Rare Passport

See page 3 for **critical alerts** and **red flags**

Identity and contact

Personal Details (Please see last page for Next of Kin/Advocate details)

Full name

Nickname/preferred name

Date of birth [DD / MM / YYYY]

Sex (as recorded at birth)

Gender identity

Preferred pronouns

Address

Patient Identifier(s)
(e.g. Medical Record number (MRN); Unit Record (UR) number)

Medicare number IRN

Expiry /

Name of condition

Where to find more information

Substitute decision-maker
(if applicable)

Administrator/ medical decision-maker
(if applicable)

My consent & communication preferences

Advance Care Directive

Rare or undiagnosed condition

About the condition (general)

Genomic variant

How my condition affects me — features, atypia, and family history

Additional diagnoses/co-occurring conditions

Critical alerts and red flags READ FIRST

Allergies and isolation status

Medication and anaesthesia alerts

Other relevant management plans that require review

Medical considerations

Sensory and communication supports

Things that help care go well

Partnership In Healthcare

The top three things to know about me to help an appointment go well.

Written by me, in my own words. These are the things I want a clinician seeing me for the first time to understand — the practical, communication, or relational details that turn a stressful appointment into a useful one.

1

2

3

Care team

Name	Role or Specialty	Department or Organisation	How to contact	Passport shared
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯
				◯

Current goals and priorities – what matters right now

My top three goals and priorities

1

2

3

Living Situation, Employment & NDIS

Living situation

Employment/Study

NDIS plan (if applicable)

Support workers/carers (if applicable)

Current treatment and therapies

My current treatments and therapies

Diet and eating plans (only if clinically relevant)

Diet and eating plans

Clinical research (optional)

Research and registries

Support groups and trusted resources

Patient and community supports

Next of Kin details

Next of Kin/Advocate (call FIRST)	**Next of Kin/Advocate** (secondary)
Full name	Full name
Relationship	Relationship
Preferred language	Preferred language
Telephone Number	Telephone Number
Email	Email

Sign-off and version control

Completed by	
Date completed	
Next review date	
Signature/Stamp	

To sign, select Fill & Sign → Add signature, then place your signature above.

This Rare Passport was co-designed with people living with rare conditions and their clinicians across Australia. It forms part of a Rare Condition Passport and Toolkit (available at rarediseasesnsw.au/), which also includes a de-identified template, guide to completion, and guidebooks for families living with a rare or undiagnosed condition.

It is intended to help support a family and their coordinating clinician share important information about a person living with a rare condition.

The latest clinical updates, medication and doses etc **MUST be checked** with the person and/or their carer and checked against the hospital, outpatient and/or primary care medical records and documentation.

Rare Diseases NSW

Stay up to date with Rare Diseases NSW at https://rarediseasesnsw.au/connectwithus/

We'd love to hear any feedback about this passport from any patient, family or clinician. Scan the QR code to register your interest in helping to improve and evaluate the Passports.