

Understanding and responding to medication refusal

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Acknowledgement of Country

I would like to begin by acknowledging the traditional owners of the land on which we are meeting upon today.

We pay our respects to their Elders, past and present and any Community members with us today.

We also acknowledge that Aboriginal and Torres Strait Islander People have a deep cultural, spiritual and historical connection to Country, and that sovereignty has never been ceded.



Positive Health Outcomes and QUM

NDS has been focusing on health through the national Positive Health Outcomes project – focused on health promotion, hospital discharge and Quality Use of Medicines. The PHO project is funded by the Department of Social Services.

NDS QUM Round Table October 2023:

Highlighted key challenges for providers in QUM including:

- Limited legislative and NDIS Commission guidance and training standards
- Lack of clarity of management and best practice
- Challenges with stakeholder coordination particularly with health services.

QUM Webinar series:

NDS in partnership with the Pharmaceutical Society of Australia (PSA) for the QUM webinar series. Webinar content will be available on the NDS website soon.

Managing medication refusal

Organisations supporting medication management must take a systems approach – this is essential in understanding and responding to medication refusal.

Medication refusal rarely starts at the time of refusal.

Organisational approach will vary on key factors:

- Participant support needs and medication needs and risks:
- Medication support vs administration
- Participant centered supports
- Balancing choice and control with organisational duty of care

Underlying principles to mitigating risks with medication refusal :

- Accessible communications
- Person centered active support
- Supported decision making
- Organisational safety culture

NDIS Commission Practice Standard:

Management of Medication Outcome: Each participant requiring medication is confident their provider administers, stores and monitors the effects of their medication and works to prevent errors or incidents.

To achieve this outcome, the following indicators should be demonstrated:

1. Records clearly identify the medication and dosage required by each participant, including all information required to correctly identify the participant and to safely administer the medication.
2. All workers responsible for administering medication understand the effects and side-effects of the medication and the steps to take in the event of an incident involving medication.
3. All medications are stored safely and securely, can be easily identified and differentiated, and are only accessed by appropriately trained workers.



Medication management must be applied with other relevant Practice Standards including person centred supports, risk management, quality management and incident management.

Medication refusal

Presented by Nicole Floyd Queensland State Manager PSA

About PSA

- PSA is the only Australian Government-recognised peak national professional pharmacy organisation representing all of Australia's 37,000+ pharmacists working in all sectors and across all locations.
- leads and supports innovative and evidence-based healthcare service delivery by pharmacists.
- provides high-quality practitioner development and practice support to pharmacists and is the custodian of the professional practice standards and guidelines to ensure quality and integrity in the practice of pharmacy.



OUR VISION

Every Australian has access to safe, quality and effective healthcare through optimising the role of pharmacists in the Australian healthcare system.

Our Mission

Embedding, equipping and enabling pharmacists to be at the forefront of healthcare in Australia.

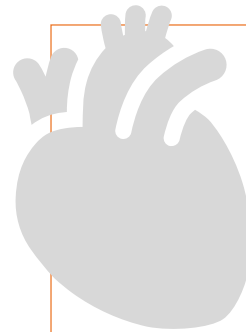
“Every person has the right to make decisions about their own lives, including people with a disability.”



Risks associated with medication refusal

Medical and health risks

- **Medication effectiveness:**
If a patient does not take medication as prescribed, they will not have the right amount of medication in their body at the right time to manage their condition.
- **Health deterioration:**
Could lead to worsening of condition, hospitalisation or death.
- **Medication-related problems:**
Medication refusal that is not well managed can lead to further medication-related problems.



If a client has high blood pressure and does not take their medications, consequences can be severe if this occurs consistently.

Uncontrolled high blood pressure could lead to long term effects – heart disease, stroke, kidney disease



Some medicines have a narrow therapeutic index and may need to be given at specific times each day.

Example: epilepsy medications

Understanding medication refusal

What is medication refusal?

Refused medication is when a person will not take any or only some of the prescribed dose of medication. Also referred to in health services as "non adherence to medication regime"

Medication refusal can include:

Active refusal

Direct:

When a person directly refuses to take a medication with verbal or behavioural communication.

Passive refusal

Less direct:

Detected **with observation**

E.g. Avoiding medication administration
Client takes the medication but spits it out or hides medication

Medication refusal may be:

- A once off or regular occurrence of medication refusal
- May be a known reason or unknown reason for medication refusal

Why does my client refuse to take their medication?

There are many reasons that might underpin a participant's choice to refuse their medication:

- The effects / side effects are unpleasant or unwanted
- Misunderstanding / worry / disagree
- The medication tastes bad
- Difficulty swallowing
- Too many medications
- Feeling unwell



Medication rights and refusal

Medication rights are an essential component of safe medication administration. A key right is the right to refuse.

Informed consent:

- Every effort must be made to encourage individuals to take the medication as prescribed, an individual must not be forced or coerced to take medication against their wishes.

Concealing medication:

- Should not trick or deceive individuals into taking medications e.g. covert medication (concealing medication without a person's knowledge)
- Concealed medication comes with risks



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Legal and ethical considerations:

Capacity and consent

A person's capacity is essential to the approach for medication management.

- Capacity:
 - appropriate clinician – assessed and reassessed if changes are noticed in the individual's level of understanding or increased complexity of the decisions.
 - Disability provider and DSW role is to identify changes or concerns and refer for assessment.
- Substitute decision maker / guardian: If the individual is not able to provide consent – the practitioner obtains substitute consent from a guardian.
- Consent to medication regime: The professional providing treatment and prescribing is responsible for establishing consent for treatment and for assessing the individual's capacity.



Emergency situations: Consent is not required if medication is administered in an emergency situation. E.g. person is incapacitated.

Person centred supports

People being actively engaged in their medication management can help identify and prevent issues that contribute to medication refusal.

Medication management approach: person centered medication approach

- Education: Participant is supported to understand their medication, purpose,
- Active consent: Ongoing consent from prescribing to day to day medication administration.
- Capacity building: Support to engage in discussions and manage some or all of their medications.

Addressing concerns with medication

Common medicines challenges:



Challenge: Misunderstanding or disagreeing with medication regime / worrying about medication.

Considerations:

- Is the client frightened of potential side effects?
- Does the client understand the need for the medication or the positive role the medication can provide?

Response:

- Ensure the participant is informed about their medications e.g. accessible information and ability to discuss concerns and questions.
- Consider a review with prescriber or a medication review to discuss the concerns and look at options.
- Connect with others in the care team like PBSP or psychologist who can support conversations

Common medicines challenges:



Challenge: Side effects that are unpleasant or unexpected can be a barrier to adhering to medication schedule E.g. drowsiness, nausea, weight gain.

Considerations:

- Does the participant understand the side effects?
- Has the organisation been monitoring and documenting side effects for new medications, as well as changes over time?

Responses:

- With the participant consent, speak to the client's prescriber about the medication side effects concerns
- Consider a medication review with a pharmacist to determine the side effects are caused by any of the medications and alternatives. e.g. Home Medicines Review (HMR) and Medscheck.

Common medicines challenges:



Challenge: Difficulty swallowing

Considerations:

- Does the person have a dysphagia plan or require a swallowing assessment?
- Has the person been supported with advice on body positioning and approaches to swallowing?

Solutions:

- Refer for review by prescriber to determine if alternates can be found:
 - alternate form – e.g. liquid, topical, oral e.g. pain patches
 - tablets/capsules can be crushed
 - medication lubricant – e.g. Gloup – aids swallowing of tablets/capsules
- Consider allied health support for swallowing techniques.
- If participant has a dysphagia plan ensure medication is included.

Common medicines challenges:



Challenge: Bad tasting or textured medicine

Considerations:

- Ensure the prescriber is made aware of any issues on taste or texture so they can consider this in prescribing.

Solutions:

- Mix with “flavouring” – e.g. honey, fruit sauce, jam (always check with prescriber or pharmacist if compatible)
- Another dose form / brand may be appropriate – e.g. tablet instead of liquid
- Swallowing aid/agent – e.g. Gloup may help mask flavour
- Compounding pharmacy can also assist with masking syrups / reflavouring
- Cold temperature medication – helps with bitter medications

Common medicines challenges:



Challenge: Too many medications / medication burden

Considerations:

- Pill burden - when a client has several different medications to be taken at multiple times across the day the chance of non compliance may increase.

Solutions:

- Can the persons dosing schedule be simplified – combined medication or long acting medications.
- Would a dose administrator help with the mental burden?
- Discuss with the prescriber or consider a medication review.

Common medicines challenges:



Challenge: Feeling unwell - Unmet health need is a common contributor to refusal of medication and behaviours of concern.

Consideration:

- Is the client feeling unwell or experiencing oral health issues and is thus refusing to take his/her medications?
- Is this due to medication side effects or underlying illness?
- Is this a once-off incident or a continuous one?

Solutions:

- If pain or feeling unwell is the underlying cause seek support from the GP or specialist.

Medication Management Review Programs

1. Home Medicines Review (HMR)

- Comprehensive reconciliation and review of medicines conducted by pharmacist in patients' home
- Collaboration: provides feedback to patient, carers and GP
- Education: can be a point to provide education to a participant and workers on medication and administration.

Accessing a HMR:

- Requires referral from a GP
- Funded by Government for eligible patients and is available every 24 months to any person at risk of, or experiencing medication related adverse effects



[Pharmacy Programs Administrator - Home Medicines Review](#)

Medication Management Review Programs

MedsCheck Programs

- One-on-one discussion and medication review provided by a pharmacist
- In-pharmacy service
- Aimed at addressing concerns or questions a person has about their medicines

Accessing a MedsCheck:

- Government funded for those with a Medicare card
- Provided by community pharmacy – check with your pharmacy on how to arrange.



[Pharmacy Programs Administrator - MedsCheck and Diabetes MedsCheck](#)



Check with your supply pharmacy about a MedsCheck for any medicine-related concerns

Responding to medication refusal

Medication refusal, seeking advice and escalation pathways and incident reporting

Manage medication refusal

Prompting the participant to take the medication

Prompt medication

- Remind the person it is time to take their medication.
- Check if they have any questions or want to discuss.
- Remember - refusal is communication

Explore issue with medication

- Refusal may be a sign something isn't right – take the time to discuss
- See if there is a reason – medication related or not in the mood.
- Acknowledge the refusal or concern

Address concerns

- Acknowledge the issue if identified – try to address
- E.g. Discuss the importance of the medication

Take a break and re offer

- Take a break - redirect or do something engaging.
- Re offer after 30 minutes
- Respect the persons choice

Manage medication refusal

Seeking advice and escalation pathways

Refusal escalation path

- If refusal persists, follow the organisation and patient care plan for the escalation pathway

Escalation of care

- Engage external supports as required:
 - GP / Pharmacist
 - Medicines information service / Health Direct / Poisons hotline
- 000 in emergency

Coordination and hand over

- Inform appropriate manager as needed
- Ensure documentation and hand over with other staff for ongoing monitoring
- Transition of care is a higher risk period

Ongoing monitoring

- Observe the persons for changes in condition or behaviour.
- Are there withdrawal effects occurring from the client refusing?
- Are they stable or deteriorating?



Advice: Advice can be given on whether the dose can be taken now, skipped or if it needs to be escalated for medical attention.

Manage medication refusal

Incident reporting and escalation pathways

Documenting refusal

- Record refusal and reason for refusal of medications with a code (i.e. "R") on the Medication Administration Record (MAR)

Escalation of care

- Notify the prescribing medical professional as soon as possible after the refusal about the incident (if necessary)

Coordination and handover

- Notify other staff or staff working subsequent shifts so they are aware and monitor

Incident reporting

- Document organisational incident reporting
- Manager consider need to report to the NDIS Commission



Incident management: Records will help determine if a pattern exists and if measures can be taken to avoid this.

Safety culture: Positive culture on reporting will help issues being picked up and reported.

NDIS Commission incident reporting

Providers have a responsibility to make timely reports to the [NDIS Commission for reportable incidents](#).

Medication incidents may fall into the following categories:

- Serious injury of a person with disability – Reporting timeframe: 24 hours
- Abuse or neglect of a person with disability – Reporting timeframe: 24 hours
- Use of a restrictive practice (If not in accordance with the participant's Behavior Support Plan) - Reporting timeframe: 5 business days

Considerations for reporting a medication incident:

- Type of incident and reason for incident
- Level of risk and impact of the incident

For detailed guidance and considerations, see the NDIS Reportable Incidents: Detailed guidance for registered providers.

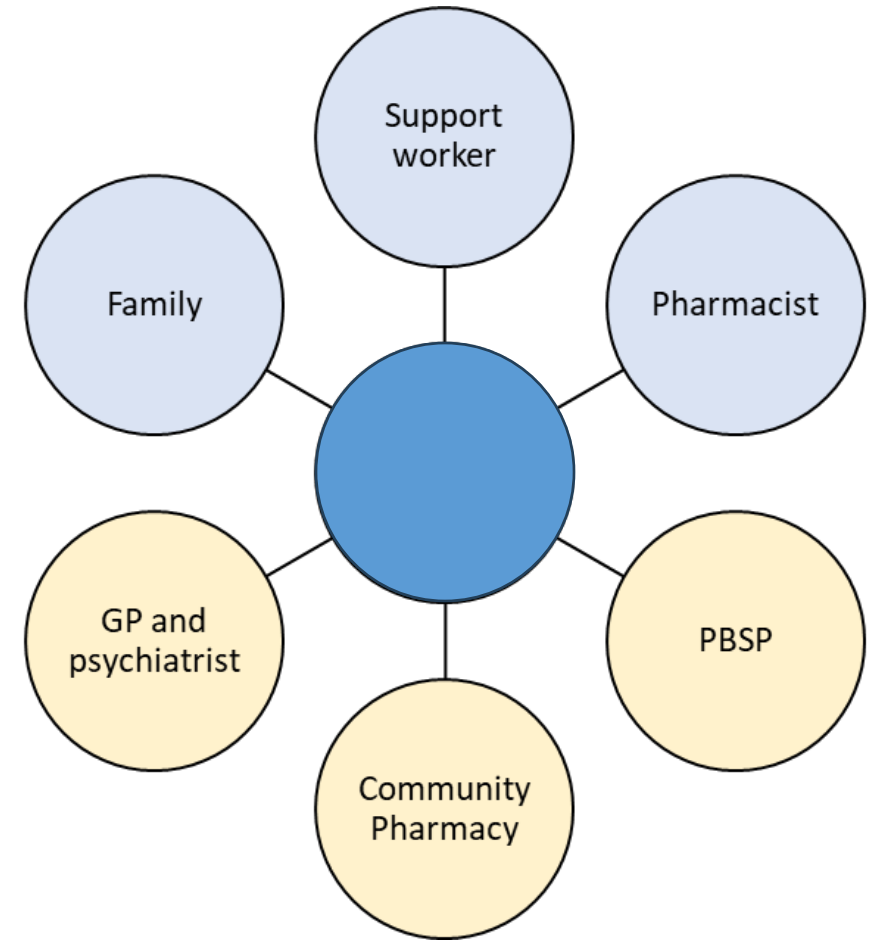
Addressing medicines issues:

Addressing medicines issues associated with medication refusal requires a coordinated approach.

Disability providers should not 'feel' alone when supporting someone with complex medicines management.

Care team members can help with:

- Identifying the underlying cause of refusal
- Adapting medicines to better meet a persons needs and preferences
- Building capacity and knowledge of the person and those supporting medications
- Coordinating care for inter related health issues e.g. mealtime management or Positive Behavior Support plans.



Case study: Ruby

Case study: Ruby

Background

- Ruby is 19 years old with ASD and an intellectual disability. She lives at home with her parents, and has in home disability support a few days a week.
- Ruby's parents have an active role in her health and management of her medicines. They currently manage her medicines in conjunction with DSWs and care team.
- The DSWs support Ruby with medication administration and daily tasks while her parents are at work.



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Case study: Ruby

Medication management

- Ruby self-administers her medications. Her parents/DSWs assist with measuring the doses of her medications and opening bottles and caps of containers.
- Ruby has difficulty swallowing medicines and usually has her medicines in liquid form or crushed and mixed with yoghurt (if appropriate).
- She also has taste aversions due to her sensory processing disturbance.
- Her parents and DSWs record when Ruby takes her medications in the Medication Administration Record (MAR)

Client's Details

Surname
Given Name
Address
Date of Birth Phone Number
Chart Start Date Chart End Date

Medication Administration Consent
Consent on file Yes No Date of consent

Allergies & Adverse Drug Reactions (ADR)
 No Known Drug Alert
Signature
DRUG ALERT LABEL ATTACH ALERT LABEL HERE AND WHERE INDICATED INSIDE CHART
Drug (or other) Reaction / Type / Date

GP & Specialist Details

Pharmacy Details

Provider Contact Details

Entitlement Numbers
Person Number
Medicine Number
Private Health Insurance Provider Number

Special Considerations - Instructions
Medication Method Tick Appropriate Box:
 Whole Halved Quartered
 Capsule opened
 Crushed and mixed with
Medication Delivery Tick Appropriate Box:
 Teaspoon - Staff guide into mouth
 Resident / Client Hand Medication cup
 Crushed and mixed with
Medication Administration Tick Appropriate Box:
 Water
 Thickened Fluids Type
 Other Preferences Type
Specific Instructions
(e.g. Anti-coagulant Therapy, Fosamax Treatment)

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Case study: Ruby

New medication commenced

- Ruby has some blood tests ordered by her GP which reveal she has iron deficiency. An iron supplement is prescribed.
- Most tablet versions of iron supplements need to be swallowed whole as they are coated/long-acting.
- The GP prescribes Ferro-Liquid (ferrous sulfate 30mg/mL) liquid 17mL to be taken daily.
- The new medication is recorded by the GP on her MAR, including low risk if medication is missed.



Case study: Ruby

New medication

- The pharmacist provides counselling to Ruby and her parents.
 - Dilute liquid with water and ingest through a straw to prevent teeth discolouration. Follow each dose with a glass of orange juice.
 - Take on an empty stomach.
 - Separate from food and milk products.
- This information is communicated to her DSWs as they will be supporting Ruby with medication administration.



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Case study: Ruby

New medication commenced

- The support worker measures 17mL and gives Ruby her dose of Ferro-liquid in a cup with a straw and ensures there is a glass of orange juice ready for Ruby to drink after the dose.
- Ruby spits this out and refuses to take anymore. When asked why, she replies **“Yuck! This tastes foul”**.
- The SW explains that the medication will help her feel less tired and it helps treat the “lack of iron”.
- Ruby refuses to take the rest of the medication.
- The DSW acknowledges Rubys rejection, and says they can talk with her parents and doctor.
- Ruby’s SW contacts the supply pharmacy (as per their organisation protocol) and asks the pharmacist for advice.



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Case study: Ruby

Getting advice from the pharmacist

Pharmacist's advice:

- Document this as a refused dose.
- There will be no adverse effects from missing this dose.
- Consider an alternative form of iron liquid that has a less offensive taste.
- The pharmacist recommends Maltofer Brand (10mg/mL elemental iron). An approximate equivalent dose is 10mL of Maltofer liquid.



Case study: Ruby

Documenting the incident

- The support worker records:
 - “R” for refused medication of the MAR and that the dose was missed.
- This is recorded as part of the organisation’s medication incident form and sent to the designated person in the organisation
- The SW records the pharmacist’s advice on the medication incident form so that this information can be supplied to Ruby’s parents who can consult with her GP regarding changing the brand to Maltofer.

Medication Distribution Record



Name of resident:

Legend:	
Staff initial – medication given and taken	B – Breakfast
R – medication refused – notify prescriber	L – Lunch
A – absent (on leave, at medical appointment)	D – Dinner
S – resident given medication for self-administration	BT – Bed Time
H – resident in hospital	
U – resident unable to take dose (e.g. due to vomiting)	
N – medication not available – obtain supply and or notify medical practitioner (e.g. waiting on delivery from pharmacy)	

Week beginning	Monday				Tuesday				Wednesday				Thursday				Friday				Saturday				Sunday			
	B	L	D	BT	B	L	D	BT	B	L	D	BT	B	L	D	BT	B	L	D	BT	B	L	D	BT	B	L	D	BT

Image generated using Adobe Firefly

Case study: Ruby

Resolution

- Ruby's parents make an appointment to see her GP
- The GP agrees to the recommendation by Ruby's pharmacist.
- Ferro-liquid is changed to Maltofer liquid 10mg/mL 10mL daily on the MAR. This can be mixed in orange juice.
- Ruby's parents get a new bottle labelled from the pharmacy with the updated instructions and disposes of old medication.
- Ruby takes a dose the next day with assistance from her parents with **SUCCESS**.
- Subsequent medication refusal for her iron supplementation is avoided



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Next steps for you and your organisation

Following today's webinar consider actions to take to uplift your organisation's approach to medication refusal.

- **Good health and medicines documentation:**
Audit participant documentation and MAR to look at instructions for missed medication, escalation pathway information, and examples of missed medication documentation
- **Policy and procedure:**
Does your organisational policy and procedure clearly cover missed and refused medications?
- **Training and supervision:**
Does your training cover missed and refused medication and how to manage this including hand over and follow ups?
- **Incident reporting:**
Is your incident reporting capturing missed and refused medications? Is this data being tracked and responses to with quality improvement approaches?

Resources

NDIS Commission Practice Standards, guidance and resources

- [NDIS practice standards | NDIS Quality and Safeguards Commission](#)
- [NDIS Workforce Capability Framework | NDIS Quality and Safeguards Commission](#)
- [High Intensity Daily Personal Activities | NDIS Quality and Safeguards Commission](#)
- [Medication purpose form | NDIS Quality and Safeguards Commission](#)
- [Medicines for health, not control | NDIS Quality and Safeguards Commission](#)
- [Australian Commission on Safety and Quality in Health Care - Joint Statement on the Inappropriate Use of Psychotropic Medicines to Manage the Behaviours of People with Disability and Older People](#)
- [Australian Commission on Safety and Quality in Health Care: Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard](#)

Resources

NDIS Commission medication related Practice Alerts

[Practice Alerts | NDIS Quality and Safeguards Commission \(ndiscommission.gov.au\)](https://www.ndiscommission.gov.au)

- [Comprehensive Health](#)
- [Dysphagia](#)
- [Epilepsy management](#)
- [Medicines associated with swallowing problems](#)
- [Polypharmacy](#)
- [Transitions of care between disability services and hospitals](#)
- [Influenza vaccine](#)
- [Cardiovascular Disease](#)
- [Pain Management](#)

Resources

Frameworks and guidelines

- Disability services Medication Management Framework (Tasmania):
[Disability-Services-Medication-Management-Framework-June-2022-FINAL.pdf](https://dpac.tas.gov.au/Disability-Services-Medication-Management-Framework-June-2022-FINAL.pdf)
(dpac.tas.gov.au)
- Guiding principles for medication administration in the community:
health.gov.au/sites/default/files/2022-11/guiding-principles-for-medication-management-in-the-community.pdf
- PSA Guidelines for Quality Use of Medicines:
ppaonline.com.au/wp-content/uploads/2020/04/PSA-Guidelines-for-Quality-Use-of-Medicines-QUM-services.pdf
- Guideline for Medication Assistance. Residential service providers (Level 3 services):
[Guideline for medical assistance \(hpw.qld.gov.au\)](https://hpw.qld.gov.au/Guideline-for-medical-assistance)

Resources:

Medicine information and participant resources

- NPS MedicineWise App: [Helping carers keep track of medicines – The MedicineWise App](#)
- NPS MedicineWise App: [Helping carers keep track of medicines – The MedicineWise App - NPS MedicineWise](#)
- Health Direct: [Consumer medicine information](#)
- Therapeutic Goods Administration Website [Guidance and resources | Therapeutic Goods Administration \(TGA\)](#)
- Medicines information service [Home - 1300 MEDICINE](#)

Resources for participants:

- [Council For Intellectual Disability: Me and my medication \(cid.org.au\)](#)
- NDIS Commission Resources for people with disability: [Resources for people with disability](#)