

One respondent described how the end to Shared Care interacted with their son's transition from child to adult services, as he had been placed on a new waiting list for adult services after being discharged from children's services:

> *This has been a complete nightmare. My son was lost when services at the lighthouse were transferred. He did not receive any information regarding these changes or the fact he needed to be transferred to adult services. He is now without any care provider to prescribe his medication as his doctor will no longer prescribe his medication and he has been discharged from children's services. We have been told there is a 2-3 year wait for adult services.*

Uncertainty and difficulty navigating care: ‘I am unsure on where to go and who to talk [to]’

Difficulties navigating care appeared to contribute to feelings of uncertainty, stress and anxiety among respondents. 19 respondents (57.6%) told us that they needed to advocate for themselves more than usual as a result of the changes. 11 respondents (33%) told us that they experienced difficulty accessing appointments with their GP or specialist.

Respondents reported feelings of uncertainty in both the multiple-choice and free-response questions. 19 (57.6%) told us that they were unsure who was responsible for their care or prescriptions, while 29 (87.9%) told us that uncertainty about their care was causing increased stress and anxiety.

In the open response question asking about people’s experiences since their GP had told them they would stop prescribing ADHD medication, respondents sharing their own experiences told us:

> *I've put so much time and effort into navigating this and have got nowhere*
>
> *I am now left in a difficult situation where I am unsure on where to go and who to talk too. […] The doctors haven't been very helpful since my diagnosis*
>
> *The sudden withdrawal of support has left me feeling destabilised and uncertain about how to maintain continuity of care. Navigating private services or alternative pathways is not only financially and logistically challenging, but it also adds to the mental load that ADHD already makes difficult to manage.*
>
> *I’m very anxious about the next steps and hoping there will be a U-turn in the decision to at least continue with Shared Care for existing patients*

Respondents also remarked that the Right to Choose system in particular was difficult to navigate, with patients and GPs lacking information about providers and struggling to navigate it. For example, one said:

> *I find the Right to Choose programme very difficult to navigate so am waiting for something to come through via the referral my GP sent*

One remarked that they had sought private assessment from a provider that offers care through Right to Choose because they hadn’t known about the option:

> *I went privately through adhd360 years ago, before I knew about right to choose, with the understanding that it'll go over to GP after a year which happened.*

Another said their GP only accepted a Right to Choose referral after the patient complained to PALS:

> *My NHS GP did (eventually, after I complained to PALS about the lack of information regarding future support and my impending financial issues) tell me that I could put in a Right to Choose request for a referral to an ADHD clinic which would be covered by the NHS and doesn't have a super long waiting list, but I gave them this paperwork over a month ago and I still haven't heard anything from them. They also said that they had a list of providers but didn't actually give me the list so that is also incredibly unhelpful.*

People responding on behalf of children or others they care for highlighted that they needed to advocate for them, constantly needing to chase up prescriptions and referrals:

> *My daughter has gone days without medication, regularly month after month, and it's only because I'm chasing it up that we managed to finally get some.*

> *It was an undue amount of stress and advocacy required. The GP sent their letter in Jan ceasing Shared Care from April. It took those 3 months chasing and waiting for info while we were in limbo. I had to learn how to get my MP involved and raise a complaint with the NHS ICB.*

Impact on ADHD symptoms and management

Respondents told us that the changes had a negative effect on their ability to manage symptoms of ADHD, causing issues with focusing and managing symptoms. Respondents sharing their own experiences said:

> *I'm struggling to focus and forget things all the time.*

> *I rely on my medication to help me work and be functional*

> *ADHD medication is not just a prescription it’s a vital part of how I manage my focus, executive function, and overall wellbeing. Without it, I’ve experienced depression, lack of motivation and anxiety about my job.*
>
> *As a result of all of this, plus other factors, I am feeling a lot more stressed about everything, and I'm not able to do the non-medical aspects of my symptom management because I don't have the time, energy or money. As a result, I'm much less on top of my symptom management, and there are days when it feels like my medication isn't doing anything, which makes me more stressed (mostly about work)*
>
> *It has impacted me in that I am currently having to get used to being unmedicated again and I am having to adjust to that in all aspects of my life.*

Those responding on behalf of their children or others they cared for noted effects on their relationships, diet, and ability to manage impulsive behaviour:

> *So have had to come off of medication completely, which had affected everybody around her, including her 2 young children who 1 of them we suspect having ADHD as well. Family life is very difficult. Mood swings, low energy, not functioning properly. Not eating properly, the list is endless.*
>
> *she becomes dangerously impulsive, and last time she had problems access her medication […] she was told she had to leave her practical class after she impulsively picked up a piece of metal gauze that had just come off the Bunsen burner.*

Impact on wellbeing and mental health

Respondents described that difficulty managing their symptoms and issues accessing their medication caused stress and anxiety:

> *Affected my wellbeing and performance [massively] in all aspects. I also have a serious mental health history (CAMHS since age 7 - 18, Adult services 18-19) and family history (suicides, serious drug addiction) so there is an arguable risk here.*
>
> *I am struggling mentally every day and it's affecting my children now too the way I am with them.*

> *This change has had a significant impact on both my health and daily functioning. ADHD medication is not just a prescription it’s a vital part of how I manage my focus, executive function, and overall wellbeing. Without it, I’ve experienced depression, lack of motivation and anxiety about my job.*

> *I feel my best on my meds when I take it very consistently and the above issues caused me to completely run out of my medication which was distressing.*

Impact on work and education

Respondents told us that difficulty accessing their medication was affecting their ability to engage with work and education, which they attributed to difficulty managing their ADHD symptoms without medication as well as to anxiety and uncertainty around the situation. Respondents in work reflected on how disruption affected their ability to work:

> *This is shockingly poor care, it will result in a lot of people becoming unwell and likely affecting their ability to work, likely myself included.*

> *I can’t function without my meds, and I have a demanding job which requires focus and concentration which I only get with the meds so stopping them is out of the question.*

> *I rely on my medication to help me work and be functional.*

Respondents in education and those sharing the experiences of children in education shared how issues accessing medication impacted their learning and attainment at school and university. This was particularly apparent during exam seasons:

> *Without her medication, my daughter cannot study.*

> *Already advised above but my stress was that I was sitting A level exams in May and June and no one would prescribe my ongoing medication, and it was about to abruptly end.*

> *I had exams the first week of January so this really threw me off and my mental health declined rapidly. […] It ran out again before summer exams which was hard to manage but I definitely managed better than Christmas and I’m proud of that.*

> *I feel like my GP made me appropriately aware of the situation however given that prescriptions would no longer be provided before my exam season, my wellbeing was negatively impacted.*

> *We chose to pay for a private assessment for our daughter as she was starting her A levels and struggling with ADHD symptoms and we knew she would not get a diagnosis in time to help her with her A level study.*

An episode of Healthwatch Essex's Hidden Voices podcast, explores the impact this change has had in detail on one individual's working life. The podcast involves an interview with Heidi, a police officer, who was diagnosed privately and found that the medication she was prescribed under Shared Care enabled her to concentrate and work more effectively. Unable to afford the cost of private prescriptions, she was now rationing her remaining medication and was worried about her performance at work, particularly in high-stakes situations such as giving evidence in court. Listen to the full story here.

Case focus: The impact on health workers with ADHD

A number of respondents reported that they worked in healthcare roles. They were worried about how being unable to access their medication would affect their work.

In particular, respondents who worked in healthcare roles told us about experiencing difficulties navigating the process of assessments and prescriptions for ADHD, despite working in the NHS themselves and being experienced in navigating referral pathways. One told us:

> *I did my research and am fairly good at navigating care systems, I do it every day as part of my job. But my right to choose referral which I found myself and completed all the paperwork except the GP bits, to RTN medical that I thought was an option, was rejected.*

Respondents who worked in healthcare roles were worried that their inability to access medication may affect their work and the support they provided to NHS service users. They told us:

> *I'm an NHS nurse and I don't know how I'm going to cope. […] This is shockingly poor care, it will result in a lot of people becoming unwell and likely affecting their ability to work, likely myself included.*

> *I am really anxious about not have medication, I work full time in a senior healthcare role where people are not aware of my ADHD diagnosis and am worried that I will struggle to manage work and family life and things will get too difficult (note: I have never had a day off related to ADHD to date).*
>
> *I also work for the NHS. So not looking after me and my brain affects me, my family, my colleagues, my service users*

The costs and impact of private assessments and prescriptions

10 (30.3%) respondents who were affected said that they were now needing to pay for private treatment or prescriptions. These individuals had originally been assessed privately and were now having to return to their private provider in order to access the prescription that had previously been issued by their GP through a Shared Care agreement.

Many respondents discussed the high prices of both that initial assessment, and the cost of private prescriptions following GPs ceasing prescribing ADHD medication, and the impact this had on their lives. For many, returning to the private provider to continuing to receive prescriptions privately was not an option, due to the high costs.

> *It cost us about £500/£700 pounds just to be diagnosed.*
>
> *I physically cannot afford private prescription cost (between £100/£200) per medication id need.*
>
> *I've not yet gone back to my private prescriber, but the cost will be over £300 a month which is huge compared to the NHS prescription cost.*
>
> *While the private provider I'm with are very helpful it's been very stressful having to pay just under £200 a month for medication.*
>
> *Going back to my private provider is not an option - I paid £1200 to get my diagnosis and meds trial before being discharged to my GP. After I returned from maternity leave, I then had to go back and pay another £1200 just to be able to receive my medication again. I rely on my medication to help me work and be functional - but I cannot continue to take money away from my family's needs for private care.*

> *Given the importance of exams, I paid for 1 month of private prescription which cost me well over £150 for both the medication cost and prescription writing fee.*

One respondent highlighted how they had slipped through the cracks in the system. They had been diagnosed by a private provider (ADHD360) that also offers Right to Choose assessments. However, ADHD360 would not take over prescribing for those assessed privately:

> *Now GP is stopping Shared Care I will be unable to get my medication as I cannot afford to pay privately. Adhd360 will only take over prescription for right to choose patients, I'm excluded as I paid for their service years ago.*

Due to the high ongoing costs, some patients were now waiting for a new assessment with an NHS or Right to Choose provider. They reflected on the use of NHS resources to re-assess people with an existing diagnosis:

> *If I get diagnosed via the NHS, then they might not even take into account my private diagnosis which is ridiculous because it was done privately via an actual doctor and cost so much money*

> *Have self-referred via Right to Choose- unclear if I will need full reassessment (do not want- a waste of time when I have clear and typical symptoms) or when I will be able to have meds again.*

One respondent described how their GP had originally advised them to seek a private diagnosis for their daughter rather than an NHS diagnosis. This was on the basis that waiting times were shorter and they would be offered Shared Care.

> *We contacted our GP who advised us of a couple of private providers that they would accept so we went with one of them and things were working fine on a Shared Care agreement. Now that has stopped, we have to pay £150 a month for her private prescription as she is completing her A levels exams at the moment, and we can't risk stopping. There was not support from the GP regarding what we could do next, and it feels like we are being penalised for going private when, given the two-year waiting list in the NHS we had very little choice.*

> *Now we have asked for her to be referred for NHS assessment so we can get her back in the NHS system which is crazy and so we will be wasting an NHS appt that someone else could have used.*
>
> *It's very frustrating that we were signposted by the GP to private providers only to have everything stopped, we should have referred to NHS at that time and then she would nearly be at the end of a two year waiting list but instead we are only just at the beginning of the wait.*

One respondent who had originally been assessed privately noted that although they had now been transferred to the local NHS service, the GP had refused Shared Care with the NHS service despite continuing the Shared Care arrangement with the private service:

> *I had Shared Care accidentally with private service. Finally received transfer to local EPUT titration service. And GP has refused Shared Care with local NHS service.*

Delays in transfer of care

Respondents discussed delays in the transition to GP federations or private providers, affecting their ability to access medication.

One participant said:

> *My GP has stopped prescribing my ADHD meds and I am in limbo waiting for Psychiatry UK to pick up my prescription so it is very likely I will run out. I have had no support from my GP.*

Another said:

> *I feel I was appropriately informed but there doesn't seem to be any immediate handover of service and support given the lead time in to the prescribing of ADHD medication ending, this should have been factored in to the process and the timings for patients who would be seeing a change to the issue of their medication.*

Shortages

Some people shared how difficulties with Shared Care had interacted with issues arising from medication shortages. One discussed that their NHS GP would only provide a prescription for a specific brand of medication, while their private clinic was more flexible:

> *Due to difficulties with medication availability in 2024, I repeatedly relied on my private clinic for prescriptions, as their pharmacy were able to provide whichever brand was available where my usual pharmacy wasn't. This was because my NHS GP would only write a prescription for a specific brand, rather than for the medication generically (which is what my private clinic do). This was a struggle financially as the prescription cost £80, and their pharmacy would charge me (rather inconsistently) anywhere between £70 and £175 for my medication.*

Another discussed how the combination of changing providers and shortages had led to them being prescribed an unsafe dosage of medication and having to stop medication independently:

> *Eventually, I managed to get a prescription for Equasym XL, only to find out that the national supply chain had essentially collapsed. I was then switched to Medikinet, which caused a severe spike in heart rate and blood pressure, triggering debilitating anxiety attacks.*
>
> *My psychiatrist, while doing her best, didn’t have a clear solution. Once I stabilized on 10mg of Medikinet, she advised I stay on that dose for a few days and then jump straight to 40mg—quadrupling the dosage. That advice, while well-intentioned, could have easily landed me in the hospital, given the cardiovascular symptoms I was already experiencing.*
>
> *I chose instead to taper down rapidly and am now off the medication entirely. The withdrawal symptoms were brutal—especially during the first few days—but I managed to push through. Despite occasional waves of depression, I’ve made it further than I thought possible.*

Another respondent also reflected on the difficulties of having to change medication unexpectedly during shortages, and how this interacted with care being managed by their GP:

> *I had been taking Concerta XL 27mg for just over two years, during weekdays and breaking on the weekends or when needed. I first had issues the Christmas of 2024 when there was a national shortage and I [couldn’t] get hold of it anywhere. I had a lot going on at home with caring*

> *for grandparents and then I had exams the first week of January so this really threw me off and my mental health declined rapidly. I went back and forth with the GP many times but had issues as I don't have the contact details for my specialist and the GP [couldn't] personally change my prescription to something that we knew was actually in stock. Eventually a couple days before exam week I got prescribed with Xaggatin but this was completely different and made me feel awful and anxiety ridden. Decreased trust in the healthcare system.*

One respondent discussing their son's experiences shared how the limit of a month's supply compounded issues with shortages:

> *It has been very stressful trying to locate the medication, and even pharmacies having stock of the medications, it is a controlled drug therefore you are only allowed a [month's] supply, then you have to wait for a repeat to be issued to be told the medicine is out of stock.*

Several respondents remarked that the situation had decreased their trust in the NHS:

> *It has left me never wanting to contact a GP again.*

> *I've lost faith in the UK's mental health system, not because of a single bad practitioner, but because the entire infrastructure around ADHD support is collapsing. The risk of running out of medication, or being advised to jump dosages without adequate oversight, makes it feel unsafe to rely on.*

2.4 Waiting for a new appointment

Following the end to Shared Care agreements, four respondents reported they were now waiting for a new assessment despite already having received a diagnosis, while a further three were now waiting for an appointment to discuss medication (e.g. titration or medication review). These respondents reported their anticipated waits ranging from one month to over two years. They described the qualitative impact of waiting for this new appointment:

> *massive- feels uncertain. [Unconfirmed] if I'll need to go through another assessment which I don't want to when there is no clinical rationale for this.*

I haven't even been contacted. I've checked the referral on my GP records, but that's the only way I know I've been referred. It's unprofessional and very damaging for GPs to offload people with ADHD and Autism without having secured treatment yet. It feels discriminatory, or like they have no idea what impact it has on someone with ADHD to not be able to access their medication.

We are giving our son this mediation from our initial appointment with no follow up to whether we should be continuing or not. We can't speak to the GP as they refer back to hospital, and the hospital are saying no further clinics at this time.

huge increases in stress

We are still waiting to hear anything

2.5 Other issues accessing ADHD medication

Participants who had previously, were currently, or were trying to access ADHD medication were also asked about other issues they had experienced accessing ADHD mediation. 66 respondents were asked these questions, including people who had never been on Shared Care agreements and people who had never accessed a prescription but were trying to. Of these 66 respondents, only 4 respondents (6.1%) said they had not encountered other issues accessing medication for ADHD.

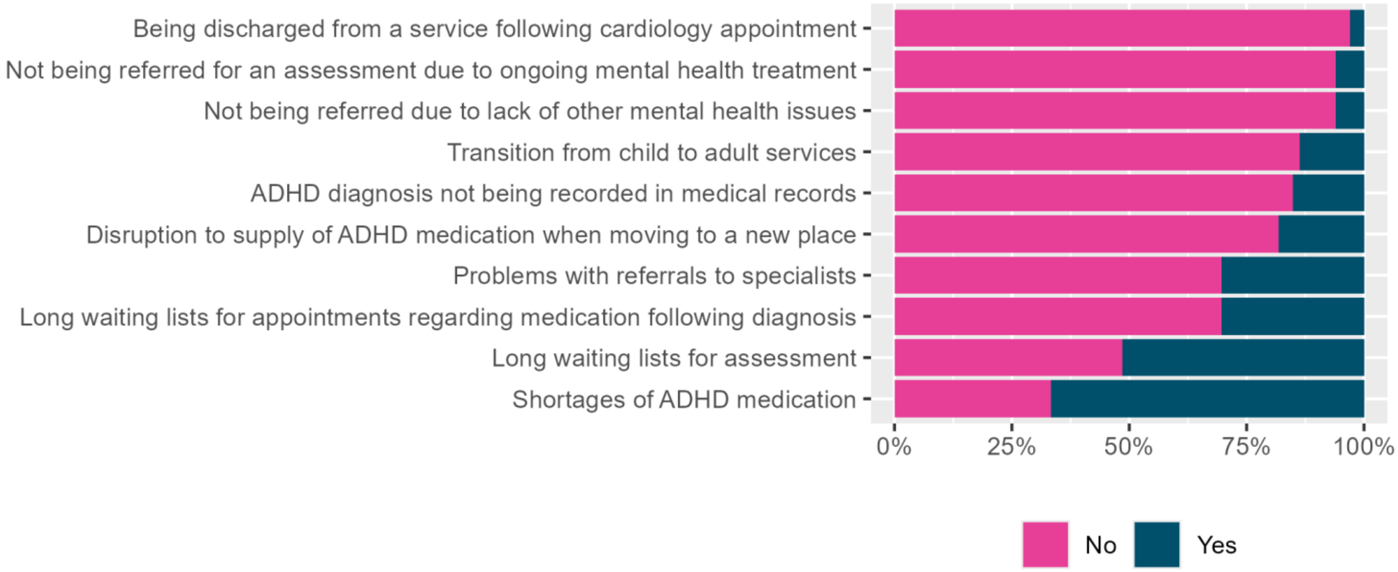


Figure 2-10 Proportion of those affected by other issues accessing ADHD medication

Figure 2-10 shows the different issues people reported. People reported the following issues:

- Shortages (66.7%, n=44)
- Long waiting lists for assessment (51.5%, n=34)
- Long waiting lists for appointments regarding medication (30.3%, n=20)
- Problems with referrals to specialists (30.3%, n=20)
- Disruption to supply of ADHD medication when moving to a new place (18.2%, n=12)
- ADHD diagnosis not being recorded in medical records (15.2%, n = 10)
- Transition from child to adult services (13.6%, n = 9)
- Not being referred due to lack of other mental health issues (6.1%, n = 4)
- Not being referred for an assessment due to ongoing mental health treatment (6.1%, n = 4)

- Being discharged from a service following cardiology appointment (3%, n = 2)

17 people (25.8%) also selected ‘Other’ to this question and described a range of other issues. Some of these described issues related to GPs not accepting or ending Shared Care agreements, and some responses elaborated on issues given in the multiple-choice section. Other issues can be summarised as follows:

- Being discouraged from accessing medication by psychiatrist
- Right to Choose being ignored
- GPs making stigmatising comments about ADHD medication
- ADHD medication being a controlled substance
- Late diagnosis
- Issues with titration, e.g. process being rushed, or being pushed to accept medication with more side effects
- Cost of private prescriptions
- Lack of medication reviews
- Difficulty getting GP appointments
- Miscommunication between services

This was followed by an open response question where people were asked, “Please tell us about the impact that issues accessing ADHD medication have had on you/them.”

Effect on symptoms

Respondents described how their symptoms worsened when they were unable to access ADHD medication. These included:

- Inattentiveness, disorganisation and difficulty focusing
- Sleep problems, ranging from trouble maintaining a regular sleep pattern to experiencing night terrors and nocturnal panic attacks
- Withdrawal symptoms from medication, such as excessive tiredness
- Binge eating
- Impulsive behaviour, including dangerous or destructive impulsive behaviours

One respondent described the effect of this over the two and a half years since they had been able to access medication:

> *It has been 2.5 years since I was last on my ADHD medication. This has had SIGNIFICANT impact on my work and homelife, as I am much more reliant on caffeine to mildly mimic the affects of the medication, my focus issues and easy distractibility, which were under control while I was medicated, have returned and are worse than before, as is my decision paralysis. I was successful and productive and dealt with anxiety and stress much less frequently or strongly while I was medicated, and the last 2.5 years have been horrible.*

Respondents described how the difficulty of managing symptoms made other aspects of life more overwhelming. One shared their experience of this:

> *[Every time] my ADHD meds have ran out I really struggle to manage life, they make the world feel less heavy and overwhelming. The times [I haven't] been able to get hold of any have coincidentally aligned with exam season which is just really bad luck I suppose, I already had a lot going on at home with my Dad having Chemo/radiotherapy, my sister sitting her GCSEs and my grandparents having Alzheimer's and my medication helps in holding [myself] together. It gives me a sense of routine that I struggle without and feels like it lifts the fog really, not being able to access it after over 2 years of learning how to function with it was really hard and I was thrown right back to where I was mentally a couple years ago.*

Impact on wellbeing and mental health

Respondents described how the difficulty on managing symptoms and the stress of shortages and other issues accessing medication compounded to impact their emotional wellbeing, contributing to mental health difficulties.

One described the complex emotions they experienced due to the impact on their work and relationships:

> *I feel such a mixture of anger, guilt, shame, emotional exhaustion, anxiety. […] And I feel so much responsibility to fix this situation, frustration that I don't know how, and guilt that I should just be able to carry on and go without treatment.*

Respondents described negative emotional impacts:

> *Very distressing, never knowing if I will get my medication. It is hard stopping and starting the meds as I get really fatigued. […] It affects my mood and things feel really hopeless.*
>
> *I'm suffering, I've suffered all my life […] oh well suffered this far, looks like it's for life*
>
> *She has become angry and very down because it feels like nobody recognises what she has and how hard life is for her.*

They described how the issues with accessing medication contributed to wider mental health issues:

> *I believe that the anxiety I experienced over the possibility of my shared Care plan being withdrawn has significantly affected me. Additionally, the medication shortages have added to my anxiety, as I was unsure whether I would be able to obtain my prescription.*
>
> *This is then affecting the whole house and all of our mental health due to the fact that my daughter is unregulated*
>
> *made me depressed*

Impact on work and education

Respondents described impacts on education, exam performance, finding and holding down work, and undertaking continuing professional development. Several described that they were unable to work or attend school or would be unable to if they weren't able to access medication.

One respondent who was not currently in work described how access to medication may help them return to work:

> *I am currently unable to work due to my mental health and ADHD symptoms and I feel if I at least had the chance to take ADHD meds and get my* symptoms *under control I could get my life on track and get back to work. I miss working and I feel if I had the help support and medication I needed I would be able to starting living again rather than surviving.*

One respondent who worked in the NHS described how the issues accessing medication were impacting their ability to undertake a nurse prescriber course:

> *The only part of the load that I can take off if I'm struggling is work, and/or the nurse prescriber course. I don't want to do either. I want to be able to carry on. […] My career for my whole adult life has been helping people and caring for people, I love it, and I like to think I'm quite good at it, I have the opportunity to help more with this prescriber course. I'm anxious that this will likely all go wrong, I will fail, need to take time off, just won't be able to cope, because the treatment I need is being taken from me and my only option is I do not have over £100 per month excess finances to pay for it.*

Impact on family and relationships

Respondents described issues maintaining relationships due to issues accessing medication. For example:

> *It's impacting on me, and as a mum of 2 young children, 1 SEN [Special Educational Needs] […] I simply have to be 'ok' to keep my family well.*

> *On a personal level I feel like I'll let down my family, my colleagues and my patients.*

> *Felt had to cut off [avoid people] in late afternoon as some gave me a worse crash or a crash then dose then a second [crash]*

Cost of private

Respondents also described the impact of the cost of private prescriptions. This was a particular strain where multiple family members had ADHD:

> *It is costly currently I only pay for checks for [myself] my GP does my prescriptions for my two girls I pay for appointments and I pay for prescriptions all in all per month. This can cost me up to £1000. This will be more if I have to start paying for my prescriptions through the private provider*

Impact of negative comments from healthcare providers

Respondents also described experiencing disparaging comments about ADHD medication from GPs and pharmacists:

> *after an provide well-being assessment I was diagnosed with ADHD, autism. My GP thinks it is a "band wagon" and I need to man up? And will not help me access medication...*

> *Honestly the main effect has been me feeling very anxious and stressed out but also made to feel like I was taking ADHD medication 'for fun' by a pharmacist who works at my GP surgery who rang me out the blue to say they don't do Shared Care and if I can't afford the medication I can 'just stop taking it'. It felt very much like no health care professional realised how much ADHD medication has positively impacted my life*

> *judgemental docs who clearly still have an attitude of it's a boys' thing and meds are only for [extreme] to them cases and for school. Total lack of comprehension of lived experience when talking to an adult who is also ADHD, has studies ADHD to MSc level in depth and works with autistic and ADHD children and adults in crisis. It is systemic bias and ignorance at its worst, which we either have to suffer or pay.*

Impact of shortages, dosing, and brand issues

Respondents described the difficulty of accessing medication even with a prescription. They attributed this in part to the fact that they were only allowed one month of the prescription at a time, which worsened the effect of shortages. Many described needing to go to multiple pharmacies to find medication or try other dosages or brands with worse side effects. Some described the difficulty of being unable to receive generic prescriptions or different brands from the specific brand of medication they had been prescribed, meaning that pharmacists were unable to dispense medication without a new prescription for a different brand. Some of the experiences people shared were:

> *You're only allowed 1 month supply at a time, and with the stock issues, by the time you go to collect your repeat, it is out of stock and you have to rush around 5 different pharmacies to try and source stock to avoid chaos of my sons routine and behaviour*

> *Also, with the shortages, given the prescriptions are only valid for 28 days as they are [restricted] drugs, sometimes it took so long for the pharmacy to have it in stock that the prescription expired and/or only had 1-2 days left, and sometimes with work schedules I wasn't able to go in time,*

> *meaning that prescription ran out and I wasn't allowed to access the medicine.*
>
> *When I was able to get medication using my NHS prescription again, I had several issues with actually receiving all of it, as the NHS prescription was for a specific brand which was out of the lower dosage (18mg) I take, so I wasn't taking my full dose. I asked for it to be changed to not specify the brand, but my GP seems to have ignored this. I did eventually get them to change the prescription to be for 2x36 mg, so I could take the full dose, but then this ran into issues with availability of the brand specified. The whole thing was massively stressful.*
>
> *Finally - the system that [prescriptions] must match the brand name, feel frustrating. I was initially prescribed 'elvanse', and there were times when elvanse was out of stock, but 'elvanse adult' was not - but even [though] they are the same drug I then had to request a whole new [prescription] as they weren't interchangeable. I now have a generic [prescription], which raises the question - why aren't all prescriptions for the generic/ underlying drug, and so the pharmacy can dispense the most [appropriate] medicine without requiring multiple back and forths with the GP, which wastes their time and delays the whole process significantly (and it's also pretty [challenging] to navigate!)*

Difficulty navigating care while managing ADHD symptoms

In particular, respondents described how navigating issues with shortages was more difficult due to their ADHD symptoms:

> *Now, I have issues with remembering to request my prescription with enough time for the request to be processed, receive the payment link, make the payment, wait for the prescription to be given to the pharmacy, be contacted by the pharmacy and make the payment to the pharmacy, which then gets delivered within 24-48 hours. This whole process can take anywhere between 5-10 days, depending on what day of the week it is, and usually when I finally receive my medication I have none left.*
>
> *I have ADHD and struggle to organise my life at the best of time. This whole process was very stressful and the fact they can't now accommodate blister packs I'm bk to square one. I now have to physically request my*

> *medication every 3 weeks. Which is something I struggle to remember. I had found a service who requested, and delivered without me having to do anything which made things easier for me to not run out of medication and now this has thrown a spanner in the works. The fact I can only get my ADHD medication from one specific pharmacy is [ridiculous]. Sounds like back handers to me*
>
> *Being unable to request more than one month at a time was a challenge (sometimes I forget), and given the shortage sometimes I end up requesting medicine almost immediately after receiving it to ensure that the 2-3 weeks it takes to arrive is not going to mean that I am without the [medication] for extended periods of time - but I also can't request it too soon or the prescription gets denied*

Waiting for assessments, prescriptions, titration, and medication review

Respondents noted long waiting times at every part of the process of accessing medication, which they attributed to services being underfunded and understaffed. Some experiences people shared included:

> *[Having] to phone the clinic every two/three weeks to try and get her medication prescribed. We [sometimes] have to phone daily, whilst at work, to keep reminding/asking for it to be issued for up to ten days. [Problems] with not being prescribed enough medication. Was told she'd have a review after 6 months and this has not happened despite asking. GP has refused to monitor and prescribe her medication. Clinic is inundated with children needing prescriptions fulfilled [as well] as actually seeing and assessing. [So underfunded] and under-staffed and it's not fair. The medication helps and the anxiety all of this causes my daughter and us can be in itself crippling and it's very time-consuming for all involved. There has to be an easier, [more] efficient way*
>
> *This time, I am being told that a doctor at Lighthouse is being chased to write the prescription but that there is a delay due to the service being so busy. Whereas before I could email the ADHD team at Lighthouse a few days before to request a repeat prescription to be sent directly to our pharmacy, we are now told 2 weeks notice is required. Yet here we are,*

> *more than 3 weeks from me requesting a repeat prescription, still with no medication. I can only assume that the changes to Shared Care with GPs, has put more pressure on the local services*

> *I originally waited 4 years to be assessed which in itself was very stressful. The only thing getting me through was knowing that at the end of the wait there was potential for medication and my life finally falling into place and me feeling some peace and stability not constant distraction and chaos. However, that wasn't the case and I now have minimum of 2 year wait for medication on top of the 4 years I waited for assessment.*

Traveling to receive prescription

Respondents described needing to travel long distances to receive medication, such as pharmacies and hospitals far from their homes.

> *Very stressful trying to find where medication was available, I've driven to other counties to collect medication from branches of boots, I've had half filled prescriptions because I needed to get the medication*

> *I have to travel half an hour to the right to choose to get a prescription which is 40 pound then drive 30mins back to a pharmacy and pay a further 75 ish pounds. The amount of travel is also adding onto the price I have to pay just for having ADHD. I have to miss work to do this as it's so far out loosing even more money. If any doctors would take me on I wouldn't have this issue however no doctors in Essex does.*

> *Having to call the specialist each month in community [paediatrics] for a prescription then going on a 25 mins car journey to collect. Where it would be easier to get form a GP on a repeat prescription*

Lack of clarity over responsibility for prescription

Respondents also noted a lack of clarity over who was responsible for prescriptions after titration, both among themselves as patients and among healthcare professionals. For example, they said:

> *The GP has been [refusing] to [prescribe] and said RTC would take over but they have a long [waiting] time and it's caused me significant stress*

> *At the moment, I am still in the [titration] period with ADHD 360. My GP has refused Shared Care and it is unclear whether ADHD 360 will continue to prescribe once I am stable.*
>
> *I feel like I was cheated out of medication due to funding as my [doctor's] surgery told me they paid for diagnosis and medication but the hospital that diagnosed me said that wasn't the case and that it's my [doctor's] responsibility and they probably just don't want to pay out for it.*

2.6 Self-medicating

Respondents who were responding on behalf of themselves were asked two questions about self-medicating via ADHD medication acquired without a prescription, and using alcohol and/or drugs, and asked to share their experience about this.

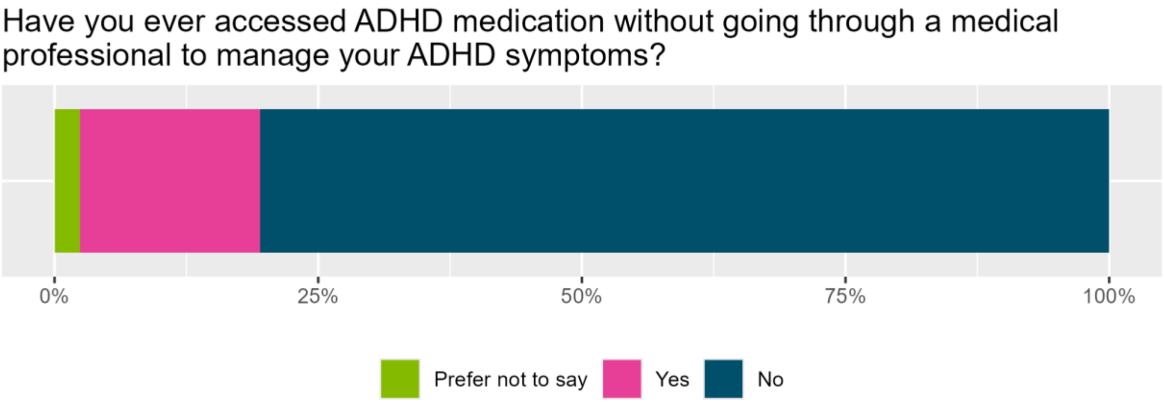


Figure 2-11 Proportion of those who had self-medicated with ADHD medication

Figure 2-11 shows that 7 (17.1%) of these 44 respondents had accessed ADHD medication without going through a medical professional. Some respondents shared their experience with this:

> *Used other people's ADHD medication to help my symptoms*
>
> *When had [prescription] couldn't fill I'd borrow if someone else had leftover old even out of date medication to replace when I could find stock legally.*
>
> *Shared care refused, I reported to doctor I was considering buying from a dealer as cheaper.*

> *I was already diagnosed with ADHD at the point but couldn’t access medication my friend had just increased his dose of ADHD medication and had some very low dose pills left which he gave to me*
>
> *Prior to my own diagnosis, a friend gave me a single, low dose from their old prescription, as they had switched to a different formulation. It did help me to realise how badly I was being affected by my symptoms, and that I needed to get a private diagnosis.*
>
> *I borrowed some from a friend who has the same prescription when I ran out and couldn't access mine.*
>
> *When there was a shortage I had a friend who gave me a couple of [theirs] to help as I was really struggling but not many as people who are prescribed it need it to function normally the way I do.*

Some respondents who responded ‘No’ to this question elaborated that they had considered it:

> *No but have [absolutely] considered doing so however don't feel comfortable as I can't 100% verify what is in the pills- I only want what I am medically [prescribed]!*
>
> *may come to the point where we will need to buy speed off the street I have never used or tried this off the street*

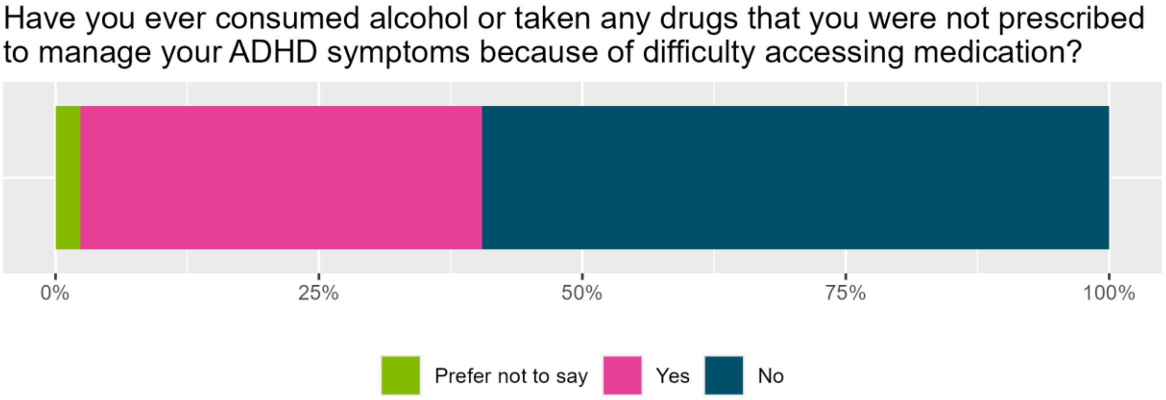


Figure 2-12 Proportion of those who reported self-medicating with drugs or alcohol

Figure 2-12 shows how 38.1% (n=17) of these 44 respondents had consumed alcohol or non-prescription drugs due to difficulty accessing ADHD medication.

Some participants shared their experiences with this, highlighting increased drinking and use of non-prescription drugs such as cannabis, mushrooms, and cocaine when they weren't able to access ADHD medication:

> *A few glasses of wine help me to relax when I feel particularly out of control and helps me drop off to sleep. Although, I then tend to wake up in the early hours with unpleasant thoughts.*
>
> *Increased alcohol consumption*
>
> *No but have been smoking/vaping due to this and resultant stress*
>
> *I stopped drinking at the same time I had my diagnoses as I understood for the first time what it actually meant, it has changed my life for the best, I also get prescribed Melatonin to help me sleep it's not a opioid and has changed my world sleeping for hours most night I don't know what I do without it!!*
>
> *Before assessment and diagnosis, I used alcohol weed cocaine and a number of antidepressants described by the mental health team Mazepa Topazan this medication has been life changing for me*
>
> *I smoked weed everyday to help my mental state, which helped me stay calm and stop me feeling overwhelmed all the time*
>
> *I did smoke weed and binge drink*
>
> *Magic mushroom at very low dose, helps with depression and anxiety and helps with autism, ADHD*
>
> *Off medication I started drinking spirits in the evening to quiet my mind and help me sleep. I also started trying herbal remedies like high dose vits and lion's mane aswaganda. Also felt had to be on PrEP daily off ADHD [medication] as was searching for casual sex with strangers*
>
> *There have been times where I have been unable to sleep and so I have had alcohol to make me feel more tired so that my brain can slow down enough to sleep*

3. Case study: Moving into Essex

12 respondents to the survey (18.2%) reported that they had experienced disruption to their access to ADHD medication when moving to a new place. Three respondents had moved to Essex from abroad, and described how they had been unable to access medication in the UK despite having a prior diagnosis. One respondent shared that they had been diagnosed previously in two different countries, but were still waiting for an assessment in Essex after more than two years:

> *The only NHS involvement in 2.5 years has been putting me on the waitlist for a UK ADHD assessment over two years ago. I am still on the waitlist in Essex, and I only just heard about the Right to Choose option a month ago. All of my actual ADHD care was in the US and Germany.*

The other two respondents who had been diagnosed before moving to the UK shared that they were still receiving prescriptions from their home countries, needing to travel back to access their medication.

Even smaller moves within England were found to have disrupted people's access to ADHD medication. We spoke with Louisa, who had been seeking support from Healthwatch Essex's Information and Guidance Team, about her experience with being unable to access the medication after moving from London.

Louisa was referred to a specialist NHS ADHD service at a hospital in London by her GP in 2019. After waiting for an assessment for four years, she moved to Brentwood around the time that she was offered an initial appointment with the service. She was diagnosed with ADHD by the service in London, and subsequently went through the process of starting Elvanse, a stimulant medication used to treat ADHD, and titration to find the correct dosage. She described starting medication for ADHD as 'life changing'.

Louisa had informed the doctor at the service in London that she was moving to Brentwood and was told that this wouldn't be an issue. In April, the service in London told her that as they had found a stable dose, they would discharge her and enter a Shared Care agreement with her GP. Louisa was subsequently left without access to any treatment or support for her ADHD: her new GP in Brentwood did not accept Shared Care, but she was still discharged by the service in London, and the specialist service in Essex refused to take over management of her care.

She described the negative impact that being unable to access medication for ADHD was having on her life. Symptoms of ADHD that she had been able to manage on medication had returned: She told me that she was struggling with binge eating, impulsive shopping, and completing everyday tasks. Being unable to access ADHD medication was having a negative impact on Louisa's mental health. She told me that she *'[didn't] want to get out of bed in the morning'*, had experienced *'four mental breakdowns'* and that she was struggling with anger and lack of patience, which in turn was affecting her relationship with her partner as well as her ability to do her job. She also indicated that she has been experiencing suicidal thoughts, saying that she had *'lost the will to live'*.

Louisa told me that she had contacted '*anyone who would listen'* to try and resolve the situation, which included PALS, NHS 111, her GP, ICB Complaints Team, ICB Primary Care Team, NHS England and her local MP. She described how *'everyone just passes it on to the next person"*, which she felt was '*frustrating*', and she said she had *'cried about it a lot'*. The local NHS specialist service in Essex told her that they would be unable to prescribe medication without conducting a new assessment, for which there would be a 48-month waiting list. Her GP was able to refer her to a Right to Choose service instead, but this still involved a six-month waiting list.

We asked Louisa what improvements she would recommend and what she felt could be learned from her experiences. She suggested that it would be useful to implement a help centre which could guide you towards where you could access support, with a clear outline of where to go.

4. Discussion

This report aimed to consider how people living in Essex have been affected by GPs withdrawing from Shared Care agreements and monitoring/prescription of ADHD medication, following guidance by the LMCs.

Respondents highlighted a number of ways they had been affected by GPs withdrawing from Shared Care, particularly:

- The financial impact of returning to a private provider
- Stress and anxiety due to uncertainty, difficulty navigating care and lack of communication from healthcare providers
- Interruption or end to access to medication having a negative impact on ADHD symptoms, wellbeing, mental health, work and education

There are several limitations in terms of sample size, so percentages may not be representative of people with ADHD with experience of medication in Essex generally. Respondents were recruited primarily via local community groups and social media and there may be a degree of selection bias, with those who had been more affected being more likely to respond. The sample is also skewed towards female respondents, especially among adults. However, analysis of the demographics of the survey respondents highlighted that Shared Care had been withdrawn more frequently from the following groups:

- People who had been diagnosed privately
- Adults
- People living in SNEE, followed by people living in MSE

A slightly higher proportion of the male respondents reported their GP has withdrawn from Shared Care, compared to female respondents. However, as more women responded than men, it is unclear whether there is any evidence for either of these groups being disproportionately affected. However, previous research has found that ADHD in females is often recognised and treated later in life, being missed or misdiagnosed in childhood (Martin et al. 2024). This may mean that females are more likely to be diagnosed as adults or seek a private diagnosis due to long NHS waiting times, and in turn may be disproportionately affected by GPs withdrawing or refusing Shared Care agreements. As one respondent to this survey put it:

> *I also feel that ADHD is massively under diagnosed in females because we're more able to mask, are just considered anxious etc. The increase in ADHD diagnosis is likely a lot of women who have managed, because we do. And the first 'Shared Care' to be withdrawn is this, mostly women finally getting some help and treatment*

There appears to be regional disparities between ICB areas, with a higher proportion of respondents from SNEE being affected compared to MSE, and no respondents from HWE being affected. Only four respondents were under Hertfordshire and West Essex, so it may be that we were not able to capture the experiences of those affected in West Essex. However, this may reflect the fact that HWE has made improving services for ADHD and ASD one of their key priorities for 2024-2026, and report that their services in West Essex have already undergone “significant service improvements” (HWE ICB 2024: 5).

Overall, this report has described the qualitative impact that difficulties accessing ADHD medication have had on people’s lives and wellbeing. Though we focused on the impact of GPs withdrawing from Shared Care agreements, responses indicated that this change was part of a wider issue with waiting times and access to appointments with specialist services, and that it compounded issues faced during medication shortages.

We reached out to services, Local Medical Committees, and Integrated Care Boards mentioned in this report for comment. The collected comments can be found here.

5. Recommendations

Engage LMCs, GPs, specialist services, and service users in decision-making

To prevent similar scenarios for other conditions and types of medication in the future, ICBs should work closely with LMCs when making funding decisions. This involves consulting them earlier in the process and providing reasonable offers for funding Shared Care or other work outside of GPs’ core contract. Changes to how services are funded and accessed should also include service users to ensure that the potential impact on them is recognised before the changes occur, allowing the effects on access to care to be mitigated.

Provide funding and training for GPs to develop additional specialism in ADHD

Some GPs may feel able to take on Shared Care with specialists if given appropriate renumeration and training. In line with Healthwatch England's (2025: 38) recommendation, we suggest that NHS England should work with the Royal College of Psychiatrists (RCGP) and the Royal College of GPs to develop ADHD training for primary and community care staff, including promotion of the GP with extended role (GPwER) in ADHD.

Invest in local NHS services

Under Right to Choose, patients have the option to be referred to private providers that hold NHS contracts, even if they are outside of their local area. However, many patients choose to use these services mainly due to shorter waiting times. Respondents told us that they find Right to Choose services difficult to navigate, and that GPs are not always aware of the Right to Choose. Not all Right to Choose services are able to prescribe medication and provide long-term support for patients. ICBs should therefore prioritise investment in local NHS services. In particular, this report has revealed adults being more widely affected by this change than children, suggesting a need for investment into adult ADHD services.

Increase awareness of Right to Choose among GPs

Many respondents reported that their Right to Choose was misunderstood by their GP, and that the system was difficult to navigate. We recommend that increasing awareness of how Right to Choose works among GPs, allowing them to support patients to enact their Right to Choose.

Invest in VCSE services to provide non-medical support to people with ADHD

Respondents described that issues accessing medication affected their ability to manage their symptoms, work and education, and wider wellbeing and mental health. It is possible that the impact of disruption to medication could be reduced through increasing the provision of other support services for people with ADHD, e.g. peer support groups, neurodiversity-informed counselling, study/work support.

Ensure continuation of care for people moving between ICB areas and into the UK from abroad

Care should not be interrupted when a person moves from one region to another within the UK. It is essential that ICBs ensure that people moving into their jurisdiction from another ICB are able to transfer their care for ADHD. Additionally, ICBs should consider recognising diagnoses from countries which follow similar diagnostic criteria, to ensure continuity of care. This may also help to address waiting times, as some people on NHS waiting lists may have pre-existing diagnoses from abroad.

Create and share plans for bringing waiting times for ADHD assessment and treatment within 18 weeks

Respondents told us that they had sought private diagnoses due to long NHS waiting times. These respondents are now faced with unaffordable private costs following withdrawal of Shared Care. Although this project did not focus on waiting times, much of the impact of Shared Care withdrawal can be traced back to the difficulty accessing ADHD assessments, titration and medication reviews with NHS and Right to Choose services. NHS England and ICBs should therefore develop plans for bringing waiting times for all NHS-funded services within the national 18 week waiting time target. Strategies to achieve this should consider whether it is viable to create a pathway for those with existing NICE-compliant private diagnoses to transfer their care to the NHS, especially in cases where the provider who made the diagnosis and titrated medication is contracted separately by the NHS under Right to Choose. Information about plans to cut waiting times should be made readily available.

Support for services that help people to navigate care

Respondents described issues with navigating care, noting a range of issues such as uncertainty over who was responsible for their care when Shared Care agreements ended, lack of communication from healthcare providers, difficulty navigating referrals and lack of understanding of the Right to Choose system. We recommend investment into services that help patients navigate the health and social care system, such as advocacy services, information and guidance services, and that ICBs work with these services in cases of policy change to ensure smooth transfer of care for patients.

National policy change to address shortage using the expertise of pharmacists

Shortages were an important issue for respondents to this survey, despite being outside of the initial scope of the project. In line with the Royal Pharmaceutical Society, we recommend that community pharmacists should be allowed to make minor amendments to prescriptions to allow them to dispense (e.g. different quantity, different strength, different formulation, generic versions), without the requirement to contact the prescriber.

Provide support for those on waiting lists

Without proper investment into ADHD services, waiting times for assessments and titration risk reaching decades. While working to reduce waiting times should be a priority, support is also needed for those who are facing waits of months or years before receiving assessments or appointments to start medication.

Address regional disparities and ensure continuation of care in the transition to a Greater Essex ICB

There is a risk of the situation worsening with the transition from three separate ICBs covering Essex to one Greater Essex ICB. However, there is also opportunity to address disparities between different ICB areas when these are combined. We recommend close monitoring of the situation during the transition to a Greater Essex ICB, and ensuring continuation of, and increases to, funding for services that support people with ADHD.

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