

We asked members to share their experience of:

Poor management of medication

Which CAMHS: Brighton & Hove

Your experience: We were previously under East Sussex CAMHS but moved to Brighton a couple of years ago. At that time my son had a diagnosis of ASC, and we were seeing an East Sussex CAMHS consultant and psychiatrist fortnightly. The East Sussex consultant was understanding but seemed to put a lot of scrutiny on my parenting in regard to my son's behaviour despite the fact that the Scott Unit paediatrics instructed his school to refer him to CAMHS as they believed that my son had ADHD. In discussions with her there was always an undertone of his behaviour being due to my parenting despite the fact that he was about to be permanently excluded from school at the age of 6 due to his behaviour being unmanageable and no childminder or holiday club would watch him due to his behaviour which caused me to have to give up my job.

On one occasion the consultant wanted me to speak to the psychiatrist without my son in the room and she said she would watch my son in the hallway while I did this. I had a very brief 30 second conversation with the psychiatrist and went in the hallway to find that my son had escaped into the carpark with the consultant attempting to chase after him. After all the scrutiny on my parenting from the CAMHS consultant, 30 seconds with my son and she nearly lost him.

The psychiatrist we were seeing believed my son had ADHD and would benefit from being on ADHD medication.

During our move, East Sussex had started my son on a trial of an ADHD medication. That particular medication did not agree with my son so they were going to start him on a different ADHD medication, but they said this should be done by Brighton and Hove CAMHS as we were moving and that they would transfer our notes to them, and Brighton and Hove CAMHS would be in touch within a couple of months to arrange continuing my son's treatment.

I contacted Brighton and Hove CAMHS after a few months, and they said my son was on the system and they would be in touch. A year later I had still heard nothing from Brighton CAMHS and coupled with the first lockdown my son's behaviour was so unmanageable I sought help from Front door for families and social services who then got in contact with CAMHS to emphasise the severity of the situation.

CAMHS then said they could not prescribe him ADHD medication as he did not have an official ADHD diagnosis, but they did conduct an ADHD assessment where he was diagnosed with ADHD. They then however said they would prescribe the medication that did not agree with my son, the one East Sussex trialled him on the year before. I explained this to them, but they said they had to as they had to see the side effects before they could give an alternative. After 3 days the side effects were so bad, I had to stop giving my son the medication, as before, and contacted CAMHS who then agreed that due to the side effects the medication had to be changed.

When I called CAMHS on one occasion to discuss the side effects my son was experiencing one particular consultant was very patronising and worryingly unprofessional. I explained to her that after taking the

medication his jaw has been visibly in a lock position and he was grinding his teeth. Her response was that maybe he was just nervous about taking the medication. I actually had to explain to her the definition of side effect, as in that it happened half an hour after taking the medication and had to explain to her that it's not something he had ever done before which is why it's clearly a side effect.

The assessment was frustrating, the clinical consultants were patronising, and it was as if they had not even had full notes from East Sussex because I was having to recount 3 years' worth of notes on my son's behaviour to them (We waited 2 years from our first CAMHS consultation to see a psychiatrist under East Sussex). They seemed to have little understanding of what it was like to have a child with extremely challenging and violent behaviour and even less understanding of how little a single parent can do in attempting to manage such behaviour. For example, FDFF (Front Door For Families) advised me to leave the house when my son was smashing things up in the house, which is reasonable advice in that situation. CAMHS advised me to take away his games console and put him on time out as if that would make such a situation calmer.

After my son had been started on his medication there was a delay of 2 weeks in between the first month's prescription and the second due to "admin issues" which meant he was then restarting the process of his body getting used to the medication, further delaying our follow up medication review which was supposed to take place after he was on the medication consistently for 2 months..

The situation with CAMHS and my son's medication has now been far smoother, however I have requested further help with his ASD traits or any other therapy available to deal with his anger problems but CAMHS have advised me that all they do is assess for ADHD and prescribe medication

How to improve things: The time to wait for an ADHD assessment should be shorter. In the 2 years we waited I had to leave my job due to my son's behaviour being unmanageable and my son missed nearly a whole year of school due to exclusions and not being given schoolwork in school for fear of him getting frustrated and his behaviour becoming challenging. Not to mention the day to day difficulties, the isolation from friends and family and the effect of that on my own mental health as a single parent.

Perhaps my situation was rare but in the event of moving the transition of notes from one local CAMHS to another should not take a year, especially when a patient is mid-way through a medication trial.

CAMHS staff need to stop treating parents as if the reason for their children's difficulties is poor parenting skills rather than ADHD/ASD or other. I appreciate that they need to be thorough and that a mis-diagnosis is just as bad as a missed diagnosis, however despite my son having an ASD diagnosis, an EHCP and a full time place at a special school, CAMHS consultants would speak to me like my efforts were lacking as a parent.

Which CAMHS: Brighton & Hove

Your experience: My child presented during Covid times acutely in crisis with low mood, significant serious suicide attempts (requiring admission), generalised anxiety well above expected social anxiety for ASC, complex post-traumatic stress disorder and dissociative identity disorder. Within 6 weeks they were seen

by a consultant psychiatrist with 2 specific goals: diagnostic labels and advice on medication. We were told medication advice would be put in a letter. I have chased and chased this and after 4 months was told no letter was ever written/dictated and the psychiatrist has left the service. We are now at 6 months and have been told to wait for transition to adult services for medication advice, and not to go to the GP. This may take several months as adult services have "currently no available practitioners and do not know when one will be available". It is now over 6 months on, and my child feels nothing has changed for them.

How to improve things: Admin needs to be improved. More engaging with GPs on medication, both individually and as a training concern.

Which CAMHS: Brighton & Hove

Your experience: My son had a private assessment while we lived abroad and on our return to the UK, he was being prescribed methylphenidate by the GP while we awaited an assessment by CAMHS. My son was having monthly checks at the GP surgery. One month his blood pressure was high, and an urgent referral was made to CAMHS. CAMHS made a call to the GP to stop prescribing methylphenidate.

My son with severe ADHD alongside other developmental disabilities then had no medication. He was unable to attend school as he cannot manage without his medication. It was incredibly difficult at home his mental health alongside everyone else in our family's mental health deteriorated. Due to this we paid another private assessment and were prescribed methylphenidate.

My sons blood pressure was checked regularly and has return to normal. No one is sure why it rose but the GP was using an adult blood pressure cuff so the reading may not have been reliable. When medication was stopped, we were given no support and no idea of timescales for assessment. Behaviourally my son was incredibly difficult to manage over this period.

All we were told was that it did not meet guidelines. While this may be accurate it is unacceptable to leave a young child struggling and not complete an urgent assessment to decide on how to respond. He now receives a monthly private prescription which we are trying to get moved onto shared care with CAMHS. I have emailed twice the neurodevelopmental team asking what evidence is needed to make this happen. I have attached reports from the private assessor but have yet to receive a response.

How to improve things: The team should have space in their caseloads to take on urgent emergency referrals. My child should have been assessed and medication restarted without us having to pay for yet another private assessment.

Which CAMHS: Brighton & Hove

Your experience: Many ND people are known to experience medication in a different way to the neurotypical population - in our case, our child has had two dangerous experiences with medication. It has been difficult to get CAMHS to recognise this - one medication reaction resulted in a suicide attempt, and another one in a pseudo-psychotic episode.

Also, CAMHS prescribing is very disjointed. A review is (sometimes) held, a letter is written to the GP who prescribes the new medication, the parent has to check GP has received letter, and then check with

pharmacy that the medication has been received - we have had to chase for medications on many occasions and thankfully have a very understanding GP practise who have been able to bridge the gaps between prescriptions being received and processed. The same applies to required tests e.g. blood tests, ECGs etc - parents have to chase and ensure that they are carried out, and that CAMHS have the results.

Finally, sleep medication is very hard to access, Neurodiverse young people are known to have issues sleeping, and 'sleep hygiene' advice is pretty useless unless adapted. Young people who are not sleeping are of course more susceptible to poor mental health, anxiety, harm etc.

How to improve things: CAMHS should have a prescriber on site, and no-one should leave a review appointment without a prescription.

CAMHS should offer melatonin earlier in their interventions with young people who are not sleeping to support better mental health.

CAMHS should be able to order blood tests, and have the results delivered back to them rather than via GP.

CAMHS should be able to direct ECGs and receive results rather than them being delivered back to GP.

Too much dependence on GPs and parents - needs rapid and radical review.

Which CAMHS: Brighton & Hove

Your experience: My daughter is currently waiting for a complete medication change that was considered very urgent in July as my daughter was extremely unwell and facing a hospital admission. Instead a CTR (Care and Treatment review) (chaired by the CCG) said a least restrictive option would be a day hospital place to get her off what she's on and titrated on to something else to stabilise her mood, regulation, and psychotic symptoms. This has not happened.

Community CAMHS have said they cannot manage the risk and the level of care she needs for it to be done in the community, along with issues of capacity. We are stuck. She's doing a bit better now; it needs to be done but her mood is just not stable. She's considered very high risk to herself.

Which CAMHS: Brighton & Hove

Your experience: My daughter is on meds, she moved to residential school last May (because Brighton didn't have a school or respite for her) and still hasn't been taken in by the local CAMHS there, the managers of ... CAMHS and Brighton CAMHS have been arguing and Brighton CAMHS tried to discharge her despite being on controlled meds, then they took her ADHD meds away, saying it was so they could up her other meds (they didn't need to do this, I checked with my other daughter's Dr who is an ADHD specialist) now they won't give her ADHD meds back and are saying the new team need to do it when they take over, despite this having a massive impact on her. but that's so far taken 16 months and nothing. The residential school put in a formal complaint so did the Independent Review Officer.....they've still not sorted it.

In the beginning they refused me meds for years, then after 2 weeks of a residential school not coping, they agreed to medicate her- the same behaviour I had been left to manage.

When she had behavioural activation with meds, it was a year before they tried anything else, despite her symptoms impacting on her to the point where she lost her residential placement.

My eldest daughter was refused meds despite telling them she was taking drugs to manage her anxiety because no one would help her. She ended up on section for 6 months.

They are incompetent, I mean that in a factual way, not as a slur.....I believe that the only way to change it is for people to take legal action.

Which CAMHS: Brighton & Hove

Your experience: I was told they had a locum psychologist, so they were only prioritising review of meds for people that were on them as covid had triggered lots of reviews and they had massive depletion of staff. Therefore we couldn't access new meds for ADHD. I therefore had to go and pay privately to start meds which also included private script costs too which we couldn't afford but couldn't wait yet another year or more to even have the consultation to start meds. Son out of school as MH went massively downhill. CAMHS also said until he's on the right meds and the right dosage and stable they wouldn't take over his care!

Which CAMHS: Brighton & Hove

Your experience: In our assessment appointment, among other empty promises, we were told my son would be seen by a CAMHS psychologist for a prescription to Melatonin for anxiety related sleep issues. After weeks of chasing, we received a letter, which was full of errors and misinformation, discharging my son. Their recommendation was to go back to our GP and get a referral to Seaside View for the sleep issues. The problem with this was that we'd already been passed from GP to SSV (Seaside View) to GP to CAMHS at this point! We did as they suggested and EVENTUALLY got him the medication he needed from the doctor at SSV, but it took an extremely long time.

Which CAMHS: Brighton & Hove

Your experience: (My child) has had reactions to 3 meds now - all listed side effects, 2 of them very dangerous, and yet even this week I've had to defend telling CAHMS that he's hypersensitive and the meds are the issue. To be specific, sertraline - hugely increased harm as soon as reached clinical dose; CAMHS refused to listen, and we were naive enough then. They carried on increasing dose until suicide attempt, and then prescribing psych literally went to ground. GP had to demand a change of practitioner and the wonderful Dr moved (my child) as safely and quickly as possible off the meds and on to others, carefully titrating and supervising - all good with new meds. Second meds for ADHD - pseudo-psychotic episode. Absolutely terrifying. Hearing voices, seeing things, totally altered state.

Had to stand my ground and demand new meds and slow careful titration which I was informed was 'not at all usual to have so many appointments' (!) New meds all good until latest titration level which has resulted in enormous skin rash. Told CAMHS (my child) wants to go back to previous dose as all was good and

stable for 3 months no rash - they said he needs to stop meds totally. Why do they not listen to us ?
Downright dangerous 2/3 times, and so frustrating this week. Got dose back down and rash abated.

Basically, I'm fed up with my kid being put at risk by them refusing to acknowledge ND folk process meds differently, not listening to me as primary carer, and essentially accusing me of lying about what has caused the reactions. It's so arrogant AND dangerous.

Which CAMHS: Brighton & Hove

Your experience: My referral for medication to be prescribed was turned down. I followed up with e-mail and then got apt . They agreed they had misread the letter the referral letter was not read correctly and if I had not followed it up, I would not have got anywhere.

Which CAMHS: Brighton & Hove

Your experience: 24 months in Brighton waiting, no appointments came so paid privately for ADHD assessment and diagnosis... medication given and wow it helped so much!! so went to CAMHS and said we just need a medication take over ...we paid privately...I called, emailed...nothing. we were looking at paying a fortune for medication daily for 3years!! (next available appointment) GP wouldn't touch itso because of CAMHS and Brighton council not allocating a school place after 18months I now live in London !!! school views happening and CAMHS Tower Hamlets gave us an appointment within 6 days! ... about 3k in debt so far because of CAMHS and B&H council.

Which CAMHS: Brighton & Hove

Your experience: I had to leave my son twice on CAMHS doorstep....

First time to get the appointment. After waiting 9mths they wrote expecting me to wait another 8mths. After leaving him there for 3hrs I got the needed appointment.

It took yet another occasion having to leave him there to get medication that was already prescribed, and he had been taking.... but due to their claimed admin mistake an email hadn't been sent to GP to continue prescribing...when pointed out their error, they again expected us to wait weeks for an appointment, so on the second time leaving my son on their doorstep, 1 1/2 hrs later I had the medication in my hand.... on both occasions I was threatened with them calling the police and social services and told I was an abusive parent.

Which CAMHS: Brighton & Hove

Your experience: Wish I could but can't get the appointment in the first place! Just been told the wait is a very long time. Happy to share that letter if helpful but just a standard brush off really.

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Your experience: I can't even get an appointment, all referrals rejected.