Pathways to care:
Down syndrome and dementia

Down Syndrome Victoria

This resource outlines best practice for monitoring and assessing signs of dementia in adults with Down syndrome. It describes recommended assessments, who should complete them, when they should be undertaken and how often.

Comprehensive cognitive baseline assessment

This assessment involves a series of questions and tasks completed with a health professional to get a baseline functioning assessment for the person with Down syndrome. 'Comprehensive' means that it should cover memory, executive function, praxis, visuospatial skills, language (speech and written), attention/processing speed, and behaviour and function.

Before attending the assessment with your chosen health professional, complete the NTG-EDSD questionnaire (see below) and take it to this appointment.

There are various tools that are appropriate for use with people with intellectual disability.

Some recommended tools for health professionals are listed below.

- Cambridge Cognitive Examination, modified for people with Down syndrome version II (CAMCOG-DS-II)
- Test for Severe Impairment (TSI) – for people with severe intellectual disability
- Cambridge Examination of Mental Disorders of Older People with Down syndrome and Others with Intellectual Disabilities version II (CAMDEX-DS-II).

Why is this assessment important?

People with Down syndrome present differently to the general population in how their brain works, their skills and functionality. This means that general dementia screening tools aren't adequate for people with Down syndrome.

Every person with Down syndrome is different, so it is important that a baseline of the person's cognition and function is documented starting in their early thirties. This will help family, supports and health professionals identify changes promptly.

Important things to note for this assessment

- This assessment can be completed by any of the following health professionals: psychologist, psychiatrist, memory clinic, geriatrician, specialist intellectual disability health clinic.
- It is highly recommended that it be completed by a health professional with experience with ageing and people with intellectual disability.
- New appointments will need a referral from a GP.
- Ensure that the healthcare professional uses appropriate screening tools for a person with Down syndrome. Don't be afraid to suggest that the health professional uses one of the appropriate screening tools listed on this page.

Screening tools for family and other care givers

This refers to a series of questions or a report completed by family and supports. This then provides a detailed baseline from which changes or decline can be monitored. It covers health, medical conditions, life changes, mental health, memory, daily activities, communication, sleep, mobility and behaviour.

This information is useful for health professionals in assessing signs of dementia. It is completed by family and support workers, but can also be completed by health professionals asking family and supports these questions in an appointment.

We recommend the:

National Task Group – Early Detection Screen for Dementia (NTG-EDSD) as it has manuals and supports, is comprehensive and free.

There are also other tools available:

Dementia Screening Questionnaire for individuals with Intellectual Disabilities (DSQIID)

Dementia Questionnaire for People with Learning Disability (DLD)

Why are screening tools important?

The baseline assessment by family and supports is a snapshot of what the person's cognition is like right now. It provides a comparison for future assessments, making it easier to show and document change. For those who see the person every day or regularly, it can be difficult to see incremental decline. Using an objective tool teaches family and supports what to look out for to recognise early signs of decline.

The earlier dementia is diagnosed, the earlier appropriate treatment and supports can be implemented.

Important things to note for screening tools

- This assessment is completed by families and supports. Ensure that it is completed by those who spend the most time with the person with Down syndrome and have worked with them for at least 6 months.
- Everyone contributes to the same version.
- It takes 15 to 60 minutes to complete.
- Consider support staff changes. Ensure staff are completing or reviewing before they finish in their role, and that documents and processes are handed over to new staff.
- It is highly recommended to write notes for each item to explain rating choices.
- Screening tools are not diagnostic but provide supportive evidence of decline for diagnosis.

Adult comprehensive health assessment program (CHAP)

The CHAP is an evidence-based health assessment tool for people with intellectual disability, used by general practitioners (GPs) for individuals over 18 years of age.

Why is an annual CHAP important?

Chronic health conditions such as cardiovascular disease, diabetes, obesity, high blood pressure and high cholesterol are all risk factors for dementia. An annual check up with a GP can help identify these health issues early and prevent them.

It can also help develop a good relationship with the GP who will then have a better understanding of the person with Down syndrome and their baseline.

Important things to note for the CHAP

- This assessment is to be completed by a GP.
- Complete annually for best results.
- The CHAP is clinically reviewed and updated every year to align with current evidence and clinical guidelines.
- Completing the CHAP requires a longer appointment with the GP.
- This assessment is covered by Medicare and has different Medicare numbers to a standard long appointment.
- We recommend that you email this to the GP prior to your appointment, the first time you complete it.

Down syndrome and dementia: Assessment timeline

Completed by families and support workers	AGE	Completed by health professionals
CHAP Complete together with a GP **Complete annually from 18 years of age.**	18+	**CHAP** Complete annually from 18 years of age **Annual review ensures care aligns with current evidence and guidelines.**
NTD-EDSD Complete as baseline in early 30s **Review if any changes or declines are noticed.**	30s	**Comprehensive cognitive baseline assessment** Complete as baseline in early 30s **Review with GP and specialist health professionals if declines are noticed.**
NTD-EDSD Complete again as new baseline in early 40s **Review every 2 years and whenever changes or declines are noticed.**	40s	**Comprehensive cognitive baseline assessment** Complete again as new baseline in early 40s **Review every 2 years with health professionals and whenever declines are noticed.**
NTD-EDSD Complete again as new baseline in early 50s **Review every year and whenever changes or declines are noticed.**	50+	**Comprehensive cognitive baseline assessment** Complete again as new baseline in early 50s **Review every year with health professionals and whenever declines are noticed.**

Monitoring becomes more frequest with age
with tools and assessments reviewed annually from 50 onwards.

What to do if there are signs of decline?

1 See a GP

Book in to see the GP to discuss your concerns and compare current assessment to baseline assessments.

2 Rule out other causes of decline

Diagnosis of dementia for people with Down syndrome is difficult. It is important that GPs rule out other health issues or concerns that could be contributing to the decline. Other causes of decline can include:

- Sleep disorders like sleep apnoea
- Mental health issues like depression
- Thyroid issues
- Sensory loss, such as loss of vision or hearing
- Life changes, big or small. It could even be a simple change like a new support worker, a new home or sleeping in new bed
- Perimenopause or menopause
- Down syndrome regression disorder (DSRD)
- Infection like urinary tract infections
- Nutritional deficiencies, such as folate or vitamin D deficiency.

3 Get referrals to specialists

The GP can provide referral to specialists who can help with further assessments or diagnoses. Specialists may include psychologists, psychiatrists, a memory clinic or specialist intellectual disability health clinic.

Links found in this document

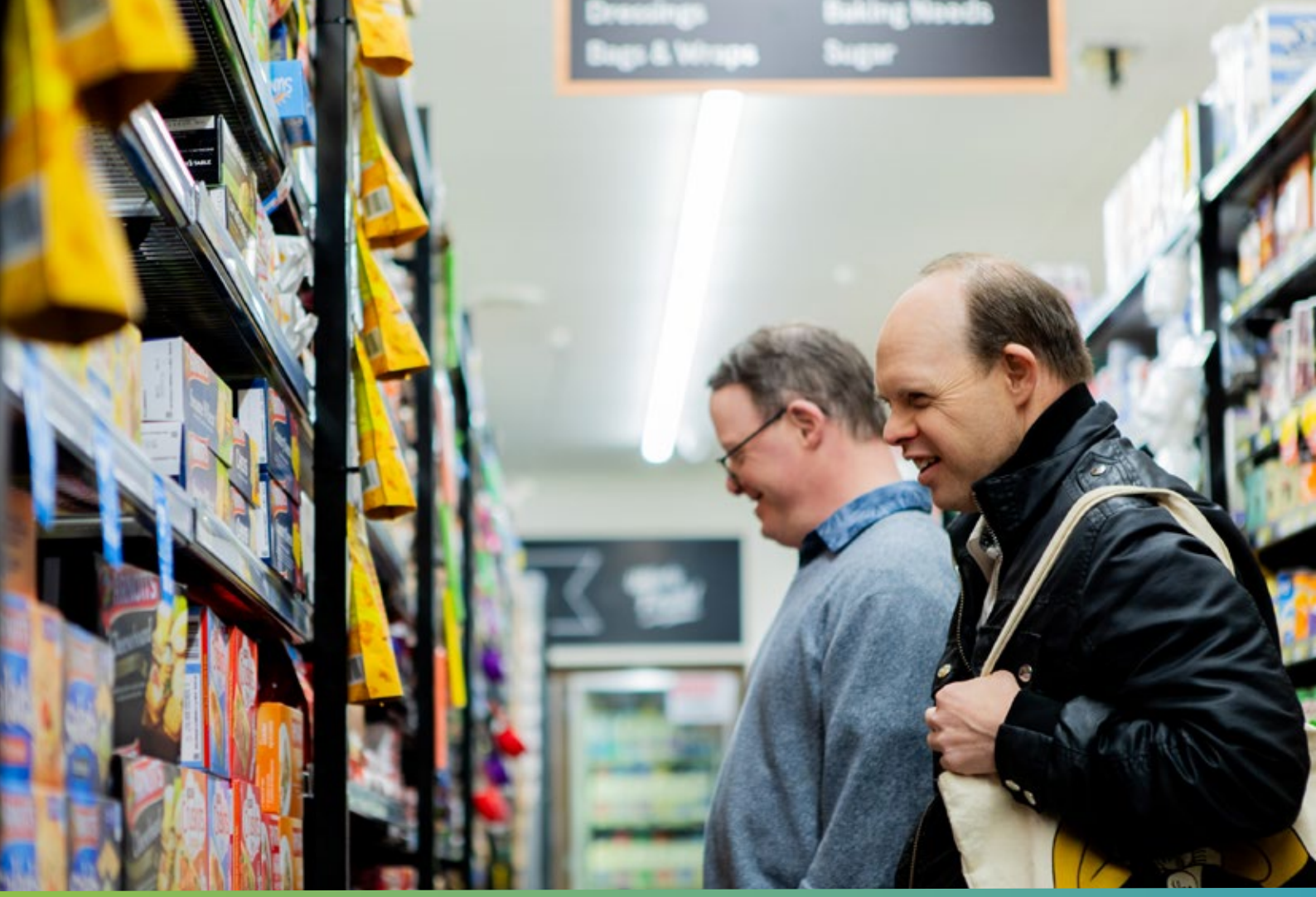
CAMDEX-DS-II, including the participant assessment:
https://pavpub.com/camdex-ds-ii

The Test for Severe Impairment (TSI):
https://agsjournals.onlinelibrary.wiley.com/doi/abs/10.1111/j.1532-5415.1992.tb02009

NTG-Early Detection Screen for Dementia (NTG-EDSD):
https://www.the-ntg.org/ntg-edsd

Dementia Screening Questionnaire for individuals with Intellectual Disabilities (DSQIID):
https://www.birmingham.ac.uk/documents/college-les/psych/ld/lddementiascreeningquestionnaire.pdf

Dementia Questionnaire for People with Learning Disabilities:
https://www.pearsonclinical.co.uk/en-gb/Store/p/P100009213



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