Tory and Courtney's story about supporting someone before and after they go to hospital

When we received the call from support staff early on a Tuesday morning, we knew the day would require coordination, clarity, and collaboration.

A participant we support through the NDIS was being transferred to hospital following a sudden deterioration in their health. While the hospital staff were responsive and professional, as is often the case they were unfamiliar with the participant’s communication needs, daily routines, and the supports that help them remain safe and regulated.

From a service provider perspective, moments like this clearly demonstrate how the NDIS and NSW Health systems intersect—but do not duplicate one another.

Immediate Response and Information Sharing

Our first step was to engage appropriate support staff to attend and assist the participant in the emergency department, while also determining clinical status and liaising with family members and appointed decision makers to ensure they were informed and supported.

While NSW Health assumed responsibility for all medical treatment and clinical care, our role focused on non-clinical supports, ensuring the participant’s needs as a person—not just as a patient—were understood and communicated.

We provided the ward with key information, including:

The participant’s communication preferences

Information about behaviours of concern and known triggers

Details of legal decision makers and emergency contacts

Daily living needs that may impact care, such as mobility requirements, personal care preferences, and sensory sensitivities

This information often fills a critical gap. Hospital environments are fast paced and risk focused, whereas NDIS supports are built around routine, familiarity, and long term wellbeing.

Clarifying Roles: Health vs NDIS

Throughout the admission, consistent communication was maintained to ensure roles and boundaries were clear and respected:

NSW Health managed all clinical decisions, medication administration, nursing care, and discharge planning from a medical perspective.

Our service supported the participant emotionally, assisted with communication, and helped them cope with the unfamiliar hospital environment—where this was appropriate and agreed.

We were mindful not to overstep into areas that sit solely within Health's responsibility. At the same time, we advocated strongly to ensure clinical decisions were informed by a full understanding of the participant's disability related needs.

Supporting the Participant, Not Replacing the Hospital

Hospital admissions can be extremely distressing for people with disability. Noise, lighting, frequent staff changes, and disruptions to established routines can quickly escalate anxiety or behaviours of concern.

Where permitted, our staff supported the participant to:

Understand what was happening and what to expect

Communicate pain, discomfort, or fear

Feel reassured through familiar faces, communication styles, and support approaches

These supports reduced distress, lowered the risk of escalation, and helped hospital staff to deliver care more effectively.

Discharge Planning: Where Systems Must Meet

Discharge planning is where the NDIS–Health interface becomes most visible—and often most challenging—if not managed well.

From early in the admission, we engaged with hospital staff regarding:

Expected discharge timeframes

Any changes to the participant's capacity or support needs

Equipment requirements, medication changes, and follow up appointments

While NSW Health determines when a person is medically ready for discharge, NDIS supports must be in place for discharge to be safe and sustainable. Where care needs change, supports cannot be assumed to adjust instantly.

We worked closely with Support Coordinators and the participant's family to ensure:

Support hours aligned with post hospital needs

Support staff were briefed on changes to care requirements

Family members and guardians understood the next steps

A rushed discharge without adequate planning or supports in place increases the risk of readmission—a risk for everyone involved.

Reflections From the Service Perspective

Hospital admissions highlight both the strengths and gaps that can exist between service systems.

When collaboration works well:

Participants feel safer and better understood

Hospital staff are supported to focus on clinical care

Transitions are smoother and outcomes improve

When roles are unclear or communication is rushed, participants can easily fall between systems.

From our perspective as a service provider, our role is not to replace NSW Health, but to bridge understanding, advocate appropriately, and maintain the participant's voice during a vulnerable time.

Every hospital admission reinforces the importance of respectful collaboration, clear

> An older woman is in a hospital bed. Her daughter is visiting her and they are holding h

Who is it for?

Family and carers,
Professionals,
People with complex disability

What is it about?

NDIS and your health,
Ways to get better health care,
When you are in hospital,
How professionals, family and carers can respect health rights

Who made it?

Tory and Courtney

When was it made?

It was shared here 3 weeks ago.

This story was made by

Tory and Courtney

Tory and Courtney work at Gresytanes Disability Services and are members of the Our Health Space Community.