

The 'Need to Know' self-management communication tool

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Background


Secondary care mental health patients can access the highly specialist mental health & ASD occupational therapy service for intervention, post ASD diagnoses.

Many neurodivergent adults (formerly referred to as neurodiverse, meaning a person who lives with Dyslexia, ASD, ADHD, Developmental Coordination Disorder and/or other neurological conditions), experience difficulties processing everyday sensory information.

Need to Know

NAME: **ADDRESS:** (↻) ✉

I HAVE A DIAGNOSIS OF AUTISM SPECTRUM DISORDER (ASD). I SOMETIMES GET ANXIOUS, I SHOW THIS BY WITHDRAWING FROM OTHERS. MY ABILITY TO COMMUNICATE EFFECTIVELY IS EFFECTED AND MY HANDS MAY SHAKE AND I MAY FEEL PHYSICALLY UNWELL.

Generally I function very well and independently. However, on occasion I can become overwhelmed and may require additional support. Please read this information so you can understand how to effectively manage my needs. 

In a new environment I can appear quiet and reserved, it takes me a little longer to adapt to new situations/ experiences. Once it becomes familiar I'm able to relax and be more myself.

Stimming, fidgeting and tapping can be more visible when I'm attempting to sit still, this helps me to concentrate.

I find uncertainty and change difficult. Please could you explain to me what's happening, why it's happening and what to expect next. If there's anything that I should be doing, please tell me step-by-step. Thank you for your patience, I'm not being difficult, I have ASD.

I may need to remove myself from the situation and find a quiet space. Once in a quiet space I will follow my meltdown management plan independently.


I find total silence unsettling and benefit from low level background noise (generally I will wear headphones). 

Figure 1

A form titled 'Need to Know'. At the top of the form, it says 'I have a diagnosis of autism spectrum disorder (ASD). I Sometimes get anxious; I show this by withdrawing from others. My ability to communicate effectively is affected and my hands may shake and I may feel physically unwell.

Beneath this are 6 boxes; 2 red, 2 yellow 2 green.

Red box one reads:

- Generally, I function very well and independently. However, on occasion, I can become overwhelmed and may require additional support.

Red box two reads:

- I find uncertainty and change difficult. Please could you explain to me what's happening, why it's happening, and what to expect next. If there's anything that I should be doing, please tell me step by step.

Yellow box one reads:

- In a new environment I can appear quiet and reserved. It takes me a little longer to adapt to new situations and experiences. Once it becomes familiar, I'm able to relax and be more myself.

Yellow box two reads:

- I may need to remove myself from the situation and find a quiet space. Once in a quiet space I will follow my meltdown management plan independently.

Green box one reads:

- Stimming, fidgeting, and tapping can be more visible when I'm attempting to sit still. This helps me to concentrate.

Green box two reads:

- I find total silence unsettling and benefit from low level background noise (generally I will wear headphones).

End of description

The 'Need to Know' document (formerly known as the Patient Passport) promotes self-management by formulating specific sensory strategies that aim to reduce the likelihood of sensory overload. The 'Need to Know' document communicates the person's sensory differences at times when they are unable to. The self-management communication tool is co-produced with the person as part of specialist intervention.

The long term vision is for people to access the tool online through an open-access mobile application, reducing the need for referral to specialist services.

Project Aims

- Explore a suitable title for the communication tool to replace 'patient passport,' anecdotal evidence suggest the title 'patient passport' is disabling for the person outside of health care settings. The communication tool has proved helpful in colleges, universities or employment settings.
- To conduct a small scale evaluation (using self-reporting questionnaires), to explore if there is an appetite to develop the existing paper document into an electronic version (App) in the CTMUHB ASD population.
- Approach reputable national ASD organisations to explore their interest and willingness to launch and host the App from their website.
- The long term vision involves securing an industry partner to further develop the communication tool into an online, open access web based application. The App could potentially be modified and rolled out beyond the autistic community for use with dementia and multiple other lifelong conditions.

Challenges

Prior to the Covid-19 pandemic, networking to explore a potential industry partner was both exciting and encouraging. Despite anticipated time management challenges associated with managing the Bevan project alongside clinical commitments. The aim of the project shifted direction, the initial idea of developing the paper document into an App was placed on hold to allow for a full evaluation of the paper format (to ensure the content of the potential App remained both meaningful and relevant).

Looking to the future, the project was presented to the University of South Wales as a potential PhD study. When Covid-19 hit, opportunities to secure funding for a PhD study became a challenge with the majority of funding being diverted to Covid-19 research. Funding issues, alongside clinical commitments, saw the idea suspended with patient caretaking priority.

Key Outcomes

Patients reflected on how the 'Need to Know' document supported them to communicate sensory differences. They told us:

"It's an amazing tool, especially when I visit my GP/ hospital. It's not always easy to express yourself. All my individualised information is detailed in the Need to know doc. Now all I have to do is show it to them. It's a great help!"

"It's a wonderful, empowering tool. It's great for communicating my needs at times when I'm unable to and avoids the need for repetition."

Next Steps

- The next steps involve continuing to work co-productively with patients to ensure the "Need to Know" document meets the identified need, resulting in improved patient outcomes and experiences.

- A small scale service evaluation of the “Need to Know” document has been approved by CTMUHB Research & Development Department.
- In readiness to undertake a PhD study, a PhD proposal and study plan will be submitted to University of South Wales.

Bevan Exemplar Experience

I have great admiration for the Bevan Commission and their support and enthusiasm for healthcare innovation. I feel grateful for the opportunity I have received.

Emma Francis

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