Australian Government

Department of Health, Disability and Ageing

CHAP

COMPREHENSIVE HEALTH ASSESSMENT PROGRAM

# Annual Health Assessment for People with Intellectual Disability

## YOUNG PERSON (12 TO 18 YEARS)

**Name of the Young Person (having the assessment)**

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This document is reviewed annually and updated to be consistent with current relevant evidence and national and international guidelines. Check the Department of Health, Disability and Ageing's website for the latest version of this document.

For more information on how the Australian Government is improving annual health assessments for people with intellectual disability visit https://www.health.gov.au/our-work/annual-health-assessment-for-people-with-intellectual-disability.

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## People supporting the annual health assessment

**Name of Family Member / Carer / Support Worker**

**Name of General Practitioner (GP)**

## Steps to follow

1. You (the person with intellectual disability), a family member and/or support staff fill in **Part 1** of this book. It is OK to get information from records, family members and staff.
2. Make a long appointment with your usual GP.
    a. Ask the receptionist if the clinic has a Practice Nurse, as they may be able to assist with the health assessment.
    b. You may wish to book the first appointment of the day to avoid long waiting times.
3. Take this book to the appointment with the GP and/or email it to your GP before the appointment.
4. The GP will look through the first part of this book and fill in **Part 2** while examining you.
5. It is important that the Action Items are recorded by the GP and that the GP makes sure that you and/or your carer know what to do next.
6. Medicare supports this ANNUAL health assessment. Please refer to page 18 for details of Medicare items.

People with intellectual disability generally have poor health. Their healthcare is generally of a lower standard. The Comprehensive Health Assessment Program (CHAP) was designed to improve the interaction between the GP and the person with intellectual disability.

It does this by:

- recording a dedicated health history from you and/or your carer
- improving communication between, and integration of, disability and health services
- educating and empowering all those involved in the health assessment
- providing guidelines for the GP on commonly missed health issues for this population.

Use of the CHAP can improve your health. Research (including several randomised controlled trials) has demonstrated its benefit in detecting new disease and enhancing health screening and promotion.

# Part 1

To be completed by you, your family and/or support staff.

Tick the boxes below if you have experienced any of the following signs and symptoms in the **last year**.

If you are unsure or don't know the answer, please tick the 'unsure/don't know' box.

To make an accurate medical assessment of your health, the doctor needs to know about these signs and symptoms.

## 1. Breathing

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Do you **cough**? | ☐ | ☐ | ☐ |
| Do you cough up **blood**? | ☐ | ☐ | ☐ |
| Do you have a **runny nose**? | ☐ | ☐ | ☐ |
| Do you cough up **stuff/mucus/sputum**? | ☐ | ☐ | ☐ |
| Do you get short of **breath**? | ☐ | ☐ | ☐ |
| Do you **wheeze**? | ☐ | ☐ | ☐ |

## 2. Heart

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Do you have a **heart disease** that you have had from birth? | ☐ | ☐ | ☐ |
| Do you have **chest pain**? | ☐ | ☐ | ☐ |
| Does your heart 'race'/**beat quickly**? | ☐ | ☐ | ☐ |
| Do your **ankles swell**? | ☐ | ☐ | ☐ |
| Do you get **short of breath** while lying in bed? | ☐ | ☐ | ☐ |
| Do you get a **blue tinge to your skin** (for example fingers/lips/toes)? | ☐ | ☐ | ☐ |

## 3. Muscles & Joints

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Do you have **joint pain or back pain**? | ☐ | ☐ | ☐ |
| Do you have **muscle pain or weakness**? | ☐ | ☐ | ☐ |
| Do you use **walking aids or orthotics**? | ☐ | ☐ | ☐ |
| Do you have **scoliosis** (curved or twisted backbone) **or contractures** (painful tight muscles)? | ☐ | ☐ | ☐ |

## 4. Stomach/Bowel

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Have you **lost weight**? | ☐ | ☐ | ☐ |
| Do you have **trouble swallowing**? | ☐ | ☐ | ☐ |
| Do you **regurgitate/vomit**? | ☐ | ☐ | ☐ |
| Do you get **heartburn**? | ☐ | ☐ | ☐ |
| Do you have **diarrhoea**? | ☐ | ☐ | ☐ |
| Do you have **black bowel motions/faeces/poo**? | ☐ | ☐ | ☐ |
| Do you get **constipated**? | ☐ | ☐ | ☐ |
| Do you lose control of **bowel motions**? | ☐ | ☐ | ☐ |
| Do you have **abdominal/stomach pain**? | ☐ | ☐ | ☐ |

## 5. Urinary System

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Do you have **pain** when passing **urine/wee**? | ☐ | ☐ | ☐ |
| Do you have **blood** in your **urine**? | ☐ | ☐ | ☐ |
| Do you **lose control** of your **urine**? | ☐ | ☐ | ☐ |
| Can you take care of your **toileting needs**? | ☐ | ☐ | ☐ |
| Do you **urinate more** than in the past? | ☐ | ☐ | ☐ |

## 6. Nervous System

Questions about epileptic episodes (fits) are covered in section 13.

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Do you have **headaches**? | ☐ | ☐ | ☐ |
| Do you **faint**? | ☐ | ☐ | ☐ |
| Do you get **unsteady** when walking? | ☐ | ☐ | ☐ |
| Do your arms or legs become **weak**? | ☐ | ☐ | ☐ |
| Do you have **tingling** or strange feelings in your skin? | ☐ | ☐ | ☐ |

## 7. Skin

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Do you have any **skin disease or rash**? | ☐ | ☐ | ☐ |

## 8. Pain Perception

How do you react to pain?

How do you communicate pain?

## 9. Medications

It is important for the doctor to know about ALL your medications.

List the medication/s prescribed by any doctor.

| Name | How often and how much is taken? | When was it first prescribed? |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

When were the medications last reviewed?

Who reviewed the medications?

List any medications bought 'over the counter' without a script, including alternative health remedies.

| Name | How often and how much is taken? |
|---|---|
| | |
| | |
| | |
| | |

## 10. Allergies

List anything you are allergic to, including medications.

## 11. Sleep

Do you experience any problems with sleeping? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, please describe:

## 12. Cause of intellectual disability

Is the cause of your intellectual disability known? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, please give details:

## 13. Epilepsy

Have you ever had epileptic seizures/fits? ☐ Yes ☐ No ☐ Unsure / Don't know

**If No or unsure,** ▶ If no or unsure, go to Section 14

**If Yes,** please describe and list the **type, number and usual duration** of seizures during the last year.

| Type of seizures | Number | Usual duration |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |

**Which doctor treats the epileptic seizures/fits?** (Please select one)

☐ GP

☐ Neurologist

☐ Other (Please describe) _____

**When did this doctor last review your epilepsy?**

Month and year if known _____

☐ Unknown

**Since this review, have the seizures:**

- ☐ Become more severe?
- ☐ Become more frequent?
- ☐ Remained the same?
- ☐ Improved?

**Do you have an Epilepsy Management Plan?** ☐ Yes ☐ No

## 14. Sexual orientation and gender identity

**What is your gender identity?** (Please tick one)

- ☐ Male
- ☐ Female
- ☐ Non-binary
- ☐ Other
- ☐ I do not want to answer

**What sex was originally listed on your birth certificate?** (Please tick one)

- ☐ Male
- ☐ Female
- ☐ Other (Please describe) _____

**Do you identify as** (Please tick as applicable)

- ☐ Straight or heterosexual
- ☐ Bisexual
- ☐ Lesbian or gay
- ☐ Other
- ☐ I do not want to answer

## 15. Relationships

The information you provide must be kept confidential.

You do not have to answer these questions if they make you uncomfortable, but it is very important you tell your GP about any concerns you have.

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Have you ever been sexually active? | ☐ | ☐ | ☐ |
| Have you ever been abused (sexual, physical or psychological)? | ☐ | ☐ | ☐ |

Comments

**For young men and people with a penis** ▶ Go to Section 17

## 16. Health of young women and people with a cervix

Are you concerned that you reached puberty too early or too late? ☐ Yes ☐ No ☐ Unsure / Don't know

Do you have menstrual periods? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes,** date of last period: _____

☐ Unknown

Do you care for your periods yourself? ☐ Yes ☐ No ☐ Unsure / Don't know

Do you use any form of contraception? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, please describe: _____

Do you have any of the following?

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Pre-Menstrual Syndrome? | ☐ | ☐ | ☐ |
| Irregular periods? | ☐ | ☐ | ☐ |
| Heavy periods? | ☐ | ☐ | ☐ |
| Painful periods? | ☐ | ☐ | ☐ |
| Abnormal vaginal discharge? | ☐ | ☐ | ☐ |
| Vaginal irritation (for example thrush)? | ☐ | ☐ | ☐ |
| Pelvic pain? | ☐ | ☐ | ☐ |

**For young women and people with a cervix** ▶ Go to Section 18

## 17. Health of young men and people with a penis

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Do you have any problems with your penis (for example, sores, scars or discharge)? | ☐ | ☐ | ☐ |
| Are both of your testes in the scrotum? | ☐ | ☐ | ☐ |
| Are you concerned that you reached puberty too early or too late? | ☐ | ☐ | ☐ |
| Do you have any erection dysfunction? | ☐ | ☐ | ☐ |

**The remaining questions are for everyone.**

## 18. Behaviours of concern

**Do you have any behaviours of concern?** ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, please describe the behaviours, any consequence (legal or otherwise), and any help you receive for these behaviours:

## 19. Mental health

**Do you have any mental health problems?** ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, please describe the mental health problem/s and any help you receive for the problem/s.

## 20. Seeing

**Do you have a known problem with seeing?** ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, please describe the problem.

**If No or Unsure/Don't know:**

Are you or other people concerned you have a problem seeing?

☐ Yes ☐ No ☐ Unsure / Don't know

Have you ever been prescribed glasses? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, do you usually wear the glasses? ☐ Yes ☐ No ☐ Unsure / Don't know

When was your last vision test?

Month and year if known _____

☐ Unknown ☐ Never

**Who performed this test?** (Please tick one)

- ☐ Eye doctor / ophthalmologist
- ☐ Optometrist
- ☐ GP
- ☐ Test while at school
- ☐ Unknown

**Result of last vision test?** (Please tick one)

- ☐ Normal
- ☐ Unknown
- ☐ Abnormality found

If an abnormality was found, please describe.

## 21. Hearing

**Do you have a known problem with hearing?** ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, please describe the problem.

**If No or Unsure/Don't know:**
Are you or other people concerned you have a problem with hearing?

☐ Yes ☐ No ☐ Unsure / Don't know

Have you ever been prescribed a hearing aid? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, do you usually wear the hearing aid? ☐ Yes ☐ No ☐ Unsure / Don't know

Do you use any other hearing device? ☐ Yes ☐ No ☐ Unsure / Don't know

When was your last hearing test?

Month and year if known _____

☐ Unknown ☐ Never

**Who performed this test?** (Please tick one)

- ☐ Audiologist
- ☐ GP
- ☐ Other

**Result of last hearing test?** (Please tick one)

- ☐ Normal
- ☐ Unknown
- ☐ Abnormality found

If an abnormality was found, please describe.

## 22. Health promotion & screening

### Dental

Date of last review: _____ ☐ Unknown

### Blood pressure

Date of last check: _____ ☐ Unknown

**Cigarettes smoked** (per day) _____

**Alcohol** (standard drinks per week) _____

**Recreational drugs** (list any used)

### Thyroid function test

If you have Down syndrome, when was the most recent test? _____

☐ Unknown

### Vitamin D test

Vitamin D deficiency appears to be quite common in people with intellectual disability.

Date of last review: _____ ☐ Unknown

### Diabetes test

Date of test: _____ ☐ Unknown

### Skin check

Date of test: _____ ☐ Unknown

## 23. Activity & lifestyle

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Have you noticed any mobility changes over time? | ☐ | ☐ | ☐ |
| Has there been any decline in your abilities (for example, memory, dealing with money, making meals)? | ☐ | ☐ | ☐ |
| Are you physically active? | ☐ | ☐ | ☐ |
| Do you have any abnormal eating behaviours? | ☐ | ☐ | ☐ |
| Do you or others have concerns about the quality of your diet? | ☐ | ☐ | ☐ |

**Inactivity and poor diet can lead to significant health problems and depression.**

## 24. Immunisations

Fill in the following about your immunisations.

Ask your GP if there are any immunisations you should get, either as a booster or for the first time.

### COVID-19

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

### Influenza

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

### Tetanus/Diphtheria/Pertussis (Whooping Cough)

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

## Hepatitis A

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

## Hepatitis B

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

## Pneumococcus

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

## Meningococcal Meningitis

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

## Measles, Mumps and Rubella

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

### HPV (Human Papilloma Virus)

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

### Shingles/Herpes Zoster

Is this immunisation up to date? ☐ Yes ☐ No ☐ Unsure / Don't know

**If Yes**, date of last immunisation: _____

**If No**, reason why:

## 25. Developmental concerns

Do you, your family or carers have any concerns about your development, such as problems with speech and communication, fine motor skills (for example, using hands), gross motor skills (for example, walking), self-care, social skills and learning or school problems?

☐ Yes ☐ No ☐ Unsure / Don't know

**If yes,** please describe the problem/s

Do you see any allied health professionals (for example, speech therapist)?

☐ Yes ☐ No ☐ Unsure / Don't know

**If yes,** please give details

## 26. Social Situation

Who do you live with?

Name of your school and grade/level.

Who has parental responsibility for you (e.g. parent, carer, child protection)?

Do you live in residential care or out of home care (for example, foster care, youth housing service, supported independent living)? ☐ Yes ☐ No ☐ Unsure / Don't know

Do you receive NDIS support? ☐ Yes ☐ No ☐ Unsure / Don't know

Are there any concerns about this support? ☐ Yes ☐ No ☐ Unsure / Don't know

Do your family receive a carer allowance? ☐ Yes ☐ No ☐ Unsure / Don't know

## 27. Family medical history

Has anyone in your family (blood relation) had any of the following conditions?

| | Yes | No | Unsure / Don't know |
|---|---|---|---|
| Diabetes | ☐ | ☐ | ☐ |
| Mental Health Problems | ☐ | ☐ | ☐ |
| Heart Disease | ☐ | ☐ | ☐ |
| Epilepsy | ☐ | ☐ | ☐ |
| Breast cancer | ☐ | ☐ | ☐ |
| Bowel cancer | ☐ | ☐ | ☐ |
| Intellectual Disability | ☐ | ☐ | ☐ |

## 28. Your medical history

List any information about your health history that has not already been recorded in this booklet. Include any medical problems, surgery/operations, gynaecological and mental health problems.

## 29. Summary of health concerns

List the concerns you, your family and/or carers have about your health.

## 30. Person who completed Part 1 of this document

**Name**

**Date completed:** _____

### Remember!

If the clinic has a Practice Nurse, speak with them about completing this assessment as they may be able to assist. This will make the consultation with the GP easier.

# Part 2: GP review

## To be completed by the general practitioner +/- practice nurse

**Date of review** _____

## Introduction

Thank you for reviewing this person's health care.

Using this Comprehensive Health Assessment Program (CHAP) can improve the health of a person with intellectual disability. Several randomised controlled trials and observational studies have demonstrated its beneficial effect to detect new disease, and enhance health screening and promotion.

This information is updated on an annual basis in line with current evidence and national and international guidelines.

### Review process

1. Review the history provided in Part 1 of this document
2. Follow Part 2 below to perform a COMPREHENSIVE REVIEW of your patient's health. This review may include:
    a. Full physical examination
    b. Vision and hearing screening
    c. Urine analysis
    d. Other tests you feel are indicated
3. Record ACTION ITEMS at the end of each page and ensure the patient and/or their carer know what to do next

## Supporting information

### Common health deficits for people with intellectual disability

See Appendix A at the end of this document for syndrome-specific common comorbidities

- Unrecognised pain or infections
- Poor dental care
- Over-use and inadequate review of anti-psychotics / anti-convulsants
- Unrecognised mental disorder/s, poor psychiatric assessment / management
- Inadequate epilepsy assessment / management
- Unrecognised / poorly managed constipation
- Unrecognised / poorly managed dysphagia and aspiration
- Unrecognised reflux esophagitis / H. pylori infection
- Unrecognised or poorly managed hearing and vision impairment ± pathology
- Incomplete immunisation schedules
- Incomplete health screens – BP, skin, breast, cervical
- Unrecognised osteoporosis and Vitamin D deficiency
- Unrecognised or poorly managed obesity / malnutrition
- Undescended testes / hypogonadism
- Inadequate information about menstrual management
- Inadequate information about human relations and sexuality
- Uninvestigated cause of intellectual disability

### Medicare Benefits Schedule

Items for Health Assessments provided for people with an intellectual disability:

- 701 (brief)
- 703 (standard)
- 705 (long) or
- 707 (prolonged)

A health assessment for people with an intellectual disability may be claimed once every twelve months by an eligible patient.

- Management Plans: GP chronic condition management plan - face to face (item 965).

# 1. Patient history and aetiology

**1. Summarise any concerns from your review of the patient's history in Part 1.**

## Aetiology

**2. Do you know the aetiology of the intellectual disability?**

- ☐ Yes
- ☐ No ▶ If no, continue to Question 4.

**3. Select applicable syndromes**

See Appendix A for a list of syndrome-specific common comorbidities at the end of this document.

- ☐ Down syndrome
- ☐ Fragile X syndrome
- ☐ Noonan syndrome
- ☐ Prader-Willi syndrome
- ☐ Rett syndrome
- ☐ Angelman syndrome
- ☐ Neurofibromatosis syndrome
- ☐ Phenylketonuria
- ☐ Tuberous sclerosis syndrome
- ☐ Williams syndrome

▶ If you have selected one or more applicable syndromes, go to Question 7

**4. Discuss genetic testing**

Discuss advantages and disadvantages of pursuing an underlying genetic diagnosis. Do genetic testing if there is no definitive diagnosis, and if you have not performed the tests in Question 6.

**Advantages of genetic testing:** Support groups; May assist with NDIS funding; Reproductive confidence; An explanation and link to specific management guidelines.

**Disadvantages (occasional) of genetic testing:** Currently limited treatments; Adjustment to a diagnosis; Chance of test being non-diagnostic, giving uncertain or incidental findings.

**5. Does the patient agree to genetic testing?**

- ☐ Yes
- ☐ No ▶ If no, go to Question 7

**6. Plan genetic testing**

Recommend:

- CGH Microarray (Medicare indication: Intellectual disability); AND
- Fragile X

If regression of skills or multi-organ involvement, order a **urinary metabolic screen**.

**7. Does the patient have cerebral palsy?**

- ☐ Yes
- ☐ No

**8. If applicable, what is the patient's autism spectrum disorder level?**

- ☐ Level 1
- ☐ Level 2
- ☐ Level 3
- ☐ Unknown

# Concerns and actions

## 2. Basic Examination

### Body measurements, eating behaviour and exercise

**1. Can you check the patient's height, weight and waist measurements?**

Height: _____ cm

Weight _____ kg

Waist _____ cm

☐ Unable to check

**2. Does the patient have any diet problems or abnormal eating behaviours?**

☐ Yes

☐ No

**3. Does the patient get sufficient exercise?**

☐ Yes

☐ No

### Blood pressure and pulse rate

**4. Can you check the patient's blood pressure and pulse rate?**

Systolic _____ mm[Hg]

Diastolic _____ mm[Hg]

Pulse Rate _____ /min

☐ Unable to check

### Vision and eyes

For those who can't name letters, please use the letter matching chart at the end of this document to aid testing.

**5. Is there an eye pathology?**

☐ Yes

☐ No

**6. Can you test the patient's vision?**

☐ Yes

☐ No

**7. Eye test results**

| | Left eye | Right eye | Both |
|---|---|---|---|
| Normal | ☐ | ☐ | ☐ |
| Abnormal | ☐ | ☐ | ☐ |
| Uncertain | ☐ | ☐ | ☐ |

If abnormal, unable to test or uncertain, consider referral.

### Hearing and ears

Whisper test both sides at 0.6 metre with aids if used.

**8. Has an otoscopy been performed?**

☐ Yes

☐ No

**9. Can you test the patient's hearing?**

☐ Yes

☐ No

**10. Hearing test results**

| | Left ear | Right ear | Both |
|---|---|---|---|
| Normal | ☐ | ☐ | ☐ |
| Abnormal | ☐ | ☐ | ☐ |
| Uncertain | ☐ | ☐ | ☐ |

If abnormal, unable to test or uncertain, consider referral.

## Concerns and actions

## 3. Full examination

Please perform a complete physical examination.

### Head, neck and oral cavity

**1. Have you assessed the head, neck and oral cavity?**

- [ ] Unable to assess
- [ ] Yes, I have no concerns
- [ ] Yes, I have concerns

**2. Is there an obvious dental pathology?**

- [ ] Yes
- [ ] No

**3. Has the patient been reviewed by a dentist in the last six months?**

- [ ] Yes
- [ ] No

### Body

**4. Have you assessed the chest, abdomen and urogenital systems?**

- [ ] Unable to assess
- [ ] Yes, I have no concerns
- [ ] Yes, I have concerns

**5. Have you assessed the musculoskeletal system and skin?**

- [ ] Unable to assess
- [ ] Yes, I have no concerns
- [ ] Yes, I have concerns

**6. Have you assessed the nervous system?**

- [ ] Unable to assess
- [ ] Yes, I have no concerns
- [ ] Yes, I have concerns

### Health of women

**7. Have you done a breast examination?**

- [ ] Yes
- [ ] No
- [ ] Not applicable

### Health of men

**8. Have you checked the patient for undescended testicles?**

- [ ] Yes
- [ ] No
- [ ] Not applicable

## Concerns and actions

## 4. Epilepsy

### Consider seizure control and SUDEP

Please review the patient's seizures, and minimise the risk of Sudden Unexpected Death in Epilepsy (SUDEP).

### Management

**1. Does the patient have epilepsy?**

- ☐ Yes
- ☐ No
- ☐ Not applicable

**2. Does the patient have an epilepsy management plan?**

- ☐ Yes
- ☐ No

### Medications and/or referral

**3. Does the patient need medication adjustment or referral to a neurologist?**

- ☐ Yes
- ☐ No

## 5. Mental Health

### Common problems

Adjustment to transitions or grief, risk of neglect or abuse, anxiety disorders, mood disorders (for example, depression) and emerging psychosis.

### Mental health risk factors

**1. Does the patient have any evidence of mental health problems?**

- ☐ Yes
- ☐ No

**2. Is the patient at risk of suicide?**

- ☐ Yes
- ☐ No

### Behavioural

**3. Is there evidence of self-injury, harm to others, or destruction of property, or withdrawal?**

- ☐ Yes
- ☐ No

**4. Applicable behaviours**

- ☐ Self-injury
- ☐ Harm to others
- ☐ Destruction of property
- ☐ Withdrawal
- ☐ Not applicable

### Abuse and trauma

**5. Does the patient have indicators of physical, psychological or sexual abuse or trauma?**

- ☐ Yes
- ☐ No
- ☐ Not applicable

## Concerns and actions

## 6. Health screening

### Gastrointestinal tract (GIT) and bladder function

**1. Does the patient have dysphagia?**

- [ ] Yes
- [ ] No

**2. Does the patient need further evaluation for gastro-oesophageal disease?**

- [ ] Yes
- [ ] No

**3. Does the patient experience urinary incontinence?**

- [ ] Yes
- [ ] No

**4. Does the patient experience faecal incontinence?**

- [ ] Yes
- [ ] No

**5. Does the patient have chronic constipation?**

- [ ] Yes
- [ ] No

### Osteoporosis

**6. Does the patient need an osteoporosis risk test?**

- [ ] Yes
- [ ] No
- [ ] Not applicable

### Sleep

**7. Does the patient have sleep apnoea or sleep problems?**

- [ ] Yes
- [ ] No

### Sexual and reproductive health

Tanner score stages can be found on the Royal Australian College of General Practitioners (RACGP) website. Search for 'growth disorders' or 'Tanner score'.

**8. Has the patient developed age appropriate sexual characteristics?**

- [ ] Yes
- [ ] No
- [ ] Not applicable

**9. Does the patient need a review of reproductive health and/or sexual relations?**

- [ ] Yes
- [ ] No

## Concerns and actions

## 7. Vaccinations

Influenza, pneumococcus and meningococcal immunisation may be indicated for people with intellectual and developmental disability. For more details, please refer to The Australian Immunisation Handbook.

**1. Review patient clinical record**

Then decide which vaccinations need to be administered for the patient.

**2. Does the patient need any vaccinations?**

- ☐ Yes
- ☐ No
- ☐ Not applicable

**3. Vaccinations needed**

- ☐ None
- ☐ COVID-19
- ☐ Hepatitis A
- ☐ Hepatitis B
- ☐ Influenza
- ☐ Herpes zoster /shingles
- ☐ Tetanus, diphtheria and pertussis (dTpa)
- ☐ Measles, mumps and rubella (MMR)
- ☐ Pneumococcus
- ☐ Meningococcal
- ☐ Human Papillomavirus

## Concerns and actions

## 8. Final Checks

### Mobility

**1. Have there been any mobility changes over time?**

- [ ] Yes
- [ ] No

**2. Has there been any functional decline over time?**

- [ ] Yes
- [ ] No

### End of Life

**3. Would you be surprised if the person were to die in the next 12 months?**

- [ ] Yes
- [ ] No

**4. Discuss advance care planning and palliative care with the patient or carer.**

- [ ] I have discussed with the patient, their family or carer

### Medications

Over-prescribing and inadequate review of medications, especially psychotropics and anti-convulsants, are common in people with intellectual disability.

**5. Have you reviewed the patient's medications?**

- [ ] Yes
- [ ] No
- [ ] Not applicable

### Blood Test

**6. Does the patient need any blood tests?**

- [ ] Yes
- [ ] No

**7. Applicable test types**

- [ ] None
- [ ] B12
- [ ] Full blood count
- [ ] Glucose
- [ ] HbA1C
- [ ] Lipid
- [ ] Renal function
- [ ] Thyroid function

# Assessment complete

Thank you for your comprehensive health review of this person. Your efforts are part of improving the poor health status of the 500,000+ Australians with intellectual disability.

## Agreed next steps or actions

Please review the actions you need to take and ensure the person and/or their carers know what they need to do to make them happen.

It may be helpful to set an agreed date of review and if appropriate perform a GP chronic condition management plan – face to face (item 965).

This document can be returned to the care provider who came to this consultation.

## Concerns and actions

# Syndrome specific list for general practitioners

| SYSTEM | CEREBRAL PALSY 1:500 | DOWN SYNDROME 1:700 | PRADER-WILLI 1:25,000 |
|---|---|---|---|
| **AUDIOVISUAL** | Visual: Increased risk of cicatricial retinopathy of prematurity, cortical visual impairment, strabismus<br>Hearing: Sensorineural hearing | Visual most common - Refractive errors (myopia, hyperopia, astigmatism), Strabismus, Nystagmus, Keratoconus, and cataracts<br>Hearing: Otitis media affects 50 to 70% DS children, conductive and sensorineural hearing loss<br>Annual assessments recommended | Strabismus Myopia |
| **ENDOCRINE** | | Thyroid dysfunction & diabetes (both hypo or hyperthyroidism) – Hypo is more common<br>Annual TFT recommended Growth, short statue Obesity and diabetes Osteoporosis | Hypothalamic & pituitary dysfunction<br>Growth hormone deficiency<br>Adrenal insufficiency<br>Hypothyroidism, Type 2 Diabetes, Hypogonadism, Osteoporosis<br>Delayed puberty |
| **PSYCHIATRIC/ PSYCHOLOGICAL** | Depression<br>Not all have intellectual disability | Depression, anxiety, OCD<br>Alzheimer's type dementia (Clinical onset uncommon before 40 years) | Hyperphagia<br>Impulse control difficulties<br>Self-injury<br>Depression, anxiety, psychosis Not all have intellectual disability |
| **C.N.S.** | Epilepsy | Epilepsy (Usually clonic/tonic) | Epilepsy |
| **CARDIO-VASCULAR** | | Congenital Heart Defects (Common - in 40 to 50%) | Hypertension |
| **MUSCULO-SKELETAL** | Contractures, scoliosis, joint dysfunction Managing pain, maintaining range of movement,<br>muscle strength and general fitness<br>Physiotherapy to monitor muscular function. | Joint laxity and hypotonia Predisposition to osteoarthritis Atlantoaxial dislocation, instability | Scoliosis Kyphosis Hypotonia |
| **ADDITIONAL** | Genito-urinary problems Incontinence, Constipation Dental problems<br>Recurrent aspiration Oesophagitis, Reflux + bleeding/ anaemia; Swallowing/eating difficulties – Speech disorders affect 40-50%; Abnormal function of oropharyngeal muscles Orthopaedic disorders; Osteopenia Pulmonary disease (caused by reflux & aspiration)<br>Growth failure | Blood dyscrasias<br>Childhood leukaemia – AML, ALL Sleep apnoea<br>Increased risk of infections Coeliac disease<br>Urological abnormalities<br>Skin disorders, alopecia, eczema Gastrointestinal abnormalities | Infantile failure to thrive, then hyperphagia and severe obesity<br>High tolerance to pain Decreased ability to vomit Sleep apnoea Undescended testes Dental Abnormalities Gastroesophageal reflux Skin picking |
| **INHERITANCE** | 75% prenatal causes<br>8-10% perinatal asphyxia | Most cases are sporadic; 4% due to translocation involving chromosome 21 or rarely, parental mosaicism | Atypical. Most cases are sporadic. |

# Syndrome specific list for general practitioners

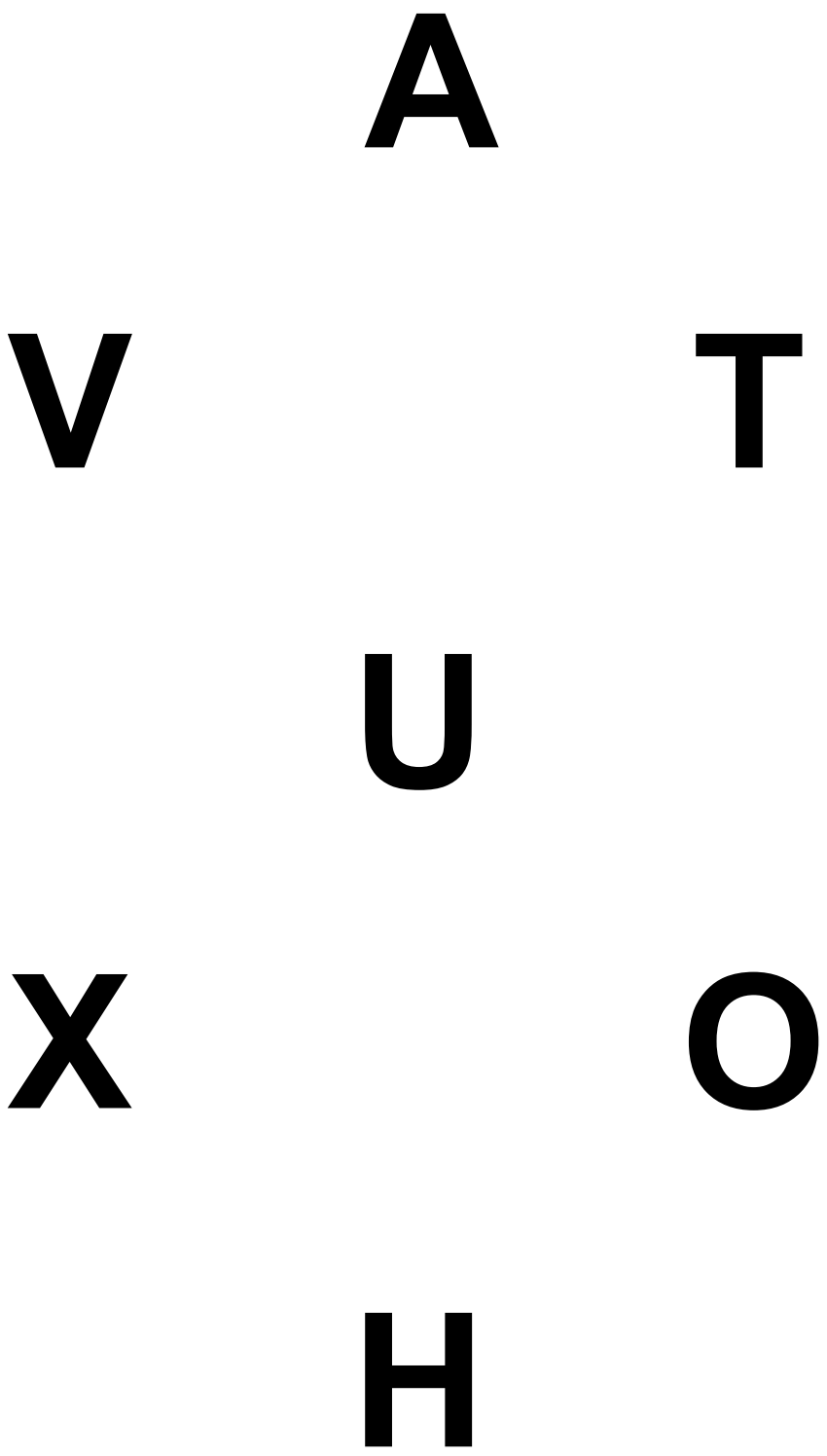
| SYSTEM | RETT<br>1:10,000 FEMALES | NOONAN<br><1:10,000 | TUBEROUS SCLEROSIS<br>1:6,000-17,000 | NEUROFIBROMATOSIS<br>Type 1 - 1:3,000<br>Type 2 - 1:30,000 |
|---|---|---|---|---|
| **AUDIOVISUAL** | Refractory errors | Strabismus, refractive errors Vision/ hearing impairments | Retinal tumours<br>Eye rhabdomyomatas | Hearing impairment (Glioma affecting auditory nerve)<br>Optic gliomas |
| **ENDOCRINE** | | | | Various endocrine abnormalities |
| **PSYCHIATRIC/ PSYCHOLOGICAL** | Intellectual disability | Intellectual disability | Variable intellectual capacity Sleep problems Hyperactivity<br>Aggressive behaviour Autism spectrum disorder<br>Not all have intellectual disability | Increased risk of attention<br>deficit disorders<br>Not all have intellectual disability |
| **C.N.S.** | Epilepsy<br>Vasomotor instability | Epilepsy | Cerebral astrocytomas Epilepsy | Variable clinical phenomena depending on site of the tumours<br>Epilepsy |
| **CARDIO-VASCULAR** | Prolonged QT interval | Pulmonary Valvular Stenosis ASD, VSD, PDA | Rhabdomyomatas Hypertension | Rarely structural cardiac complications Increase in blood pressure with age |
| **MUSCULO-SKELETAL** | Osteopenia Fractures Scoliosis<br>Gait abnormality | Scoliosis<br>Talipes equinovarus Pectus carinatum/ excavatum | Bone Rhabdomyomata | Skeletal abnormalities esp. Kyphoscoliosis |
| **ADDITIONAL** | Hyperventilation Apnoea<br>Reflux<br>Feeding difficulties<br>Growth failure<br>Partial or complete loss of acquired spoken language<br>Partial or complete loss of purposeful hand skills<br>Impaired sleep pattern | Abnormal clotting factors, Platelet dysfunction Undescended testes, Deficient<br>spermatogenesis<br>Lymphoedenoma Hepatosplenomegaly<br>Cubitus valgus, Hand abnormalities Characteristic facial features<br>Short stature (80%) | Kidney & lung hamartomata Polycystic kidneys<br>Liver Rhabdomyomata Dental abnormalities Skin lesions<br>Subependymal nodules | Variable clinical phenomena depends<br>on neurofibroma location<br>Tumours susceptible to malignant change<br>Cafe au lait spots<br>Axillary and inguinal freckling Usually back pain & headaches<br>Phaeochromocytoma & renal artery stenosis rare |
| **INHERITANCE** | Usually sporadic. X linked | Autosomal dominant, may be sporadic | Autosomal dominant | Autosomal dominant |

# Syndrome specific list for general practitioners

| SYSTEM | FRAGILE X<br>1:4,000 to 7,000[1] | PHENYLKETONURIA<br>1:13,500-1:19,000 | ANGELMANN SYNDROME<br>1:10,000-52,000 | WILLIAMS<br><1:20,000 |
|---|---|---|---|---|
| **AUDIOVISUAL** | Visual Impairment – Multifactorial, Strabismus<br>Hearing Impairment - Recurrent ear infections | | Glaucoma<br>Strabismus is possible | Hyperacusis Strabismus |
| **ENDOCRINE** | Primary ovarian failure in carriers | | | Diabetes Hypercalcaemia Hypothyroidism |
| **PSYCHIATRIC/ PSYCHOLOGICAL** | Attention deficit/ hyperactivity Social difficulties<br>Anxiety & Autism Spectrum Disorders Not all have intellectual disability | Phobic anxiety<br>Social difficulties<br>Excessive sadness, fear & anxiety; sense of isolation & poor self-image<br>Not all have intellectual disability | Easily excitable Hyperactive Intellectual disability | Attention deficit problems in childhood<br>Not all have intellectual disability |
| **C.N.S.** | Epilepsy<br>(Usually clonic/tonic, complex partial) | Epilepsy Hyperactivity<br>Tremor & pyramidal tract signs<br>Extrapyramidal syndromes | Epilepsy | Perceptual & motor function reduced |
| **CARDIO-VASCULAR** | Aortic dilatation, Mitral Valve prolapse (related to connective tissue dysplasia) | | | Cardiac abnormalities<br>Hypertension, CVAs Chronic hemiparesis |
| **MUSCULO-SKELETAL** | Connective tissue dysplasia Scoliosis<br>Congenital hip dislocation | Osteopenia | Joint contractures & scoliosis (in adults) | Joint contractures Scoliosis Hypotonia |
| **ADDITIONAL** | FXTAS in carriers Herniae (CT related)<br>Abnormalities of speech & language Avoidant behaviour<br>Delayed language development<br>Obesity & hyperphagia | Eczema<br>Low phenylalanine diet provides considerable benefit | Speech impairment, Movement & balance disorder; Characteristic EEG changes; Gastrointestinal problems; Orthopaedic problems; Sleep problems; Obesity; Microcephaly | Renal abnormalities Short stature<br>Characteristic facial features (elfin)<br>Gastrointestinal problems |
| **INHERITANCE** | X linked | Autosomal recessive | Variety of genetic mechanisms on Chromosome 15 | Microdeletion on chromosome 7 |

**Adapted from an original unpublished version by Michael Kerr and Glyn Jones.**

1 Permutation prevalence – 1 in 130-250 females; 1 in 250-810 males (see: http://www.irdrjournal.com/files/IRDR_2014Vol3No4_pp100_182.pdf)




**If the person has difficulty naming letters from the Snellen Chart, ask them to point to the corresponding letter on this page.**