Answers to Questions on Notice

26th September 2023 Public Hearing Lived Experience Panel

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Question 1

SENATOR STEELE-JOHN:

If there was one thing that we as a committee could recommend, what would it be?

ANSWER:

My personal soapbox issue is recognising the association with symptomatic hypermobility conditions such as Ehlers Danlos Syndrome, per the supplementary material already forwarded to the Committee including the *Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain* study. The connection with autism is better established, but the link to ADHD also needs to be acknowledged and is especially relevant for those of us in the 'AuDHD' category.

The specific recommendation I would like to see here is for the explicit inclusion of *'Ehlers Danlos Syndrome/Hypermobility Spectrum Disorder'* alongside other potentially co-occurring conditions in the Australian ADHD Professionals Association *Australian evidence-based clinical practice guideline for ADHD*. Please see the commentary in my supplementary material for further information.

The other matter I flagged during the hearing is on cross-border regulation problems. I specifically want to stress the need for understanding and transition support when patients move interstate.

When trying to make arrangements for my own interstate move, I was horrified to read the following statement on SA Health's website:

> ### *Typical tactics*
>
> *The dependent person may admit dependence and offer one or more of the following reasons in support of his or her request for treatment:*
>
> - *Has just arrived from the country or interstate and needs to continue treatment. A letter of introduction, often forged on letterhead may be presented.* ***(If this claim were true, proper arrangements <u>should have been made prior to departure</u>).*** *[Emphasis added]*

This assertion could falsely label an ADHD patient as drug dependent or drug seeking for life, *for a completely predictable and valid manifestation of ADHD*. This is extraordinary ableist and discriminatory, and it was only due to unexpected delays in moving plans that I stumbled upon it before arriving in SA and likely finding myself in this trap.

It caused stress I didn't need at an already stressful time, when I discovered everybody in Adelaide had closed books and had to write to the Drugs of Dependence Unit to confirm my Victorian psychiatrist could continue treating me.

Whatever recommendations the Committee makes on cross-border arrangements, *please* urge state regulatory bodies to show a little compassion and understanding, because with the current shortage of prescribers, they are setting us up to fail and punishing us for it with such assumptions.

<u>Question 2</u> ***(I didn't get the opportunity to answer on the day)***

[UNCERTAIN OF SPEAKER OVER TELECONFERENCE]:

Most of you have experience of working and we've had a bit of discussion about workplace adjustments. I'm interested in the best workplace adjustments that have worked for you. I was going to ask about what hasn't worked, but let's go with the strengths!

What workplace adjustments have you had that have really helped you in being someone with ADHD in a workplace?

ANSWER:

For the love of neurodivergent brains, please understand – and recommend – that fully-remote work is an accessibility need, not just a pandemic convenience for everybody else that can now be rolled back.

I've been unable to work for some time but was actively looking for remote work before COVID arrived and couldn't find it. Then, people who didn't need it for access reasons immediately snapped up all the sudden opportunities that lockdown brought.

The workplace adjustments that would make part-time work accessible to me now are:

- Understanding that you are actively excluding me from your workplace if the job can be done remotely and you won't allow it.
- Understanding that 100% remote work is the key to my productivity.
- Understanding that giving me the freedom to work an agreed number of hours at *any* time over the course of a week allows me to use my most effective hours on producing results for you, even if it's at 3am (I wrote most of my Master's thesis between 12am and 6am, during a self-imposed six-week 'lockdown', because that's the natural rhythm I fell into with no external demands).
- Understanding that some of us aren't cut out for teamwork and not insisting on draining my capacity with unnecessary 'collaboration' or team meetings, even remotely.
- Understanding that ADHD is inseparable from Autism for me, that AuDHD is also inseparable from my associated physical disability, that this makes anything other than working from home completely impossible, and that the above adjustments are how you can benefit from the unique strengths I have to offer and get the most out of every hour I work for you.

Government of South Australia
SA Health

Recognising and handling drug dependent patients

Routine inspection of dispensing records by officers of the Drugs of Dependence Unit have resulted in the detection of prescriptions for drugs of dependence written by prescribers for persons known to the Unit to be dependent on opioids or other drugs.

Drugs obtained on such prescriptions do not help dependent persons overcome their dependency; they delay or disrupt proper treatment and add to the pool of illicit drugs traded and used. Dependent patients regularly 'do the rounds' of prescribers to obtain additional supplies and frequently attend two or more prescribers concurrently.

Characteristics

Dependent persons usually present as:

- A new patient; and/or
- A young person.

Typical tactics

The dependent person may admit dependence and offer one or more of the following reasons in support of his or her request for treatment:

- Has just arrived from the country or interstate and needs to continue treatment. A letter of introduction, often forged on letterhead may be presented. (If this claim were true, proper arrangements should have been made prior to departure).
- Is awaiting admission to hospital. (There is no delay for acute cases).