

## **List of Questions for Health and Social Security Panel Review into ADHD**

1. What is your experience (or that of your patients) of accessing ADHD medication?

My Personal experience is very poor in trying to get my ADHD medication. This has become harder not only with the lack of medication available, but also that my doctor from Adult Mental Health Dr Jack, left the department to go "alone". Dr Jack was absolutely fabulous, he had a straight manner, but he was to the point, empathetic and attentive to the needs of his patients.

Currently I am only able to get 4 weeks supply. This sounds reasonable to the average person, however I am not the average person. I am a person with diagnosed ADHD and diagnosed Autism trying to function in an unaccepting society causing a HUGE amount of anxiety. I find it extremely difficult to make phone calls, take phone calls, make appointments and go to crowded places.

Life on the spectrum is like walking through a public place full of people and you (me) are the alien. You know all the people around you are going about their business and doing their thing and yet just stepping foot out of the car and into a public space is like being asked to strip naked in town. It's terrifying. Yes, I am a successful individual, I work in finance in compliance and doing well in my field, however, even this is a burden on my brain. To work in this environment, concentrate for long periods of time, work to an outstanding level of accuracy and read law like the bible I MUST be able to have peace in my brain. My medication allows me that peace, it allows me to organise my thoughts and articulate required information, feedback and thoughts.

At this very moment I have been without ADHD medication for 2 weeks, by the time I may get medication I am looking at over 1 month without medication. Not only does this affect my job, but it affects my wellbeing and I am a high risk individual without appropriate medication.

2. Have you (or your patients) had experience of long waiting lists for ADHD medication?

Currently yes I am experiencing a long wait for my medication to be processed and provided to the hospital pharmacy. I'm currently 2 weeks without medication and looking at a further few weeks wait.

3. What feedback have you (or received from your patients) with regards to overall experiences. Could you provide examples?
  
4. What impact do you believe the following have on your (or your patients) health and wellbeing;
  - Waiting times for medication
    - I have nothing to comment on this as this month is the first time I have struggled to get medication. This has been since Dr Jack has left the department. Previously he would always make sure he saw me in time to get my next set of meds, or scheduled a call with me to arrange my next set of meds. I'm now looking at well over a month until I receive medication by which time I will also be off island, so likely 2 months without medication.
  - Frequency of prescriptions issued
    - Prescriptions are issued once a month which is inconvenient. It means chasing the prescription, often several times before one is issued. For example, this month I have had to chase almost daily for a prescription to be issued. When I was first prescribed meds I was provided with more which reduced the anxiety of constantly worrying whether or not I will struggle getting my next prescription. It feels like a constant vicious cycle that I can't get out of and comes around so quickly that I resent my diagnosis. I resent who I am and what I am. I so desperately want to be normal and not have these worries on a continuous basis.
  - Ease of access (costs, timing, location, etc) for prescriptions and medication
    - Ease of access doesn't exist, there is nothing easy about 1, getting my prescription and 2, collecting my prescription. The hospital pharmacy is not the place to be collecting from each

month. They appear understaffed, supplying the hospital, supplying outpatients and others like myself. It has often taken me well over an hour to get to the pharmacy, line up, collect my prescription and get back to work. I then need to work a longer day to make up this time adding further stress and likely for many ADHD people our meds do not last us all day and so we lose concentration needing to do more hours to make up what we have lost. This is a monthly issue and something I have had to take measure with work to explain which is embarrassing.

It is extremely difficult for me to get myself to the hospital to collect prescriptions. I have anxiety days before I collect it, the walk there, the queuing and then the walk back can be so worrying that someone may have to collect them for me if I am desperate and can't make it myself. I'm often accompanied to the pharmacy so that I have the confidence to go. Often my anxiety about collection can be so high I will struggle with my working day.

5. Do you believe that the frequency of prescribing medication could or should be decreased and do you believe that the authority to prescribe medication should be expanded to GP's?

I think a risk-based approach would need to be taken on individuals. Risk assessments should be conducted on each individual. Such as "will they cause harm to themselves if supplied with a lethal amount", "do they have a drug addiction existing that may cause harm to the public should they have enough to sell on" or "do that have an anxious disposition that it detrimental to the timely collection of regular prescriptions". So, positives and negatives should be taken into account on individuals as to whether they are as frequent as monthly or longer.

Yes, GPs should be able to prescribe, however should receive a copy of the risk assessment and confirmation that the mental health of the individual is stable and this confirmation should be dated within 3 months for example. The concern would then be that it would cost us money to be prescribed and some of the ADHD persons are non working. This should be either free or subsidised, although this sounds costly, having appropriately qualified people to do monthly check ins, prescriptions etc is also costly. It may be

that the cost is equal and spreads the overall burden allowing mental health to operate on high risk cases where needed and freeing time to allow the list of over 700 pending diagnosis.

6. What ideas do you have, if any, that may help improve the situation (which could also assist the Panel in its recommendations to the Minister)?

To cover the issue of collecting prescriptions there should be pharmacies that are adequate to dispense controlled substances. Surely there are pharmacies that are allowed to dispense methadone, why not ADHD medication? Having several collection points island wide would again spread the load, make collections less stressful, reduce the hospital pharmacy activity and waiting times. Precautions can be put in place to ensure to ensure safety.

Please also see the above suggestions in question 5.

7. Are you aware of any shortage of ADHD medication on the Island?

Yes I am aware.

8. Do you have any specific experience or ideas that you wish to share with the Panel which may help inform our review?

I fully understand the struggle the mental health department is under and can appreciate the staffing issues as locally we do not have the qualified individuals. However, if we are so woefully understaffed it would be an idea to encourage people into the field by paying for that education and supporting them financially. In return a contract is in place that they MUST work for the Mental Health Department in Jersey for a set number of years which would equal out the amount of funds spent in training and supporting that individual.

For instance, I would absolutely become an ADHD specialist however the schooling, rent, bills and availability to train are not open to me. There are many that would go into this field given the support and opportunity. The government did something similar for midwives I believe, so why not Mental Health?

With confirmation via a “specialist” to the GPs ADHD medication should be made available as it is in the UK via a GP.

I feel the waiting list should not be closed, this may have a detrimental effect on those already feeling hopeless and not being able to be on a list may cause issues. I understand that adding to the list is pointless due to the numbers, but for some just being on a list means there is hope. It should however be communicated to them that the wait is several years and suggested help in the meantime be provide/suggested.

There are varying degrees of ADHD, some people will be unlikely to work, some like myself will succeed but with great difficulty and some will hop from job to job. It is beneficial the economy of the island to invest and help those that need it allowing them to add to the economy and not drain such funds. A person with ADHD can apply themselves in the most brilliant of ways when they understand what is expected, provided a routine and allowances/alternations to their working environment. With the right system in place and understanding more people could be placed into work and made to feel valuable as ADHD can cause people to feel like an alien walking in a human world, it is not a nice feeling and being able to add value is highly important.