

## 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? Private prescription – no issues accessing ADHD medication through non hospital pharmacy
2. Have you (or your patients) had experience of long waiting lists for ADHD medication? In terms of assessment and diagnosis publicly to verify need for medication yes – decision to go privately no experience of any issues to date
3. What feedback have you (or received from your patients) with regards to overall experiences. Could you provide examples? very streamline service via private psychiatrist in collaboration with non hospital pharmacy.
4. What impact do you believe the following have on your (or your patients) health and wellbeing;
  - Waiting times for medication – stress, frustration, worry on the thought of potentially missing doses – missed doses would impact on symptoms potentially returning – those titrated on higher doses would be at risk of unwanted side effects from missing doses and restarting especially if on long acting medication
  - Frequency of prescriptions issued – As this is a controlled drug during the titration/monitoring period this is guided by the psychiatrist frequency of prescriptions can differ in the first few weeks – after titration medication is prescribed monthly -
  - Ease of access (costs, timing, location, etc) for prescriptions and medication - for private prescriptions this has a financial impact. For example if your dose is 40mg and the pharmacy only has 20mg available you are paying for x2 of the medication plus dispensing fee . ( paid just over £200 this month)
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 definitely

believe that that this should be expanded to the GPs. The needs of each individual should be carefully discussed. However following titration of medication – monitoring and review by the psychiatrist , once stability is achieved then arrangements should be made to discuss the need for ongoing medication and management and the consideration of a shared care agreement with GP.

This would have a positive and noticeable impact in reducing the waiting list for assessment and diagnosis for those waiting on the public list. Collaborative partnership is vital and will contribute to reducing the workload in the smaller teams of psychiatrists/psychologists, allowing them to concentrate on assessments and titration management.

This would be advisable for both public and private patients.

It would also achieve a greater understanding of ADHD its management and support required in the wider care groups.

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)?

Good organisation of care across the interface between primary and secondary care is crucial in ensuring that patients/people receive high quality care – and in making the best use of clinical time and Island resources in all care. Good professional practice requires care for patients to be seamless; patients should never be placed in a position where they are unable to obtain the medicines they need, when they need them.

It is essential however, that workloads are not shifted around a system, without overall gain. Using a systematic approach, identify the risks, issues but also what is being done well. Outline opportunities for improved safety and efficiency, identify key barriers that need to be addressed, draft recommendations and invite key

stakeholders to a consultation meeting, include representation from islanders to ensure you have the peoples voice included.

Keep people informed, explain the process, who is involved what are the barriers that affect the system at present i.e local system variants and team cultures? what work will be required to overcome these, what could go wrong.

7. Are you aware of any shortage of ADHD medication on the Island? I have not personally had any issues. However it is key that information goes out via Government communications to care providers and those receiving treatment in a timely manner, to ensure awareness and potential alternative provision can be made and necessary support given- Publicly are their current guidelines for care givers for these situations ? – information for services users ? i.e ‘About your ADHD treatment’ – including what to do if there is a medication shortage

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

One issue I have come across is anyone coming to live in Jersey already with a diagnosis / or residents returning to jersey after diagnosis at university for eg already on medication, are unable to access support to review medication, without going back on the public waiting list (once eligible) or if able to afford it go privately.

In relation to cost privately this needs to be addressed. When you compare the drug tarrif cost – private prescription cost which includes the dispensing fee there is a significant financial concern for those seeking diagnosis.

Eg

June - Drug Taffif price - £82.97      Price paid      £135.91

What are the figures if any on days lost at work through ADHD related sick days those with a diagnosis and those currently on the waiting list – what is the financial report on this ?

More recognition of the recognition and financial support needed for nonprofit groups such as ADHD Jersey who are providing much needed support for Islanders with very little resources. They are an invaluable group who provide courses/ Education/information and support for those already diagnosed and those who are waiting.