

DLO advocacy for patients with intellectual disability

Lived experience acknowledgement

We value and celebrate the potential of all people and honour the lived experience of disability as a vital form of expertise.

We respectfully acknowledge the diverse experiences of people with disability, their families, carers and supporters.

We remember that we come together today because of the lived experience of people with disability who have not had a seat at the table before.

DLO services at Alfred Care Group

Clinical services include:

- Supporting patients and their networks through planned and unplanned admissions
- Liaison with other health and DLO services to support patient transitions
- Liaison with clinical services to maximise equitable access to care

Non-clinical work includes:

- Education sessions to upskill staff and promote DLO services
- Advocacy via participation across internal and external steering groups and working groups
- Quality improvement and research projects through co-design

Case study: 'Mai'

About Mai:

- 18-year-old female with epilepsy and ID, living with parents and siblings in a rural area
- Attended the Video Epilepsy Monitoring (VEM) clinic for a 5-day admission
- First time attending Alfred Hospital, and first hospital appointment since turning 18
- Wanted to 'be her own boss' and do things herself, with some parental support
- Needle-phobic and had not experienced a hospital stay on her own before

DLO involvement in broader advocacy:

- DLO involvement in the pre-admission process for VEM patients with disability
- Development of social scripts for VEM patients to know what to expect during their admission

DLO involvement in patient advocacy:

- Pre-admission contact with Mai and her parents to develop a Disability Adjustment Summary
- Liaison with VEM clinic to advocate for suitable bed space, social visits by volunteers, and needle phobia supports
- Joint development of an Easy English discharge summary with clinic staff
- Explanation of the Hidden Disability Sunflower program to empower Mai's independence

Questions?

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