



Government of **Western Australia**
Department of **Health**

Hospital Stay Guidelines: Part 1

A guide for people with disability, families
and carers

CONSULTATION
DRAFT

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Introduction

This guide has been developed to assist people with disability and their support networks to be better prepared and have more confidence when interacting with hospital staff when:

- Attending the emergency department
- Attending an outpatient clinic at a hospital or health campus
- Being admitted to hospital
- Preparing for discharge.

It includes tools for people with disability to use to help hospital staff to understand individual care needs, including:

- Individual Health Profile
- Hospital Passports
- Tips of what to say when responding to questions.

A person with complex disability needs may have:

- high support needs which require a persistently high level of supervision
- an intellectual disability
- a developmental delay
- Autism Spectrum Disorder or a neurodivergent diagnosis
- Acquired Brain Injury
- Degenerative neurological conditions such as Huntington's disease, Motor Neuron disease
- behaviours which can be seen as challenging
- complex communication needs.

Being prepared

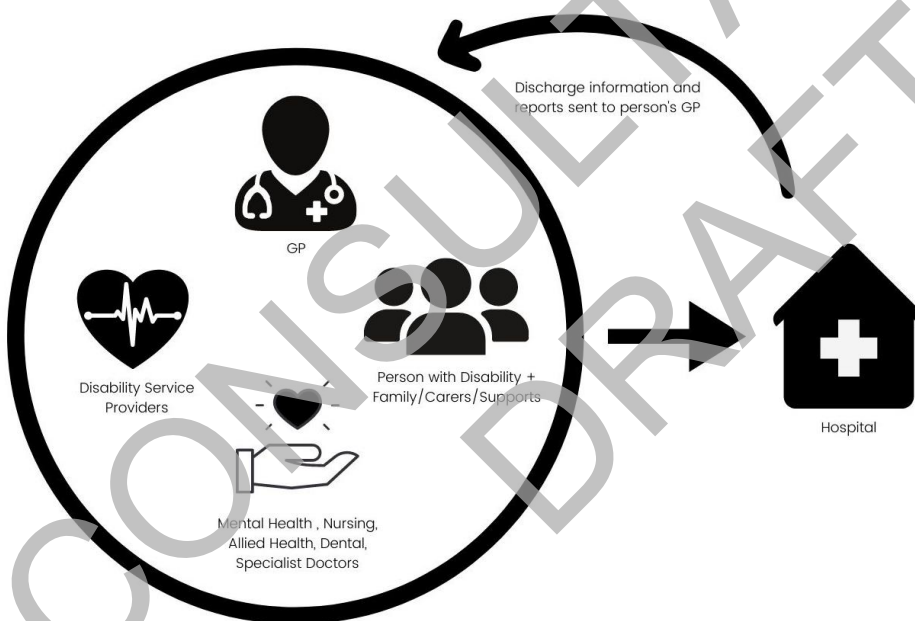
Keep connected with the GP

It is important to build and maintain a strong relationship with the General Practitioner (GP). Attending an emergency department at a hospital should be a last resort. Consider booking an appointment with the GP in the first instance when a health concern arises. Consider asking for a longer appointment, especially if more than one problem needs to be addressed.

The GP will make sure routine medical assessments are undertaken in the community where possible. Early detection is important for the management of most medical conditions, so these routine assessments are important and should be attended to as a priority.

If the individual has been in hospital, the GP should automatically receive a discharge summary from the hospital and will coordinate the necessary follow up medical appointments and medical referrals. Make sure the hospital staff have the individual's current GP contact information.

Take any documents provided at discharge to the next GP appointment in case the GP did not receive the discharge letter from the hospital.



Information Sharing

It is recommended that the following documentation is completed and ready prior to seeking medical help.

1. Individual Health Profile (see page 5)
2. Health Passport (Julian's Key) Please note many versions of Health Passports are available and acceptable to use (see page 6).

A completed Individual Health Profile contains essential and current information to assist medical staff in clinical decision-making and communication.

Provide a copy to hospital staff upon arrival and request that it be added to the medical records.

A completed Health Passport contains more detailed information to assist medical staff to provide person centred care and to understand individual needs.

Taking Someone in Your Care to Hospital

To help hospital staff deliver the best possible care, it is important to communicate what is typical for that person when they are healthy and unwell. A short video of what is typical functioning may assist with this along with a completed Health Passport.

The United Nations Convention on the rights of Persons with Disabilities, Article 21 states: “persons with disabilities can exercise the right to the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice including by augmentative and alternative communication”.

This means people with disability who have complex communication needs, must have somebody with them during a hospital stay who knows them well, or have access to a device to assist with communication.

To support a person with a Development Disability or an intellectual impairment to prepare for a hospital visit, the following creative strategies may assist:

- Using social stories well before engagement in medical/dental services
- Creating and modelling the use of medical communication boards
- Using photos and actual medical equipment so it becomes familiar and not frightening
- Doing medical/dental role plays
- Playing medical/dental games or playing with medical/dental themed toys, etc

See **Appendix 1** for more resources

Being Prepared for an Admission

Being Prepared for a Planned Admission

The GP or specialist may initiate a planned admission for a non-urgent treatment or investigation.

1. Accompany the individual to their appointment.
2. Support the individual to participate in the consultation.
3. Ensure that appropriate people are present to help facilitate informed consent. The individual who has legal responsibility for consent should accompany the individual to this appointment – if this is not possible, the carer should attend.
4. Take the Individual Health Profile and Health Passport.

Being Prepared for an Emergency Admission

If the individual is transported by ambulance, ensure:

- the individual's documentation (Individual Health Profile and Health Passport) and required aids/equipment go in the ambulance
- the attending paramedics are briefed on:
 - The presenting circumstances that required the ambulance call-out
 - Any characteristics that may impact on the individual's ambulance journey and presentation to the Emergency Department (ED).

If the individual is transported by ambulance, but the carer does not accompany the individual, ensure:

- the paramedics have the necessary contact details for the carer(s) and/or guardian
- the carer(s) are advised which hospital the individual is being transported to.

It is essential that an appropriate person attends ED to support the individual. This may be a staff and/or a family member or carer.

What to Pack

Documentation

- ☐ Individual Health Profile Form
- ☐ Make a short video of how the person you support functions and communicates typically
- ☐ Health Passport (Julian's Key)
- ☐ Cards – Medicare, concession, private health care
- ☐ GP contact details, (& or Paediatrician / Specialist)

Medical / Equipment (all clearly labelled with name tags)

- ☐ Medications (do not assume all your medications will be available at the Hospital)
- ☐ Dosages / strengths of medications
- ☐ Equipment such as orthotics, splints, continence aids, ventilator (Bipap; CPap)
- ☐ Feeding / drinking aids
- ☐ Wheelchair /s
- ☐ Communication devices
- ☐ Any charging cables

Sensory / Comfort

- ☐ Items of comfort such as familiar blanket, pillow, night light
- ☐ Books, magazines or activities that might be enjoyable
- ☐ Personal toiletries
- ☐ Pyjamas – often button up is best
- ☐ Slippers / socks

Support Person Checklist

- ☐ Your own medications
- ☐ Pen and notebook to record any questions, or information you need to learn, and reminders for yourself
- ☐ Mobile phone and charging equipment
- ☐ Access to money for parking, snacks & maybe phone calls
- ☐ Toiletries
- ☐ Comfortable clothes, some entertainment for yourself (e.g. book; magazine)

Individual Health Profile Form

Please use ID label or block print

PATIENT TRANSFER FORM	SURNAME: _____	URN: _____
	GIVEN NAME: _____	
	DOB: _____	SEX: _____
	DOA: _____	
SERVICE: _____		

Resident/Client Status: ☐ High Care ☐ Low Care ☐ CACP/ EACH Package ☐ Rehabilitation/Young Disabled

Important Numbers Transfer to: _____ Medicare Number: _____ Private Health Insurance No: _____ Pension Number: _____ Next of Kin Details Name of NOK: _____ NOK Address: _____ NOK Phone Number: _____ NOK aware of transfer? <input type="checkbox"/> Yes <input type="checkbox"/> No Does the resident/client have: <input type="checkbox"/> High ACAT <input type="checkbox"/> Low ACAT <input type="checkbox"/> N/A Diagnosis: _____ Reason for transfer: _____	Service Details Service's Address: _____ Phone Number: _____ Fax Number: _____ GP Details Resident/Client's GP: _____ GP's Phone Number: _____ GP's Fax Number: _____ GP aware of transfer? <input type="checkbox"/> Yes <input type="checkbox"/> No
---	--

Drug Alert Sticker (if applicable)	ALLERGIES: _____ _____	ALERTS: <input type="checkbox"/> Dysphagia <input type="checkbox"/> Falls Risk <input type="checkbox"/> Other
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Medications – Please see attached photocopy of medication profile

Cognitive/Emotional State – attach relevant correspondence

Past: _____ Present: _____

Diet/Fluids: _____ Mobility <input type="checkbox"/> Independently ambulant <input type="checkbox"/> Standby supervision only <input type="checkbox"/> 1 person min assistance to transfer <input type="checkbox"/> Bed/Chair hoist transfer (specify hoist) <input type="checkbox"/> Standing Hoist <input type="checkbox"/> Full Hoist <input type="checkbox"/> Equipment (specify) _____ Behaviours <input type="checkbox"/> Very Aggressive <input type="checkbox"/> Unpredicted Responses <input type="checkbox"/> Restlessness Other Information: _____	Skin Integrity/Wounds: _____ Eating & Drinking <input type="checkbox"/> Independent <input type="checkbox"/> Supervise <input type="checkbox"/> Assistance <input type="checkbox"/> Full Assistance <input type="checkbox"/> Nil by Mouth <input type="checkbox"/> PEG Toileting <input type="checkbox"/> Independent <input type="checkbox"/> Supervise <input type="checkbox"/> 1 Assistant <input type="checkbox"/> 2 Assistance Showering <input type="checkbox"/> Independent <input type="checkbox"/> Supervise <input type="checkbox"/> Assistance Dressing <input type="checkbox"/> Independent <input type="checkbox"/> Supervise <input type="checkbox"/> Assistance Urinary Continence <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Catheter in situ Dentures <input type="checkbox"/> Lower <input type="checkbox"/> Upper <input type="checkbox"/> None Glasses <input type="checkbox"/> Yes <input type="checkbox"/> No Faecal Continence <input type="checkbox"/> Yes <input type="checkbox"/> No Bowels last open _____
---	--

Prostheses: _____ Valuables: ☐ Ring ☐ Watch ☐ Other: _____


Documents: ☐ Yes ☐ No Xrays/Imaging: ☐ Yes ☐ No Equipment: _____

Name: _____ **Designation:** _____ **Date:** _____

PATIENT TRANSFER FORM

Health Passport

There are many different Health Passports available and all are suitable to use when you are coming to the hospital.

	<p>Julian's Key – Queensland Health</p> <p>Julian's Key is a patient/carer-controlled tool designed to improve communication and empower people with disability, their families and carers to be more involved in their healthcare.</p> <p>https://www.health.qld.gov.au/_data/assets/pdf_file/0032/858362/3.-Julians-Key-Health-Passport-100gsm-LHC-staple.pdf</p>
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See **Appendix 2** for other Health Passports.

During Hospital

In the Emergency Department (ED)

- Support the individual with information and assistance to reduce fear and anxiety and to help them feel as comfortable as possible.
- Advise the hospital staff of the current GP's name, practice and contact details.
- Assist the hospital staff with any other required information.
- Ensure the individual's Individual Health Profile and Health Passport is passed onto hospital staff.
- Report to hospital staff any observations of behaviour that may be difficult to interpret or any other responses by the individual.
- Familiarise the hospital staff with, and demonstrate if necessary, the individual's method of communication.
- Remain with the individual during admission until decisions are made about the individual's care coordination and treatment plans.
- Participate in any other care coordination discussions as required.
- Communicate care coordination and transfer of care discussions to the individual and/or their representative.

Triage

Triage is a system of assessment which identifies who needs to be treated first in ED.

At triage:

- be prepared for a possible lengthy wait
- keep the individual comfortable and ensure they do not become distressed
- support the individual to participate in the triage process
- be available to answer any questions from hospital staff
- be prepared to advocate for the individual if required (speak up if you think the individual is deteriorating and you have concerns).

On admission, communicate to hospital staff any risks or needs. These may be:

- Whether the individual be left alone?
- What support needs are required in relation to feeding, self-care, mobility, continence, communication, behaviour management?

The carer should be aware that they may be included in a case conference around the health care management plan for the individual.

Care Call

If the person you are supporting is at **Perth Children's Hospital** and you are concerned that their condition is deteriorating, and you feel the critical care they need is not being provided, you can make the care call.


CARE call


Are you worried about the condition of your child in hospital?


We will listen to you.

There are different ways to let us know that you are worried. The CARE Call steps will help you progress your concerns.

CARE call steps

 Step 1
Talk to your child's nurse or doctor
Use the bedside call bell or go to the nurses' station to talk to your child's nurse or doctor about your concerns and ask for an assessment.

 Step 2
Talk to the Nurse Coordinator
Ask to speak to the Nurse Coordinator in charge of the ward. They will be wearing a yellow sash around their neck.

 Step 3
Make the CARE call
If you think the condition of your child is urgent, or your concerns still have not been heard, you can make a CARE call on 6456 0337.

What will happen when you make the call?

Making a CARE Call will reach the Medical Emergency Team (MET), who will ask for:

- your name
- your child's name
- the ward and bed number.

Someone from the MET team will come and provide an urgent review.

When shouldn't I make a CARE Call?

CARE call is only for patients who are at Perth Children's Hospital.

“Aishwarya’s Care” has been implemented in all WA public hospitals with paediatric services. This builds on the existing CARE Call system which allows people to escalate care for themselves or their loved ones whose condition is deteriorating in hospital. People can make the CARE call from their mobile – look for the signs in the ED.

In the adult system you can speak to the Nurse Coordinator on the ward or contact the ‘Patient and Family Liaison Officer’ to express your concerns.

The Roles and Rights of Carers in Hospital

Part of your role as a support person is to provide relevant information to medical staff, especially when complex needs are involved.

The **Western Australian Carers Recognition Act 2004** and the **Carers Charter** outline how carers are to be treated and involved in delivering some services which impact on them. Hospitals and health workers must comply with this.

The Western Australian Carers Charter states that:

- Carers must be treated with respect and dignity
- The role of carers must be recognised by including carers in the assessment, planning, delivery, and review of services that impact on them and their role as carer
- The views and needs of carers must be considered along with the views, needs and best interests of people receiving care when decisions are made that impact on them and their caring role
- Complaints made by carers in relation to services that impact on them, and their role must be given due attention and consideration.

Goals of Patient Care

The Goals of Patient Care is a clinical care process used during an admission to hospital or other care facility. It helps determine which treatments would be useful for the patient if there is a deterioration in their condition, using a shared decision-making approach.

- A conversation is led by the doctor with the patient and where relevant, family or carer(s). This is an opportunity to ask questions and hear the opinion of the treating clinician.
- Together, a decision is made about which treatments would be appropriate and acceptable. Decisions are made considering the individual's current health and preferences regarding future care.
- Having an open discussion about the Goals of Patient Care with the person you support, will enable preferences for care to be discussed and perspectives shared.

For further information visit the [Healthy WA](#)

Substitute Decision Maker/Giving Consent

If the individual you support is:

- 18 years or older, and unable to give consent or make reasonable judgments about proposed treatment, and
- an applicable **Advance Health Directive** does not exist, then the **Hierarchy of decision-makers for treatment** must be used to identify a substitute decision maker as a 'person responsible' to provide consent on their behalf and make decisions in their best interest.

In these situations, Health Professionals should consult with the 'person responsible' if they have questions or concerns about the **Advance Health Directive** or a treatment decision.

The **Hierarchy of decision makers for treatment** identifies the criteria and the order of priority for the 'person responsible' empowered to make treatment decisions for a patient (except for sterilisation).

A treatment decision made by a 'person responsible' on behalf of a patient has the same effect as if the decision had been made by the patient themselves. The treatment decision should be made by the first person in the hierarchy who is:

- 18 years of age or older
- of full legal capacity
- reasonably available
- willing to make the treatment decision.

See page 5 of [Preparing an Advance Health Directive](#) for more information.

Advocacy

Advocacy is about helping people express their needs and protect their rights.

Below are some common areas of concern expressed by families and carers regarding how people with complex disability may respond in non-typical ways when in a hospital environment:

- pain
- communication
- distress or sensory overload
- understanding procedures
- supported shared decision making and informed consent
- medication requirements
- education and training of support people/s.

Please see **Appendix 3** for possible scenarios followed by an example (or script) of a response that can be tailored to your individual situation and person you are supporting. It may be helpful to 'rehearse' what your response could be in such situations to help you feel confident to advocate for the person you support.

Who is responsible for what?

The public health system is responsible for:

- diagnosis and assessment of health conditions, including mental health conditions and disabilities
- medication
- specialist and clinical care in hospital
- surgery and post-surgical care
- rehabilitation and sub-acute care
- palliative care
- planning and preparation for a patient to discharge.

The NDIS (for people under the age of 65) funds:

- home modifications, personal care and development of skills to help a person become more independent
- aids and equipment relating to a person's disability
- therapeutic and behavioural supports for people with psychosocial disability
- allied health and other therapy needed because of a person's disability
- prosthetics and artificial limbs.

The Disability Support for Older Australians (DSOA) Program supports people over the age of 65 with disability who received services from the [Continuity of Support \(CoS\) Programme](#).

People who are over the age of 65, not eligible for DSOA may be eligible for support and services via [My Aged Care \(MAC\)](#).

People who are under the age of 65, not eligible for NDIS may be eligible for programmes such as [Community Aids and Equipment Programme \(CAEP\)](#).

Preparing to Go Home

Transport back from ED

Attendance at ED does not automatically result in a hospital admission.

When the individual is discharged from ED:

- have transport prepared in advance – discharge will occur regardless of whether or not transport is available
- ensure transport strategies are available as discharge can occur at any time (e.g. 2am)
- ensure the individuals medication and any aids/equipment are with them.

Preparing for Discharge from hospital admission

As the person you support approaches the time for discharge it is important to obtain documentation to ensure continuity of care at home, this can include:

- discharge summary (copy provided to patient and copy sent to GP automatically)
- medication requirements (this will be in the Discharge Summary)
- referrals for outpatient care or follow up appointments
- wound care plan
- letters or reports about changes to functional capacity or mobility that may be relevant to any NDIS plan changes of circumstances
- transport to home plans (e.g. Patient Assistance Travel Scheme if required for rural patient with no other means of transportation).

Note: the hospital is not responsible for the transport home. This is the responsibility of the carer / family / care provider.

After Discharge

Monitor the individual and if you are concerned seek further medical attention and in an emergency return to the ED.

If it is not an emergency call the GP, Practice Nurse or After Hours GP locum service.

Acknowledgements

The Disability Health Network acknowledges the following individuals, groups and organisations for their contributions to this document:

- Ready to Go Home Project
- Developmental Disability WA
- National Disability Services
- Dr Jacquie Garton-Smith

Appendix 1 – Other Resources

 Microboards Australia	Health and Wellbeing Planner http://microboard.org.au/health-wellbeing-planning/
	Going to Hospital for Surgery – Council for Intellectual Disability <p>This easy-read resource has been created to help people with developmental / intellectual disability to better understand the processes when you go to hospital for surgery and being supported to make decisions about treatment.</p> https://cid.org.au/resource/going-to-hospital-for-surgery-guide/
	Going to Hospital – Department of Health <p>This guide is designed to help you prepare for your hospital visit.</p> https://www.healthywa.wa.gov.au/~media/Files/HealthyWA/New/Going-to-hospital/13285-Patient-First-Going-to-hospital-V1.pdf
	Staying Safe in Hospital – Department of Health <p>This guide is designed to make your stay in hospital as smooth and comfortable as possible.</p> https://www.healthywa.wa.gov.au/~media/Files/HealthyWA/New/Going-to-hospital/13286-Patient-First-Staying-Safe-in-Hospital-V1.pdf

	<p>Now you are home– Department of Health</p> <p>This guide is to help you settle in at home after your hospital stay</p> <p>https://www.healthywa.wa.gov.au/~media/Files/HealthyWA/New/Going-to-hospital/13298-Patient-First-Now-You-Are-Home-V1.pdf</p>
	<p>There's no such thing as a silly question - Developmental Disability WA</p> <p>A practical guide for families living with a child with chronic illness, disability, mental illness or a life-threatening condition.</p> <p>https://ddwa.org.au/resources/theres-no-such-thing-as-a-silly-question/</p>
	<p>Prepare to Care – Carers WA</p> <p>Carers WA understand that when a patient is discharged from hospital their family members or friends may play an enormous role in their life and ongoing care.</p> <p>The Prepare to Care booklet is full of relevant and useful information including places to write down information provided by health professionals, an A to Z directory of supports and services, and much more.</p> <p>https://www.carerswa.asn.au/prepare-to-care-booklet/</p>

Appendix 2 - Other Health Passport Options

 <p>The image shows the cover of a 'My Health Matters' folder. It has a purple background with a white heart and a pulse line. The text 'My Health Matters' is at the bottom. There is a small logo in the top right corner.</p>	<h3>My Health Matters Folder – Council for Intellectual Disability</h3> <p>A simple resource can be printed out to help medical staff know:</p> <ul style="list-style-type: none"> • How the individual communicates • What emotions they are expressing • Health and personal history information <p>It was co-designed by GP's and people with an intellectual disability.</p> <p>https://cid.org.au/resource/my-health-matters-folder/</p>
 <p>The image shows the cover of a 'WA Emergency Care Plan' from Kalparrin. It has a purple background with a white heart and a pulse line. The text 'Emergency Care Plan' is at the top. There is a small logo in the top right corner.</p>	<h3>WA Emergency Care Plan – Kalparrin</h3> <p>This document is tailored towards children and could also be used to inform new support providers.</p> <p>https://www.kalparrin.org.au/wp-content/uploads/2021/04/Kalparrin-Emergency-Care-Plan-WEB.pdf</p>
 <p>The image shows the cover of a 'My hospital passport'. It has a green background with a white heart and a pulse line. The text 'My hospital passport' is at the top. There is a small logo in the top right corner.</p>	<h3>My Hospital Passport – Developmental Disability WA</h3> <p>This passport is in Easy Read format and is also child-relevant, developed by Fiona Stanley Hospital.</p> <p>https://ddwa.org.au/wp-content/uploads/2021/08/FSH-Paediatric-Passport.pdf</p>
 <p>The image shows the cover of a 'Valued Lives My Health Passport'. It has an orange background with a white heart and a pulse line. The text 'MY HEALTH PASSPORT' is at the top. There is a small logo in the top right corner.</p>	<h3>Valued Lives My Health Passport – Health and Disability Commissioner of New Zealand.</h3> <p>https://valuedlives.org.au/wp-content/uploads/2020/06/Valued-Lives-Participant-Health-Passport.pdf</p>

Appendix 3 – Communication Scripts

Scripts to help communicate needs in a hospital setting

Pain	<p>Possible staff observation - “They are not in any pain/they don’t seem to be in pain”</p> <p>Response - “He doesn’t show pain in the usual way, but we know he’s in pain by [the paleness of his face/clenching of his hands.</p> <p>See FLACC Pain Scale</p>
Communication	<p>Possible staff observation - “So she is non-verbal/can’t talk/doesn’t understand what I am saying?”</p> <p>Response - “She is able to understand, she just communicates in other ways, with [Auslan/ braille/ natural gestures/ using her iPad/ visual symbols]. If you speak directly to her, I can help explain to her what you mean, or we can use this picture communication symbols board.</p> <p>See Medical Signing Board.</p>
Distress	<p>Possible staff observation - “You’ll have to calm him down/stop this behaviour or take him home/come back another time”</p> <p>Response - “His fear of unfamiliar surroundings is increasing his distress. If we can help him regulate his emotions by doing... [giving him his favourite thing to hold/ by distracting him/ turning the lights down] he’ll be better able to co-operate” or “We have a Positive Behaviour Support Plan that documents strategies to help, I have a copy to share with your team.”</p>
Coping with procedures	<p>Possible staff observation - “Don’t move/stop them moving, I have to insert this canula”.</p> <p>Response - “Can I just let her know what is about to happen, and check she is ok with you holding her arm first please?”</p>
Supported shared decision making and informed consent	<p>Possible staff observation - “I’ll need you to just sign this form for him.”</p> <p>Response – “If you can outline the possible risks, I’ll explain in a way he can understand, to tell him what we are signing and give him a choice.”</p> <p>“If you can simplify the language and take a little more time he can decide.”</p> <p>See Individualised Supported Decision-Making Booklet.</p>
Medication	<p>Possible staff observation - “I’ll just need you to take your tablets now.”</p>

	<p>Response - “We have had a concern in a past admission with a wrong dose/ wrong medication/ wrong timing. Could I ask if we can cross check before he takes these medications, please.”</p>
<p>Education and Training of support people/s</p>	<p>Possible staff observation - “If you watch me insert the naso-gastric tube/ Peg tube a couple of times then you’ll be able to do it yourself if it comes out again.”</p> <p>Response - “I really feel under prepared to be able to take on a task like this, which needs almost nurse-level training. Can I take a video of how you do it to refer back to later please, and is there someone I can call after discharge to guide me for this?”</p> <p>Using carefully considered, respectful alternatives can change the entire experience of a hospital journey, all the way from admission to discharge.</p>

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