

# PHARMACOLOGICAL STRATEGIES FOR CHILDREN WITH DEVELOPMENTAL DISABILITY DURING INVESTIGATIONS/ PROCEDURES

## PRACTICE GUIDELINE<sup>®</sup>

### DOCUMENT SUMMARY/KEY POINTS

- Patients with intellectual disability (ID) or developmental disability (DD) often find hospitalisation and undergoing tests and procedures difficult and may present with behaviours which are challenging
- Information, proper planning, and preparation will reduce anxiety and behaviours which are challenging and allow staff to understand, communicate and plan care needs more effectively
- After assessment, a combination of adjunctive and/or pharmacological strategies can be utilised to assist in reducing anxiety and challenging behaviours.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

<b>Approved by:</b>	SCHN Policy, Procedure and Guideline Committee	
<b>Date Effective:</b>	1 <sup>st</sup> April 2024	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Consultant	<b>Area/Dept:</b> Child Development

## CHANGE SUMMARY

- This policy has been reviewed by the working group Oct 2023.
- References updated
- Changes made throughout, recommend to re-read the entire document.

## READ ACKNOWLEDGEMENT

This practice guideline is used for:

- Hospital staff working with patients with intellectual disability, developmental disability such as autism who are planning an admission for these patients who may have significant challenging behaviours and will not tolerate standard procedures.
- Health Professionals who would like to access guidance on how to plan and prepare for such admissions.
- Doctors who wish to obtain guidance on how to prescribe pre-medications for anxiolysis of these patients.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

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## Purpose

Children and young people with intellectual and developmental disability (ID, DD)<sup>1 2</sup> such as autism spectrum disorder are known to be at higher risk of complex health problems requiring further investigations, intervention, and monitoring. This guideline has been developed to assist treating clinicians in the appropriate use of pharmacological and adjunctive strategies to enable investigations and procedures to be completed, while minimising the likelihood of distress, negative behavioural responses and adverse events, and result in a more positive experience of the health care journey for the patient, family and health care staff.

The guidelines were developed in consultation with anaesthetic, medical, allied health and nursing staff experienced in caring for persons with ID, and they are based on the best information available at the time of publication. The guidelines serve as a general guide, to be used in conjunction with local hospital protocols and procedures, and subject to the medical practitioner's clinical judgment in each case. However, they do not apply to patients with complex medical issues that require a higher level of supervision or monitoring or a higher level of sedation for better control of physiologic states (e.g. hypertension / uncontrolled seizures). In such cases, treating physicians should refer to more relevant guidelines.

## Introduction

Children with ID and DD, have an increased rate of hospital contact for multiple reasons and also an increased risk of adverse events occurring during hospitalisation or procedures<sup>(1)</sup>. Adverse events are more likely if these interactions fail to take into account what is known about the child's routines, special interests, sensory sensitivities, and level of understanding<sup>(2-4)</sup>. It is important to keep in mind that a person with ID will have the cognitive abilities of someone much younger than their chronological age e.g. a teen with moderate ID could behave like a 3- 5 year old and hence expectations of actual emotional, cognitive, linguistic and social ability need to be modified accordingly.

While there is little evidence to support the use of pharmacological and adjunctive techniques to alleviate the anxiety of children and young people with ID-DD, they are variably practised in many centres<sup>(5)</sup>. There are also anecdotal reports that many children and young people with ID are physically restrained during investigations or procedures and a potentially higher level of sedation or anaesthesia is then employed than if a pre-medication strategy had been employed. In addition, this traumatizing experience results in greater difficulties in completing the investigation or procedure and heightened patient responses in subsequent encounters to the point of these children suffering significant anxiety and understandably responding with behaviours which, show their distress and challenge us as clinicians. Often, patients' parents

<sup>1</sup> Intellectual Disability definition: Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning) and begins before adulthood, with a lasting effect on development. (WHO 2017)

<sup>2</sup> Developmental Disability definition: Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime. This includes conditions such as autism (CDC 2021).

and carers are also fearful of returning as they themselves have been adversely affected by the experience (more information on patient and family experiences is available at the ACI website <sup>(6)</sup>. <https://aci.health.nsw.gov.au/networks/intellectual-disability>

These challenges have highlighted the need for clinical guidelines, based on best available evidence and expert consensus, to aid clinicians in planning investigations and procedures, particularly for children and young people known to have challenging behaviours.

Some of the recommendations in this guideline are based on research into the management of preoperative anxiety in the general population <sup>(7)</sup>. There are also behavioural or psychological interventions that should be employed for all medical encounters. Modalities that can be used to support investigations and procedures include pharmacological approaches to produce varying levels of relaxation, sedation, and analgesia.

The guidelines are provided while recognising the need for further research to evaluate the effectiveness of these behavioural and pharmacological modalities, both individually and as combined approaches. It is also recognised that clinicians may need to advocate for the availability of particular pharmacological agents, individualised support behavioural management options, and reimbursement systems, to enable access to the most appropriate treatment options for the individual patient.

## Section A: Assessment and Preparation Phase

### Assessing risks and benefits

During a health assessment for a patient with ID-DD, there may be an indication for further investigations or procedures. There are a significant number of patients with ID whose behaviours create difficulties in accessing basic health-related procedures, investigations or treatment. A comprehensive health and disability assessment will identify risks and benefits and help the treating clinician to weigh up the need to go through with an investigation or procedure <sup>(8)</sup>. If the benefits outweigh the risks and the parents/carers agree, a carefully planned and coordinated approach is more likely to result in a successful outcome.

Key considerations in the assessment process might include the following:

- What is the nature of this procedure? (Does it require the patient to be still and relaxed? Does the patient require analgesia? Is it short or is it long? Does it involve multiple phases?)
- What can you learn about the patient and their family?
  - Past history (include attempted sedations that worked or those that have not worked) - patient's health history, current health and physical state
  - Status now
  - Known and suspected stress triggers
  - Known and suspected antecedents to challenging behaviours
  - Strategies that work to calm the patient e.g. having a quiet space, distraction techniques: include a favourite toy, blanket, iPad, chewy toy etc. These resources

can also be used to refocus a child's attention during the procedure. Parents should be encouraged to bring these resources to any health appointments

- Communication strategies - patient's type and level of disability and how they communicate, such as simple words, gesture, or visuals)
- Level and type of information that the patient can understand and use, such as pictures, spoken words, written words, sign language or is an Augmentative and Alternative Communication (AAC) systems being used
- Supports available e.g. carers, Child Life Therapists etc. if a Child Life Therapist has been involved has there been a prior procedural plan in place? Was it a positive experience/outcome and can it be adapted this time? Consider referral to Child Life Therapy if appropriate?
- What medications are they already taking, and of the behaviour modifying ones, which might help for this?
- Which options would the child and family prefer? (Some families seem to strongly prefer "just getting on with it" rather than sedation etc. in our experience – at the very least considering this might prompt us to ask preferences and explore why).
- Use of local anaesthetic cream such as LMX (lidocaine (lignocaine) 4%) applied where appropriate 30 minutes prior to venepuncture/procedure Ability of their parent/ carer to understand the information provided about the investigation or procedure – consider using services that can support the process (e.g. Interpreters, Aboriginal Liaison Officers, Ambulatory Care Nurses)
- Social environment and support available for the child and the family
- What environment will you be working in? (Can it be adapted to be less noisy/busy/visually stimulating? Note that smell can be a consideration too)
- Will you need sedation to facilitate the procedure? What are the risks or side effects?
- Time and effort required from the family and health care providers
- Alternative approaches
  - Is there anywhere else better equipped to do this?
  - Can it be done under the same general anaesthetic if other procedures are going to be performed?
  - Past medication history and family history of response to medication, allergies and idiopathic responses.
  - Limiting events is essential if a GA is planned - all possible procedures should be completed including dental and immunisation

## Indications for the use of pharmacological and adjunctive strategies

Clinical indications for the use of pharmacological and adjunctive strategies to support investigations, procedures and treatments may include:

- Likelihood of significant distress due to difficulty in understanding what is involved in the test / procedure / treatment or why the procedure is needed in spite of the use of usual means of communication or communicative adjuncts e.g. social stories etc.
- Patient anxiety that might prevent them from receiving the intended test / procedure / treatment
- Patient difficulty in waiting their turn or if clinicians are likely to be running late
- Patient behaviours that would limit their ability to sit or lie still for the test / procedure / treatment and which might result in behaviours that put themselves and others at risk of harm
- Patient's prior negative experience with a similar test / procedure / treatment and likelihood of re-traumatisation
- Patient unable to complete the test / procedure / treatment with local anaesthesia, requiring premedication or heavier forms of conscious sedation.
- Preparing the child by trialling the pharmacological management prior to coming to the procedure so a response is known and dosing can be adequate for the procedure
- Giving a dose of a pre-medication prior to arriving at the procedure may help with the associated anxiety

## Preparing for a health encounter

Preparation for a health encounter is key. Prior to making decisions about types of support that may be of benefit, it is important to define and closely consider the procedure being planned. The following questions may be a helpful starting point in team discussions and in discussions with family members. Remember to document this information in the patient management plan/ All About Me tile in the electronic health records:

- What is the aim of this procedure?
- When will the procedure take place? Consider not just the day or date but also the time of day and whether it can be managed within existing timeframes.
- Where will the procedure take place? Consider not only the environment for the procedure, but also where preparations will begin and where the patient will be at the start of the process. Does it need to start by deploying strategies or medications at home before coming in?
- Who is involved? Who will be primarily responsible for the procedure? Who will be mainly responsible for the child? Consider who needs to be included in the plan.
- How? Are you aiming to get by without sedation? If using sedation, what's your ideal plan? What will you do if the ideal plan fails? Do you have a point at which you'd be happy to abandon? Can the procedure be done without the patient waiting and becoming distressed? Can everything be ready when the child comes for the procedure to go ahead straight away?

## **Management options**

The decision about the use of pharmacological and adjunctive strategies in preparing the patient for a health encounter depends on several factors. As every child and young person with ID and DD has a different level of cognition, communication style, and behavioural response, the strategies employed need to be suited to their individual needs and circumstances as much as possible. Consideration of alternative approaches should also be done in consultation with the parent / carer, in their role as a support person during the health encounter.

The options include the following:

### ***Behavioural interventions***

Behavioural interventions can be used as adjunctive or alternative strategies. Examples include use of an individualised 'social story' to prepare the patient for what to expect, 'visual schedules' to enhance understanding of what will occur, and 'if and then' charts to facilitate understanding and therefore cooperation during the health care encounter. [For more information please see Visual Resources](#). If possible, consider organising an orientation visit for the patient and family to the site prior to the actual day to familiarise them with the setting and staff. Alternatively, a video of the patient journey could be recorded by staff and sent to the parents to view with their child as many times as required. The above strategies can be used in conjunction with personal profiles to familiarise health staff as to the individual needs of the patient prior to the event. [All About Me Hospital Passport](#)

### ***Environmental interventions***

What can be put in place to support the child and family – lighting, noise, smell etc.

### ***Pharmacological strategies***

Consideration needs to be given to the choice of medication, time of onset of action, duration of action, dose, frequency of administration, and monitoring for side effects. Refer to the following section for commonly used anti-anxiety medications and sedatives. In cases where the patient is on regular psychotropic medications, consideration needs to be given to possible drug interactions (e.g. synergistic or effect reducing). It might be worthwhile conducting a trial run of administering and observing the level of relaxation and sedating effect of the medications if they have not been used before in a safe environment <sup>(8)</sup>.

## **Commonly used pre-medications**

A range of commonly used anxiolytic and sedative medications are listed below, with an outline of the advantages, disadvantages, and practical considerations in the use of these drugs. Table 1 presents details of recommended doses, administration route, timing of administration, side effects and the level of evidence supporting their efficacy. Combination therapy can be used to reduce doses and side effects of each agent.

**Clonidine (oral)** Several studies have shown premedication with oral clonidine to be effective and superior to midazolam in its effects on preoperative sedation <sup>(9-12)</sup>. It is often used to alleviate anxiety and induce sleep in patients with developmental disability. Clonidine will disperse in water in 2 minutes so could be dispersed in 10-20 mL of water and given via an oral syringe <sup>(13)</sup>.



**Chlorpromazine (oral)** Important to ensure hydration. Chlorpromazine may sometimes be used as a sedative in non-psychotic patients with excessive anxiety and agitation. In addition, the drug has been used to relieve nausea, vomiting, and persistent hiccups. It is not usually used as first line treatment for sedation, but its sedative effects can be utilised by increasing pre-existing doses <sup>(14)</sup>.

**Diazepam / Valium® (oral)** Easy route of administration. Effective as a muscle relaxant, which is an additional benefit for people with Cerebral Palsy. Can cause cardio-respiratory suppression hence the need for monitoring if drowsiness is observed. A reversal agent is available but needs monitoring for rebound effects. Disadvantages include has limited effectiveness with severe management problems but has probably been employed in too low dosage. No analgesic properties. Be aware the benzodiazepines can result in idiopathic arousal <sup>(15)</sup>.

**Olanzapine (oral/IM)** Olanzapine tablets, wafers and IM forms are available. The disintegrating wafer dissolves in saliva but must be swallowed for absorption, Onset of action same as conventional tablets and IM form also available. Its peak effect orally is 5 hours (1-12 hours) and IM 15-45 minutes <sup>(16)</sup>. Has anti-nausea properties. Disadvantages: can cause somnolence and rarely, extrapyramidal side effects (e.g. dizziness, light headedness, stomach upset and dry mouth) and with metabolic effects of weight gain long term <sup>(17)</sup>.

At times, the child may require a staged approach in the administration of anxiolytics. If the premed administered is not enough to sustain an anxiolytic state especially when the child still shows distress when he/ she is in the hospital setting, a second more rapid onset medication can be administered when the child arrives at the hospital and under supervision with appropriate monitoring.

**Midazolam (Buccal/oral)** Advantages include amnesic properties, shorter half-life than diazepam or lorazepam. Has a more rapid onset of sedation than diazepam or lorazepam. A reversal agent is available. Disadvantages include variability of absorption rate and short duration of action (30-40 mins). There may be problems with respiratory depression in IV doses but less so for oral doses, akathisia, and emergence phenomenon <sup>(18)</sup>.

### **If the child is still distressed after a trial of oral sedatives in a hospital setting**

**Dexmedetomidine<sup>2</sup>** is a centrally acting selective  $\alpha_2$ -agonist, which has an anxiolytic and sedative effect and is devoid of respiratory depression. Few preliminary studies suggest that dexmedetomidine shows promise as a premedication for children to reduce anxiety and potentially reduce the occurrence and/or severity of emergence delirium <sup>(20, 21)</sup>.

### **Nitrous oxide**

Advantages include:

- Very safe used in most paediatric dental practices.
- Raises the pain threshold, which is especially useful in procedures creating minor discomfort, such as prophylaxis.

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<sup>2</sup> There is some literature suggesting that Dexmedetomidine (same family of receptor activity as clonidine) has a role in premedication amongst the general population. It can be given in small volumes under the tongue or via nasal spray with onset around thirty minutes and in some studies superior to midazolam. There is limited experience with it as a premedication by the clinician authors of this document.

- It is easily administered and is quickly absorbed and released by the patient.
- Easily, effectively, and safely augments other sedative medications.
- Often assists in venepuncture procedures.

Disadvantages include:

- It has limited effectiveness when used alone with moderate to severe management problems.
- It requires appropriate devices to administer, and training is required in its use.
- It can generate nausea when used for prolonged periods and at higher concentrations.
- Nitrous oxide has potent analgesic properties through the release of endogenous opioids but the analgesic effect wanes after about 45 minutes.
- It can potentiate the sedative effect of other drugs. Its use involves major equipment costs <sup>(22)</sup>.

**Table 1. Oral sedatives used prior to hospital presentation**

Medication	Dose	Route of administration	Timing of administration	Duration of action	Side effects
Clonidine/ Catapres®	2-4 microgram/kg (max 300microgram/per dose per DAY)	Oral	Onset of action 30-60 minutes post administration (adults) Micromedex	8 hourly	Drowsiness, dry mouth, bradycardia, hypotension, rebound hypertension on sudden withdrawal
Chlorpromazine/ Largactil®	0.5-1.0 mg/kg/dose (max 5mg/kg/d)	Oral	2-3 hours	4-6 hourly	Not for use in epilepsy QTc changes
Diazepam/ Valium®	0.1-0.3 mg/kg/dose Max 15mg /d (<12 years) Max 40mg/ d (>12 years)	Oral	1-1.5 hours	6-12 hourly	Drowsiness, ataxia, prolonged half-life in neonates
Olanzapine / Zyprexa ®	2.5mg-15 mg (5-17 yr) max dose 10mg < 40kg	Oral (Orodispersible wafers - to be swallowed for onset)	Peaks 5-8 hours post administration		Postural hypotension, affects liver transaminase and lowers seizure threshold
Midazolam	0.3mg/kg (buccal), 0.25-0.5mg/kg (oral) mg/kg/dose (max 15mg/dose)	Buccal/ Oral	30–60 minutes before procedure.	30-60 mins	Monitor if drowsy for respiratory depression. Reversal available with Flumazenil.

† Explanation of evidence rating system: studies mostly conducted in the neurotypical paediatric population. If applying to the developmental disability population, class level IV applies with grading recommendations: Level D

Doses taken [AMH Children's Dosing Companion \(hcn.com.au\)](http://hcn.com.au)

## Section B: Planning and Implementation Phase

### Informing your patient's parents or carers

Planning for the child or young person with ID-DD to have investigations or procedures done can be very daunting for families. Some parents have had negative experiences in the past. Respectful discussion as well as including the parents' input into the planning process is critical to its success. Take into consideration parents' concerns about particular 'at risk' points during the patient journey and address them by asking parents for their suggestions on how to manage these situations. If they have no suggestions, provide them with examples and discuss options with them. Discuss with the parent / carer any plans to use medications prior to the admission and address any questions or concerns.

If using pharmacological support, provide the prescription to the parent / carer for the medication to be administered and advise them about the dosage and timing. Provide them also with an admission plan, including the time they should arrive and a contact person in case there is a need for additional medication, so that the registration process is done as quickly as possible and a medication chart with the prescribed drug is available for use on that day (which can be done as a future order). If there is a patient journey plan, arrange to send it to the parent once it has been agreed on by all staff looking after the patient on the day. You may need to call or make another appointment to take them through the plan so that they understand where to go, who they will meet, and what to expect.

### Obtaining consent

Obtaining appropriate consent from the parent / carer and patient is an important step in the process. Attempts should be made to explain, as practically and clearly as possible, what the procedure or investigation entails and why it is required. Consent is to be obtained from the parent / carer for children under 16 years or who do not have the mental capacity to consent for the investigation or procedure.

### Knowing what medications the child is usually on

Having a means to identify the patient with ID being admitted for a procedure requiring sedation paves the way for a planned and coordinated approach. Preadmission clinic forms should identify what medications they are currently taking and dose and if they require any additional anxiolytic or sedation for the admission and prior to the procedure. Ask the parent / carer if any were required for previous procedures and how they were administered. If none were employed before, then some consideration should be given as to whether some anxiolytic is required for a smoother and less stressful journey. The choice of medication to be used is dependent on what the patient is currently taking, if these medications have been tried in the past, and what their effects and side effects were.

### Knowing what medications have been given that day

On the day of admission, check that the medications that are to be dispensed are in storage in the appropriate ward. Check with the parent / carer what medications have been given that day and if a top up is required, that it is available and ready for administration.

## Knowing any health conditions that may potentially cause adverse events

Check for any allergies and for existing health conditions in the patient file and confirm with the parent /carer. Discuss with the parent / carer any previous reactions / consequences from using the planned medication.

### Additional considerations

If your patient has a gastrostomy or jejunostomy, be aware of variability of absorption of medications. Speak to your pharmacist for advice if you are concerned that the pharmacokinetics of certain medications could be affected by certain conditions (e.g. timing and dose of medications if the patient has a long journey to the hospital). Check for drug interactions if they are on regular medications and if they require renal or hepatic adjustments due to existing organ impairment. Sometimes the medications are based on weight and you may be providing a very high dose to your patient if prescribing by their weight. Check for effects by using lower (standard) doses during a trial run prior to the actual event.

### Mapping out the patient journey and communication strategy

On the day, ensure that all staff who are responsible for managing the patient are aware of the sequence and steps of the patient journey so that appropriate steps can be taken to mitigate risk and make for a smooth and pleasant journey. This can take the form of a Patient Journey plan, which is discussed and agreed upon by all staff managing the patient and distributed prior to the admission date.

### Use of adjuncts

Use of adjuncts can be helpful to alleviate anxiety in addition to the use of premedications. Parents may already be using visual supports, social stories, AAC or picture exchange communication system (PECs) <sup>(22)</sup> with their child and that these can be adapted for the hospital visit in the style and format the child is accustomed to.

In addition, consider referral to a Child Life Therapist who with parent/caregiver and child can develop a procedural preparation plan for upcoming procedure(s). The type of support can include developing social stories, providing medical play, (pre appointment tour) and procedural support if required on the day <sup>(23, 24, 25)</sup>. Cognitive behavioural therapy has been used extensively for children with autism to reduce anxiety in social situations <sup>(26)</sup>. Consider referral to a psychologist with experience in developmental disability to assist patients with more severe reactions. For pain management please refer to the Perioperative Pain Management guideline/ policy. <sup>(20)</sup>

### Preparing for discharge

The following need to be considered:

- The patient is to be awake
- Adequate consideration needs to be given to what medications will be used post-discharge and the patient's level of consciousness
- Review to be organised prior to discharge
- Instructions need to be given to the family so they can monitor the patient.

- Provide a plan as to when the family will receive the results of any investigations and the plan for follow up

### **Feedback for future patient journeys**

Each patient journey should be mapped and refined through a feedback process. You may choose to do it as part of a quality assurance activity or process mapping exercise. Contact Clinical Governance Sydney Children's Hospital Network for more guidance. You may wish to enclose your patient journey plan in the patient's personal disability profile or hospital passport in order to inform the planning of future patient journeys. For emergency or unexpected encounters (which is out of scope for this guideline), the use of the "TOP 5" resource or the "Say Less Show More" can be used to improve communication and reduce anxiety. For more information, please go to [All About Me Hospital Passport](#) or the [Say Less Show More](#) links.

## **Related Resources**

For more information on understanding patients with ID and DD and the use of communicative strategies or other adjuncts please go to:

[Developmental Disability Patients – Acute Management Plan Flowchart](#)

[Non-restrictive Care for Paediatric Inpatients with Co-morbid Intellectual Disability and/or Autism Spectrum Disorder](#)

HETI Training courses: Intellectual Disability and Challenging Behaviour

For more information about inpatient pain management please go to:

[Pain Management - CHW](#)

### **Autism**

[What do health professionals need to better understand autism?](#)

### **Communication Disorders**

[Communication disorders in children](#)

### **Augmentative and Alternative Communication**

[Our Services - UR Medicine Speech Pathology - University of Rochester Medical Center](#)

### **Hospital Passport and Top 5**

- [All About Me Hospital Passport](#)
- [All About Me Family Factsheet](#)
- [All About Me Staff Factsheet](#)
- [Top 5 for Children with Special Needs](#)

## **Visual supports**

### [An introduction to Visual Supports](#)

## **Social Stories**

### [Going to a Covid-19 Testing Clinic](#)

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