

Going to Hospital Training for Disability Support Staff



Admission2Discharge Together Project

HOSPITAL SUPPORT INFORMATION

A2D Admission 2 Discharge Together

For a person with an intellectual disability going to hospital

STOP Do not proceed without your patient's **Medication Chart & Blister Pack**

CAUTION Be familiar with your patient's **Top 5 Tips for Support** **TOP 5**

GO You have in place your patient's **Hospital Support Plan**

- Mealtime Management Plan
- Behaviour Support Strategies
- Bowel Management Plan
- Procedure Care Plan
- Manual Handling Plan
- Recent Medical Reports

Name: _____

Person likes to be called: _____

If you are supporting this person in hospital please read this. It contains important information about their health and personal support needs.

If person is unable to consent to treatment please call:

Name: _____ Name: _____

Relationship: _____ Relationship: _____

Contact: _____ Contact: _____

This information belongs to the person named. Please return it when person goes home.

Place a copy of the **TOP 5** in nursing notes

The rest of the information stays with this person at all times.

Developed by: FACS South Eastern Sydney District & South Eastern Sydney Local Health District.

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Improving the hospital experience for a person with an intellectual disability

This training manual was developed in response to the release of NSW Health and Ageing Disability and Homecare (ADHC) Joint Guideline (2013) to Support Residents of FACS disability (formally ADHC) Operated and Funded Accommodation Support Services who attend or are admitted to a NSW Public Hospital. The Joint Guideline outlines responsibilities of FACS and NSW Health in the development and implementation of protocols to ensure people with disability are well looked after and are treated with dignity when admitted to NSW public hospitals with the primary focus being on person centred care and the upholding of the persons human rights.

Target Group: Disability support staff and Managers who support people with intellectual disability who live in supported accommodation.

Prerequisite to “Going to Hospital” training:

- Read and understand the Joint Guideline “*Support residents of ADHC group homes who attend or are admitted to a NSW Public Hospital*”
- Complete “Hospitalisation” training on ELMO. To access ELMO please use the link below.

<http://www.elearn.com.au/adhc/goodtogreat>

Login details are:

1. user name: **adhc**
2. password: **goodtogreat**

Resources:

- A sample of **A2D** Together Folders
- Copy of Joint Guideline “*Support residents of ADHC group homes who attend or are admitted to a NSW Public Hospital*”

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Learning Outcomes

Understand the legislative framework that supports the rights of people with disability to receive the same standard of healthcare as all Australian citizens.

Discuss and understand the Ombudsman report into preventing deaths of people with disability in care

Understand the importance of supporting the health needs of people with intellectual disability and what your duty of care is

Understand the principles of The Joint Guideline and how to implement this when a person goes to hospital in either a planned / unplanned admission.

Understand the role of the guardian and consent to medical and dental treatment.

Understand the purpose of the A2D Together folder, how to put one together, keep it current and who is responsible for ensuring that the person takes it to hospital.

Understand the roles and responsibilities of the disability support staff when supporting a person go to hospital in both a planned and unplanned admission.

Understand WHS issues for staff who support a person who goes to hospital.

Understand what discharge planning is and how to ensure that the person's "transfer of care" is coordinated effectively to ensure a positive outcome for the person.

Thank you for taking the time to engage in this important training

Introduction

Health of people with disabilities

In 2007–2008, 46 per cent of people aged 15-64 years with severe or profound disability reported poor or fair health, compared to only 5 per cent for those without disability. The average person with disability has more than three long-term or chronic health conditions that may not be directly associated with their disability.

People with disability have a rate of hospitalisation significantly higher than the rest of the NSW population; particularly those aged over 65 years. People with disability using FACS (ADHC) and/or HACC services were found in 2012 to be consistently over-represented in admissions for conditions such as diseases and disorders of the nervous system, the respiratory system and the kidneys and urinary tract. People with disability who have a mental illness are also over-represented in NSW in hospital use.

There are many challenges for people with disability, their support staff, families and the health system in providing the kind of support that a person needs and is entitled to when they are admitted to hospital either in a planned way or in an emergency situation.

Healthcare needs of people with an intellectual disability

Healthcare for people with intellectual disability has been characterised by a lack of communication, poor understanding of their everyday and special health needs and poor procedures for the delivery of services.

Contemporary research indicates that people with intellectual disability continue to experience poorer health outcomes and have more difficulty in obtaining the necessary health services in comparison with other populations (Krahn & Drum 2007). They experience a high prevalence of significant medical and mental health problems compared to the general population as well as conditions often being unrecognised, misdiagnosed and poorly managed (AIHW 2008, Lennox & Kerr)

Legislative Framework

The *Disability Inclusion Act 2014* was implemented on 3rd of December 2014

The objects of the Act include:

- To acknowledge that people with disability have the same human rights as other members of the community and that the State and community have a responsibility to facilitate the exercise of those rights.
- To enable people with a disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports and services.
- To provide safeguards in relation to the delivery of supports and services for people with disability.
- To support, to the extent reasonably practicable, the purposes and principle of the United Nations Convention on the rights of Persons with Disability.

Article 25 of the United Nations Convention on the rights of Persons with Disability states:

Persons' with disability have a right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

NSW Disability Inclusion Plan

The Plan was launched by the Hon. John Ajaka (Minister for Disability Services) in February 2015. The NSW Disability Inclusion Plan supports NSW Government's commitment to remove systemic and attitudinal barriers so that people with disability have a better opportunity to live a meaningful life and enjoy the full benefits of membership in the community. Achieving an inclusive society is a long term vision that will require consistent efforts from government and the wider community.

The four focus areas of the **NSW Disability Inclusion Plan** are:

1. Developing positive community attitudes and behaviours
2. Creating liveable communities
3. Supporting access to meaningful employment
4. Improving access to mainstream services through better systems and processes.

Preventing deaths of people with disabilities in care

NSW Ombudsman

The NSW Ombudsman's office reviews the deaths of people with disabilities in care, including residents of accommodation services operated or funded by FACS. The purpose of these reviews is to identify deaths that were preventable and to make recommendations to prevent or reduce such deaths.

On average people in disability services die around 25 years younger than the general population

Key Messages from the Reviewable Deaths Report:

In 2012-13, the deaths of **239** people with disability in care were reviewable.

- **121 (51%)** of these people lived in FACS accommodation
- **101 people (42%)** lived in non-government (FACS-funded) accommodation
- **14 people (6%)** lived in assisted boarding houses
- 3 people (1%) were living in private or community housing with FACS or NGO support
- On average people were **55 years old** when they died, **25 years younger** than the general population.

The leading causes of death include:

- **Respiratory** diseases (24%) mainly pneumonia and aspiration pneumonia
- **Nervous system** disease (17%) mainly epilepsy and cerebral palsy
- **Neoplasms** (16%) mainly lung and bowel cancer
- **Circulatory diseases** (13%) primarily ischemic heart diseases
- External causes (7%) mainly **choking** on food

MANY OF THESE DEATHS ARE PREVENTABLE

*Have you read the Ombudsman fact sheet on “**Preventing deaths of people with disabilities in care**”? (Information for staff in disability services – available in Appendix 5)*

Below are some of the most common health conditions for people living in supported accommodation

- Dysphagia / Aspirational pneumonia
- Epilepsy
- Constipation and Bowel obstructions
- Obesity
- Heart problems.
- Mental Illness

Many residents experience problems with eating and drinking that require their meals and / or fluids to be modified in some way to minimise risks of choking or aspiration.

⇒ **Discussion:**

Please refer back to the Ombudsman fact sheet: *“Preventing deaths of people with disabilities in care Information for staff of disability services”* and look again at the main causes of death on the first page. What do you notice about the information on the fact sheet and the common health concerns that the people living in supported accommodation experience?

It is extremely important that you are aware of the specific health and support needs of the people you provide day to day support to.

It is essential that you **know the person you support** and understand the specific support people need to stay healthy and well and know how critical it is that they receive the required help and assistance . An example of this is that a person you support needs to have their food chopped and they need full supervision all all mealtimes because they are at risk of choking.

⇒ **Discussion:**

What is your duty of care to a person who has a Mealtime Management Plan, a bowel Management plan, Mental Health plan, Epilepsy Manangement Plan?

What could be some consequences to the person's health if you didn't follow this plan?

“Prevention is Better than the Cure”

You need to be able to tell if the person is sick or needs help. Spending time with the person and taking notice of their day to day health and general wellbeing will be a key element in preventing health complications. Annual health assessments and regular reviews with their GP can provide valuable assistance in managing many of the risks to the person's health.

The NSW Ombudsman has noted in their Fact Sheet that people with disabilities die very soon after showing signs of illness so it is important that you get medical help for the person as soon as possible.

The tool below (DRAFT) “Growing Concerns Tool for the Disability Sector: Supporting People with Intellectual Disability when you think they might be unwell”, has been developed by the Agency for Clinical Innovation (ACI) as another way to assess the health needs of a person.

Growing Concerns Tool for the Disability Sector

S	Seems different / not themselves / less interested in things
T	Talks or communicates less / more / differently
O	Overall needs more help
P	Pain - is there something which might be causing them pain?
A	Ate less than usual
N	No bowel movement in 3 days (or diarrhoea)
D	Drank less than usual
W	Weight change
A	Agitated or nervous, more than usual
T	Tired, confused, drowsy, upset
C	Change in skin colour, coughing or breathless
H	Help with walking, moving, toileting, more than usual

CALL Triple Zero (000) and ask for Ambulance assistance if there is a medical emergency.

If you notice any changes in the person’s health, behaviour, mood, motivation, sleep patterns, eating, weight loss / gain, a change in bowel habits (i.e. the person is constipated or person has very loose bowel movements) it is important that you:

- Speak with the person (and their carer) about your concerns
- TALK to your team leader and let them know your concerns.
- Document your concerns in the person’s notes so other staff are aware and they can observe the person too. Take the person to their GP and discuss the concerns.
- Always follow the advice from the GP and other health professionals.
- **Make sure you know what to do in a medical emergency.**
- Where a person is on five or more medications, a Domiciliary Medication Management Review (DMMR) may be appropriate. The person’s GP can organise this.

Duty of Care

⇒ Discussion:

You have a duty of care to the people you support. *Considering the common health issues that were discussed, what do you think your duty of care is the people you support?*

The definition of Duty of Care is:

‘To take reasonable steps to prevent foreseeable harm’.

In other words, as an employee your duty of care means that you are in a position where someone relies on you to be careful (take reasonable steps), and where, if you are not careful, it is possible (foreseeable) that the person might suffer harm or distress.

Case Study

A 74 year old man who lives in a Group home was admitted to hospital in an emergency situation. He went to hospital by ambulance and he was not supported by staff. He has a severe intellectual disability, is deaf, has reduced mobility and is non-verbal. He needs his food modified as he is at risk of choking. The staff at the ED had no information about this man and it wasn’t clear if information was sent with him or it got ‘lost’ in the transfer of care. Luckily a nurse working in ED at that time had met this man before and knew that he lived in a group home. This nurse was then able to make a call to someone who was able to provide a contact number for the staff. This man was in hospital on his own, unable to speak and therefore unable to tell the nurse why he was in hospital.

What are the risks associated with this scenario? How does this fit with your duty of care?

What action would you take to address this situation?

Remember; the people you support rely on you to follow proper procedures. If you are not careful, it is possible (foreseeable) that a person might suffer harm as a result of an error that you made or failure to follow up on an identified health issue.

Breach of duty of care: You can be found to be in breach of your duty of care if all of the health care procedures are in place, you have been trained in the procedures but you haven't followed them.

If it can be proven that you did something you should not have done, or failed to do something that you should have done which resulted in an injury, illness or harm, then you have breached your duty of care.

Negligence: Negligence is where there is a failure to provide the standard of care required by a staff member's position, qualification or experience which results in injury. This can result in a civil action against the staff member and / or the employer.

To be found negligent in a court of law it must be proven that:

- a duty of care existed;
- a harmful incident was reasonably foreseeable;
- harm has been suffered; and
- harm is a result of not taking reasonable care.

NSW Health and FACS Joint Guidelines

Following recommendations made by the NSW Ombudsman regarding the appropriate support of people with disability during hospitalisation, NSW Health and FACS (ADHC) operated and funded accommodation agreed to develop The Joint Guidelines to assist staff of respective agencies to establish and implement agreed local arrangements. As a result of The Joint Guidelines, The Admission2Discharge Together project was launched in 2015, in collaboration with South East and South West Local Health Districts.

The aims of the project Admission2Discharge Together - Improving the hospital experience for people with intellectual disability' are to:

- Assist clinical staff to meet the needs of persons' with an intellectual disability, who may be non-verbal or display behaviours of concern in the hospital setting.
- Involve carers / Disability Support Staff as partners in care through the development of a **TOP 5** and a Hospital Support Plan. An Admission2Discharge (A2D) Together folder will be used to present this information in a consistent and easy to access format.
- Increase the integration of care and a smooth transition in and out of hospital for people living in FACS operated and funded group homes.
- Implement The Joint Guideline (GL2013_001) *Supporting Residents of ADHC Operated and Funded Accommodation Support Service who present to a Public Hospital.*

Principals of the Joint Guideline

Person centred approach

Person Centred approaches underpin the way people are supported and reflect a different way of thinking about the person. Person centred thinking places the person at the centre, it looks at the whole of someone's life from the person's perspective to discover what is important to them and what is important for their health and wellbeing and how they will be supported to achieve this. For the person to be at the centre of decision making he or she needs to be well informed about what is going on during a hospital stay.

Patient Centred Care

Patient centred care is geared toward developing a culture where the patient is both at the heart of the system, and the driver behind every change.

Communication

Good communication between the person, their family / guardian, medical / hospital staff, disability support staff is vital for the person and can make a positive difference to the person's health outcomes and their hospital experience. NSW Health Policy emphasises the need for hospital staff to communicate directly with the person, and include the person's family and guardian, disability support staff / nurses.

Disability support staff have a responsibility to ensure that hospital staff are aware of how the person communicates. This information will be included in the person’s hospital support plan and in the **TOP 5** in the person’s **A2D Together** folder. Specific communication needs, communicate aids, unique signs and behaviours that communicate specific messages will be discussed at the time of the hospital admission and included in the person’s notes and **TOP 5**.

Communication and Decision Making when in hospital

Effective communication is essential to ensure that the person receives the care they need for a speedy recovery. Effective communication can also ensure that the rights and dignity of the person are upheld. Communication is difficult for some people with disability (e.g. person may be non-verbal and unable to tell the health professional what is wrong). It may also be a challenge for health staff who may not know/understand how to communicate effectively with the person. This can sometimes lead to communication breakdowns between Health staff, the person / disability support staff .Faulty perceptions can also impact on the provision of patient centred care. Relevant information will be included in the person’s hospital support plan and in the **TOP 5** in the person’s **A2D Together** folder. It is important that the health professional reads this information to understand the specific communication needs of the person.

Remember: Do not assume that the person will have communication barriers because they have a disability, but they may. **Listen to the person and you will hear them.**

⇒ Discussion:

Case Study

Anne has quadriplegia (paralysis caused by illness or injury that results in the partial or total loss of use of all four limbs and torso). Anne was admitted to hospital for pneumonia. The attendant doctor assumed that she did not talk and could not understand him. The doctor spoke to the support nurse who had accompanied Anne to hospital. When questioned by the nurse about why he wasn’t addressing his patient directly, the doctor replied: “Does she talk?”

If you were supporting Anne in the scenario what would you do to address the situation?

Sharing Information

Key information that hospital staff need to know about the person and their support needs should be provided in a universally consistent format and travel with the person around the hospital so that any health care professional can access it. The person will take their **A2D Together** folder to any and ALL planned / unplanned admissions.

Two to three copies of **TOP 5** are included in the folder. One copy is given to the hospital staff at the time of admission to be placed in the nursing notes, and the other copy stay in the A2D Together Folder .The A2D Together Folder must stay with the person at all times.

Part 1 of the Hospital Support Plan contains all of the relevant and personal information, consent, medical and support information for hospital staff to provide safe and effective healthcare that is person and patient centred. The Hospital Support Plan is kept in the green section of the **A2D** Together folder and this is kept with the person at all times.

Sharing expertise

Sharing expertise ensures that people with disability receive the best care and the best health outcomes. Establishing collaborative and respectful partnerships between the hospital staff and the disability support staff is essential to achieve the best health outcomes for the person. Best health care outcomes are central to The Joint Guideline.

Part 2 of the Hospital Support Plan is designed to facilitate the sharing of clinical and disability support expertise. It is completed in partnership with the hospital staff and the person, the disability support staff , Nursing Unit Manager, person responsible/ guardian at the pre-admission meeting or as soon as the person is settled following an unplanned admission to hospital

Capacity to Consent

It is the responsibility of the treating practitioner to determine if the person is able to give consent for medical or dental treatment. Disability support staff cannot provide consent for medical or dental treatment under any circumstance but must ensure that the person responsible for giving consent is recorded on the front cover of the **A2D** Together folder and in the person's Hospital Support Plan.

Consent requirements will vary depending on the capacity of the person to give informed consent about medical treatments. Some people will be able to consent to their treatment but if the person isn't capable of doing this the responsibility will fall to the person responsible.

The Guardianship division of the NSW Civil & Administrative Tribunal has the authority to designate substitute consent authority and in some cases provide consent to medical treatment for people 16 years and over who are not capable of consenting to their own treatment. They can also provide all advice and information related to consent requirements. They can be contacted on the numbers below.

Consent requirements can differ for different types of treatments so it is important that Managers and Disability Support Staff have sound knowledge of consent requirements (refer to the appendix for more information on NCAT fact sheets on consent requirements).

Guardianship Division

Tel: (02) 95567600
Fax: (02) 95559049
Email: gd@ncat.nsw.gov.au
Website: www.ncat.gov.au

⇒ Discussion:

Case Study

A Disability Support Worker was asked by a doctor in a public hospital if they would give permission to refuse medical intervention for a client in palliative care. The doctor knew they were a paid employee, not a family member. It has also been recorded that medical staff can be unwilling to accept a person with disability consenting to treatment themselves, even where this is entirely appropriate. It is the law to assume that every person has capacity to make their own decisions.

(Page 20 "People with disability and hospitalisation: Challenges and opportunities in NSW", NDS Background Paper, National Disability Services, NSW, April 2014)

Discuss this scenario with your partner? What would you do if this happened to you?

Remember:

Disability Support Staff do not give consent for medical treatment; this can only be provided by the person themselves, their appointed guardian or the person responsible. The role of the support staff is to support the person whilst they are in hospital and to provide the health professional with the contact details of the person responsible/ guardian. This information will be included on the front page of the **A2D Together folder** and in **Part 1 of the person's Hospital Support Plan**

Going to Hospital

Imagine the following scenario

You are on holidays in a country where you don't speak the language. You are on your own and as you cross the road you are hit by a car. You hit your head on the ground. You are disorientated and can't remember what happened or where you are. People rush to your aid and someone calls an ambulance.

In all of the chaos someone steals your backpack that holds your passport and your driver's licence. You don't have any identification so nobody knows who you are.

You are admitted to the ED and there are people rushing around you and asking questions. You don't understand what they are saying and you don't know what's happened to you and you don't know why you are there. People are putting tubes in your arms and talking about you as if you aren't there.

They might be saying things about you but you don't understand so you can't be sure. You don't know what happened to you and nobody is telling you anything. They just keep talking with each other as if you aren't there. You know they are helping you but you don't know what they're doing. You ask them what happened but they ignore you. You become very distressed and try to get out of the bed. They hold you down.

⇒ **Discussion:**

Take a few minutes now and think about how you would feel

Going to hospital can be a very scary experience for most people. It can sometimes feel a bit like the scenario above. Think about a time in the past when you had an experience of going to hospital or your supported someone who had to go to hospital. This can be a planned or unplanned admission.

Can you describe what that experience was like?

*Write down some of the potential risks the people you support **could** experience to their health and wellbeing if important information didn't go to the hospital with them?*

Discuss some the common health/behaviour/communication issues that the people you support experience, what are some of the additional risks to the person when they go to hospital?

Do you think good planning is needed when a person you support needs to go to hospital? Why?

Planning for and supporting hospital stays for people with disability

The positive or negative experiences (of time spent) in hospital for a person with disability depends largely upon effective communication between disability support staff, hospital staff and treating doctors. It also depends on the sharing of accurate and relevant information that will help everyone involved understand how best to support the person while in hospital.

Health and Disability Professionals play a key role in planning for, and supporting people who need to go to hospital. Don't ever underestimate the importance of your role in the person's health outcomes. Remember this person is someone's son or daughter, brother or sister, aunt or uncle and they rely on you!

When a person is admitted to hospital in a planned or unplanned way they will need to have a current **Admission2Discharge (A2D) Together Folder**.

The purpose of the **A2D Together Folder** is to provide:

- Accurate, up to date and relevant information to hospital staff about the specific personal and medical needs of the person.
- Information that is accessible and easy to find so that the support needs of the person can be easily met.

Case Study

Valentine is a 68 year old man who lives in a group home. Val is a very sociable man with a great sense of humour. He enjoys chatting to people and responds well to staff who present as calm, positive, motivated to engage in Val's interests and who are respectful of his space and wishes.

Val has an intellectual disability and paranoid schizophrenia. Val can present in the hospital setting with complex behaviours due to his mental health diagnosis. If Val is admitted to ED he may become distressed and engage in aggressive behaviours. He is at high choking risk and his food needs to be modified and he needs full supervision while eating. He has Type 2 Diabetes, Epilepsy and Oedema in both legs. He needs assistance with transfers and walking. Val suffers from chronic constipation. He has recurrent chest infections.

Valentine was admitted to hospital (2014) by ambulance due to a medical emergency. His support staff was unable to go with him as they were supporting the other 3 residents. Valentine doesn't understand the risks associated with his eating so didn't tell the nursing staff that his meals needed to be modified. He went to hospital with his **TOP 5** tips for support and this included information about his choking risk. It is not clear what happened to this information during the time of his admission.

Staff from his home went to visit him and found him sitting in a recliner chair and he was eating a white bread sandwich. The Disability Support Staff was able to intervene at this time and tell the hospital staff of the significant risk to Val. It was reported by the Team Leader of the home where Val lives that this happened on more than one occasion even though all of the information about Val's health and wellbeing needs were sent to the hospital.

⇒ Discussion:

What went wrong for this man?

How can a situation like this be prevented?

What's your role?

This case study is based on an actual event that occurred and 'Val' now has an **A2D Together Folder**. As Val is ageing and showing early signs of dementia he has had multiple admissions to his local hospital since 2015.

His **A2D Together Folder** goes with him every time he goes to hospital and it has made a positive difference to his hospital experience and provides the health professionals with important information about his specific needs.

Hospital Admissions

What disability support staff would be involved in the hospital admission of a person they support?

What do you think your role as a disability support worker is in supporting a person who needs to go to hospital?

Role of disability support staff and managers in supporting a person to go to hospital

The key to a successful hospital experience for the person is to be prepared for ALL hospital admissions **before they happen**. This can be achieved when everyone works together and clearly understand the complex issues that people with intellectual disability experience in NSW hospitals.

Tips to make this experience possible:

- Understand the health problems that the people you support experience and know when to call for ambulance assistance when the person is not well.
- Read and understand [NSW Health & Ageing and Disability and Home Care \(ADHC\) Joint Guideline: Supporting residents of ADHC operated and funded accommodation supported services who present to a NSW Public hospital \(2013\)](#).
- Complete an A2D Together folder. Have it located in a place in the house where all staff can see it (including casual and agency staff). Keep it up to date by reviewing it monthly or sooner if the person's needs change.
- Have a clear understanding of the challenges that people experience in the hospital setting and ensure that all efforts are made to minimise risks by including all of the relevant information in their *A2D Together Folder* and ensure that any health professional involved with the person has access to this information.
- Make sure staff know what to do if the person is admitted to hospital in an emergency situation (including casual and agency staff).
- Include Hospital Support Planning in the team meeting agenda.
- Make sure staff are trained in how to support a person in hospital (including casual and agency staff).
- Make sure that the appropriate support is provided to people when they go to hospital.
- Be clear about what a Disability Support Staff can and cannot do in the hospital setting.

Tell the hospital staff about your role.

Going to hospital – Planned versus emergency

⇒ Discussion:

What sorts of things do you see as your role in supporting a person to go to hospital in a planned way?

How does this differ from what your responsibilities are when supporting them in an unplanned way?

Emergency (unplanned) admission to hospital

Step by step guide for disability accommodation services

In an emergency or unplanned admission, a Disability Support Staff familiar with the person should accompany them to hospital unless that person is the only staff member on duty. If there is a medical emergency staff must:

1. Ensure the immediate safety of the person by applying first aid procedures and **call Triple Zero 000 and ask for an ambulance**. Provide contact details and the reason for calling.
2. Get the person's **A2D** Together Folder ready.
3. Put the person's medication chart and blister pack / other medication in the red section of the folder.
4. Give the **A2D** Together folder and all medication to the paramedic team.
5. Tell them it's important that they hand this to the hospital staff during transfer of care because it contains very important information about the person's health and personal support needs.
6. Show them the person's **TOP 5** and explain that it will help them to understand the person's specific communication needs, likes dislikes, preference for support etc.
7. Reinforce the importance of keeping the information with the person.
8. Ask the paramedic which hospital they are taking the person to (note this can change if the paramedics get redirected to another hospital – you can call the hospital's switch to confirm that the person is in the hospital)*.
9. Contact the line-manager / on call manager and let them know the situation. If necessary the line-manager / on call manager will organise for another staff to go to the hospital to support the person. This will depend on the needs of the individual.
10. Contact the person's family if needed or requested.

The Manager or appointed Disability Support staff is responsible for going to the hospital as soon as possible after the person has been admitted to provide support to the person and if necessary to complete **Part 2** of the hospital support plan.

This time will also allow the support staff to:

- Check that the person's A2D Together Folder is with them and it is visible to the nurses, health professionals and that they have read the information.

- Check that their TOP 5 has been placed in the nursing notes and on the wall next to the person's bed.
- Check that the hospital staff have read and understand the contents of the folder. Explain the purpose and importance of the folder if the hospital staff are unfamiliar with it. Answer any questions they may have about the person or the information.
- Support the person and make sure they are comfortable and their needs are being met.
- Report to hospital staff any observations or concerns they have about the person's wellbeing
- Familiarise hospital staff with and demonstrate if necessary, the person's method of communication. If the person has a communication aid, show this to the nurses.
- Stay with the person until decisions are made about the person's treatment plan.
- Communicate treatment plan to the person's family, person responsible or guardian.
- Communicate treatment plan and care coordination with the Team Leader, team via the person's daily reports and the communication book. It is important to keep everyone up to date.
- Once the person is settled in a ward, a treatment plan is complete and Part 2 of the HSP is complete; planning for transfer back home should begin.

When the person is settled and all relevant information has been discussed with health the staff member is to document the circumstances leading to the admission in an incident report and provide this to the Team Leader.

Planned admission to hospital

Step by step guide for Disability Accommodation Services

Planning and preparation should start as soon as the admission is scheduled. This helps to prepare the person for the admission and ensure their safety and wellbeing during the hospital stay. The NSW Council for Intellectual Disability have a fact sheet titled "Going to hospital for surgery" which is in plain English and can be used to explain the hospital experience to the person. It can be found in the following link:

<http://www.nswcid.org.au/health-fact-sheets.html>

Disability support staff and manager are responsible for arranging the pre-admission meeting with the identified health professional (usually the nursing unit manager).

- When possible, include the person and the person responsible at this meeting.
- Take the A2D Together folder to the pre-admission meeting and explain the purpose and contents of the folder to the hospital staff.
- Complete all of the relevant admissions documents.
- Ensure the hospital admissions staff has the contact details of the person who is able to consent to the person's treatment.

- Discuss the person's **TOP 5** in detail and any additional support the person may need.
- The level of support needed for the person during their admission should be discussed at this time. **Part 1** of the hospital support plan should be used during this discussion to help complete **Part 2**. Having a plan ensures that adjustments can be made to accommodate the risks and barriers that may impact on the person's hospital experience and actions are included in the plan to minimise any impacts on the person.
- If there is a key hospital contact person whose role is to support a smooth and coordinated patient journey during the hospital stay and the transfer out of hospital.
- Planning for the transfer out of hospital. It is important to let the hospital staff know from the beginning that disability support staff are **not medically trained** and any new medical treatment required by the person when they leave hospital will need to be documented in the transfer of care plan to support the smooth transfer out of hospital. Disability support staff and managers need to consider whether support from a community nurse or therapist and/or additional training in the new procedure is required. This must be discussed before the person is discharged.

The role of disability support staff in hospital

It is important for everyone's health and wellbeing that staff involved in the hospital setting are clear from the onset what their roles and responsibilities are. Having a clear understanding of the key stages in planning for and supporting a smooth hospital journey are an essential ingredient for the person's recovery. This will also ensure that disability support staff remains safe and well whilst providing effective support to the person in the hospital setting.

Key roles of disability staff can be found in The Joint Guidelines and include:

- Stay with the person until they are settled and comfortable following admission to the hospital.
- Complete **Part 2** of the Hospital Support Plan and other documents with hospital staff. Discussion would include determining risk areas that may impact on the person's health and safety during their hospital stay; identifying additional support arrangements and how they will be resourced; and if any additional on-ward assistance is required from disability support staff.
- Ensure that hospital staff is aware of information provided in the Hospital Support Plan and act on this information.
- Visit regularly to ensure that the person is comfortable and settled.
- Assist hospital staff to communicate with the person.
- Obtain regular updates on the person's progress and treatment.
- Communicate progress, treatment plan, care coordination, and transfer to another ward to the person's family, person responsible or guardian.
- Maintain contact with the key hospital staff person agreed to at the pre-admission meeting, particularly if the person is moved between wards.

- Support the person during any transfer of care movements within the hospital. The hospital support plan should be reviewed jointly if the person's care is transferred to other wards within the hospital, and if the person's treatment plan is changed.

If the person is moved between wards ensure that their A2D Together Folder has accompanied the person to the new ward. Make sure the person's TOP 5 is given to the nurse on the new ward and inform the staff that this folder has all of the information they need to know about the person. You may need to take some time to explain the person's communication and personal requirements again.

Personal Items

Another key factor in facilitating a smooth hospital experience is making sure personal items are with the person that, keep the person occupied, facilitate communication and make the stay as comfortable as it can be. Some examples of this may include;

- Clothing
- Toiletries
- Communication aids
- Any item that will provide the person comfort (e.g. Special blanket, pictures, radio, books / magazines, sensory box / bag, etc.). These comfort items may be very important to the person and reduce their anxiety and / or fear in the hospital setting.
- Money to pay for TV access.

Disability Support Workers should not provide the following support:

- Bathing or showering (see below)
- Administering medication (see below)
- Assistance with PEG feeding
- Assist with feeding unless stated in the Hospital Support Plan Part 2
- Performance of specific health procedures e.g. pressure care
- Assistance to other patients
- Write in hospital files
- Provide clinical notes on the person.

Bathing or showering

If the person needs additional support with personal care or has some specific needs when it comes to personal care (e.g. they will only cooperate with someone they know well), this will be discussed and documented in Part 2 of the HSP. The manager will inform the disability support work the level of support that has been agreed to and the disability support worker will assist according to this agreement.

Administering medication

There may be times when the person will not take their medication from a nurse and the disability support staff may need to help out. It is the responsibility of the nurse to dispense

the medication, hand it to the disability support worker and observe them giving medication to the person. The nurse will record all medication administration on the hospital medication chart. This will be discussed and documented in **Part 2** of the HSP and the manager of the home will organise for staff to attend the hospital at specified times to provide this additional support

Note: Disability Support Staff **MUST NOT** dispense or give the person their medication from their Blister Pack as this could put the person at risk of being double dosed.

Assistance with feeding*

The person may need some additional support from the disability support worker during mealtimes. This will be discussed and documented in **Part 2** of the HSP and the manager of the home will organise for staff to attend the hospital at mealtimes to provide this support.

Transfer of care – Discharge planning

⇒ **Discussion:**

Why do you think it is important to plan for the person’s discharge from hospital?

What do you think might be the consequences if the person is discharged from hospital without a plan?

Why transfer of care (discharge) planning?

Given the complex health needs of many people with disability, it is important that their transfer of care (discharge) from hospital is planned and coordinated whilst the person is still in hospital. Poor transfer of care planning can result in:

- The person being discharged without proper guidance for disability support staff to support the person’s newly identified health needs.
- The person being discharged without consideration of whether their health needs can be met by the existing supports in their home.
- Inadequate guidance provided to the disability support staff about what follow up appointments are needed and necessary to support the person’s ongoing health needs.

These factors can result in poor health outcomes for the person, increase the person’s level of distress and can result in multiple presentations to hospital and unnecessary readmissions.

NOTE: *There is a perception in NSW Hospitals that residents living in supported accommodation are supported by **registered nurses**. Decisions about the person's ongoing care can sometimes be made by health professionals based on this faulty perception. It is extremely important that the disability support staff and managers remind them often that they are **NOT** nurses. This will allow for a better understanding of what needs to be considered at the person's discharge planning meeting.*

Always keep in contact with the person's family, person responsible, guardian to let them know what is happening.

Planning for transfer back home should commence as soon as possible so smooth transfer of care can occur between Disability Services and Health NSW. Transfer of care is carried out in accordance with section 5.1 of the *NSW Health Policy Directive: Care Coordination: Planning for Admission to Transfer of Care in Public Hospitals (PD2011 015)*. This requires that a Transfer of Care Checklist by hospital staff be used.

The **transfer of care checklist** ensures the following information is developed and documented:

- Estimated date of transfer
- Destination of transfer
- Notification / transport booked
- Personal items returned
- Referral services booked
- Care Plan
- Transfer of care summary provided to the patient that includes medication information, community and GP referral information and follow up appointments. This should all be provided in plain language and explained to the disability support staff. Referrals may include mental health, palliative care etc.

Managers are responsible for organising a meeting with the relevant health professionals, family and the person to make the final decision regarding discharge based on the person's current health needs including the reason/condition the person was hospitalised for. Part 2 of the Hospital Support Plan should be used and completed at this meeting.

Key questions for Disability Support staff and Managers to discuss in the person's Transfer of care (discharge) planning meeting

Transfer of care (Discharge) plan

- Is there a Transfer of care plan for the person?
- What information needs to be contained in the plan?

Recovery

- What are the normal signs of recovery and what signs might indicate medical attention should be sought?

Mobility

- Are there any changes to the person's mobility?
- If yes, what **equipment** is needed – i.e. hospital bed, wheelchair, walking frame, commode chair, hoist?
- Is this a **permanent** change or just **temporary** and is the person likely to return to how they were before they went to hospital?
- Who will provide the equipment both in the short and long term if needed? Has a **mobility management plan** been developed which includes a full assessment of their manual handling needs? Have staff in the home been trained in the manual handling plan? Who will provide this training?
- Are there any limitations to the person's positioning or movement that staff need to be aware of?
- How long are these in place for and are there any exercises or therapy that is recommended for the person?

For the above two items please **ensure a Physiotherapist / Occupational Therapist is involved**. For example: If the person is going in for knee surgery, it is likely they will not be returning home as able bodied as when they went into hospital. Having an Occupational Therapist (OT) or Physiotherapist liaising with the Hospital OT or Physiotherapist can assist in ensuring all supports are in place when the person returns home. For example equipment such as hospital beds, wheelchairs, frames, commodes, and mobility plans can be arranged.

Bowel / Continence needs

- Has the person's bowel movements been affected due to the treatment received in hospital?
- Is the person's continence status changed?
- Are they on new or additional medication to manage bowel or continence issues or do the new / additional medications have an impact on these body systems?
- Are staff required to perform treatments which require them to receive training before they can implement these treatments? The person can be discharged from hospital if *interim arrangements* are made for support from a suitably qualified person to administer the procedure pending the training of the disability support workers in the person's home. *This must be organised before the person is discharged.*

Rehabilitation needs

- Would the person benefit from a stay at a Rehabilitation Centre?
- Would the person benefit from a **Private Rehabilitation**? Consider this as an option if the person has private health insurance. The hospital may be able to recommend a therapist.
- Who are the most appropriate community rehabilitation specialists to work with the person when they are home? Can a referral be made to these therapists?

Pain Relief and Medication

- If the person cannot express they are in pain, is regular pain relief recommended as a precautionary measure, rather than relying on PRN?
- Is the person prescribed any medication that **cannot be administered** by a disability support staff (i.e. injections)? If yes, is there a plan for who will administer them – such as a **community nurse**? The community nurse may visit the person when they return home for a short period of time, to change dressings or to teach staff how to perform other simple procedures.
- Are the **new medications** written up in the Transfer of care (discharge) summary? Check if any items are only available from the hospital pharmacy.
- For new medications, can staff be provided with consumer **medicine information sheet** from the hospital pharmacist? This will give the most common side effects to look out for and also the actions to take to manage these.
- Can all medications be packed in a Webster Pack ready for discharge?
- Can the hospital pharmacy send the script to the person usual pharmacy to expedite matters? Staff will still need to get the medications charted by the GPs. Sometimes the hospital Registrar might write up the medications in the medication chart.

Swallowing Issues

- Are there any changes to the person's swallowing ability / eating and drinking?
- Have they had teeth removed? What is the transfer of care (discharge) plan in this area?

Note - If the person's food or fluids now need modifying the person cannot be discharged from hospital until a full assessment and **Mealtime Management plan** is completed. For example; if the person has been admitted to hospital with Pneumonia / Aspiration Pneumonia or for the removal of teeth, it is **best practice to liaise with the Hospital Speech Pathologist** to ensure the correct assessments are done while the person is in hospital and that the person leaves with the correct support plans.

- Are there any other changes to the ongoing support needs of the person which will have an impact on training needs of the disability support staff?

For example, if a person is to be discharged with a PEG in place, the disability support staff must receive training by a suitably qualified person to carry out the procedure. This must be organised before the person is discharged. If the person needs to have medication administered through a PEG this must be carried out by a community nurse.

Referrals

- Has the Transfer of care summary been reviewed to ensure all necessary specialist referrals have been made? Once the person returns home, ensure these appointments are booked as soon as possible.

Significant deterioration in health

- Has the person had a significant deterioration in health requiring a referral to a palliative care team?
- If a palliative care plan has been developed; do all disability staff have a good understanding of the continued support needs of the person to ensure they can be carried out.

There may be cases where the person is discharged from hospital but may not be well enough to stay home. In these cases they will need to go back to hospital. Disability support staff must be aware of the circumstances under which the person needs to go back to hospital and when to Call Triple Zero (000) for Ambulance assistance.

Summary

Supporting a person with an intellectual disability to go to hospital is everyone's responsibility. The smooth transition in and out of a public hospital can happen with good planning, a clear understanding of the NSW Health and FACS (ADHC) joint guideline 2013 and an understanding of the many challenges that people with disability experience in NSW hospitals.

People with disability have the same right to the highest standard of health care as any other Australian. People with disability also have a right to be heard and be listened to. If we follow proper processes we can help to improve the person's hospital experience.

Self-reflection

⇒ Discussion:

Look at the learning outcomes again on page 4. Do you think that the learning outcomes have been achieved?

Please write down 2-3 things you will do differently as a result of doing this training.

Thank you for your time

Further information

1. How to develop a TOP 5

http://www.a2d.healthcare/wp-content/uploads/2017/01/TOP-5_-Information.pdf

2. Fact Sheets

Person responsible, NSW Civil and Administrative Tribunal (NCAT) Guardianship Division
http://www.ncat.nsw.gov.au/Documents/gd_factsheet_person_responsible.pdf

Consent to medical or dental treatment, NSW Civil and Administrative Tribunal (NCAT) Guardianship Division
http://www.ncat.nsw.gov.au/Documents/gd_factsheet_consent_to_medical_or_dental_treatment.pdf

Consent to special medical treatment, NSW Civil and Administrative Tribunal (NCAT) Guardianship Division
http://www.ncat.nsw.gov.au/Documents/gd_factsheet_consent_to_special_treatments.pdf

Preventing deaths of people with disabilities in care; Information for staff of disability services, Ombudsman NSW
https://www.ombo.nsw.gov.au/_data/assets/pdf_file/0009/9468/Information-for-staff-of-disability-services-factsheet-1.pdf

References

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<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

National Disability Services (NDS), NSW, People with disability and hospitalisation: Challenges and opportunities in NSW NDS Background Paper April 2014
http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0007/307159/NSW_Hospitalisation_background_paper_final.pdf

NSW Agency for Clinical Innovation, improving the experience of hospitalization for people with Intellectual Disability <https://www.aci.health.nsw.gov.au/resources/patient-experience/stories/improving-the-experience>

NSW Department of Family and Community Services, NSW Disability inclusion Plan, 2015
https://www.facs.nsw.gov.au/_data/assets/file/0007/313495/FACS_NSW_DIP_080316.pdf

NSW Health, NSW Health & Ageing and Disability and Home Care (ADHC) Joint Guideline
http://www0.health.nsw.gov.au/policies/ql/2013/pdf/GL2013_001.pdf

Ombudsman NSW, Report of Reviewable deaths in 2012 and 2013 Volume 2: deaths of people with disability in care <https://www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths-vol-1/report-of-reviewable-deaths-in-2012-and-2013-volume-2-deaths-of-people-with-disabilities-in-care>