

Ageing and Down Syndrome

**Interactive Session - Help Us Identify
Crucial Needs**

Miriam Philomena and Julie Loudon
July 2024
Parramatta Leagues Club

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INITIATIVE

WELCOME

DOWN SYNDROME
NEW SOUTH WALES 



Apologies

Emily was due to attend today but unfortunately is not available to be here.

She is very keen to hear your feedback to understand what you need from this program.

Emily sincerely apologises for not being able to attending today but as you know she plays an instrumental part in the running of all our programs, and we are all very excited to launch this new initiative.

Julie also sends apologies - Covid has hit her household, and she is too unwell to be present today but will be online to assist with any questions.

OVERVIEW

- Introduction
- Workshop
 - Ageing and Down syndrome
 - Common medical conditions
 - Introduction to Dementia / Alzheimer's disease
- Interactive session
- Lunch

WHO AND WHY



Julie and Bridie



**Miriam, Bridget
and Francesca**



INTRODUCTION

Individuals with Down syndrome are living longer and healthier lives, thanks to advances in medical care and social support.

Life expectancy over 60 years; 10 years in 1907.

Higher prevalence of age-related conditions, including dementia.

Understanding the unique challenges and increased risk of dementia in individuals with Down syndrome is crucial for providing effective support and care.

AGEING & DOWN SYNDROME

Similarities

- Becoming more set in one's ways
- Slowing down
- Different activity preferences

Differences

- Earlier ageing
- Living arrangements
- Health conditions



COMMON MEDICAL CONDITIONS

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It is important to discuss all of these with your GP as every individual is different.

- General ageing
- Celiac disease
- Cervical spine disease
- Dental disease
- Diabetes
- Functional decline
- Menopause
- Mental health
- Obesity / Overweight
- Obstructive sleep apnea
- Osteoarthritis
- Osteoporosis
- Sensory losses
- Thyroid dysfunction
- Dementia / Alzheimer's disease



INTRODUCTION TO DEMENTIA



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DEMENTIA

- Dementia describes a collection of symptoms caused by disorders affecting the brain.
- Dementia may affect thinking, communication, memory, behaviour and the ability to perform everyday tasks.
- Dementia is not a normal part of ageing
- Everyone experiences dementia differently.
- Symptoms will depend on the cause of dementia and the parts of the brain affected.
- Dementia is generally progressive. Symptoms will begin slowly and become gradually worse over time.
- Over 55 million people worldwide live with dementia, and nearly 10 million new cases are diagnosed each year.

The prevalence of dementia, particularly Alzheimer's disease, is significantly higher in people with Down syndrome compared to the general population. It is important to remember that no 2 people experience dementia in the same way. People often lead active and fulfilling lives for many years following their diagnosis.

TYPES OF DEMENTIA



Dementia

An umbrella term used to describe a collection of brain diseases and their symptoms, which include: memory loss, impaired judgment, personality changes, and an inability to perform daily activities.



Alzheimer's Disease

Prevalence

60-70% of dementia cases

Characterized by

Amyloid plaques and beta tangles.

Symptoms include

Impairments in memory, language, and visuospatial skills.



Vascular Dementia

Prevalence

10-20% of dementia cases

Characterized by

Disease or injury to the blood vessels leading to the brain.

Symptoms include

Impaired motor skills and judgement.



Frontotemporal Dementia

Prevalence

10% of dementia cases

Characterized by

Deterioration of frontal and temporal lobes of the brain.

Symptoms include

Personality changes and issues with language.



Lewy Body Dementia

Prevalence

5% of dementia cases

Characterized by

Lewy body protein deposits on nerve cells.

Symptoms include

Hallucinations, disordered sleep, impaired thinking and motor skills.



Other Dementias

Prevalence

5% of dementia cases

Dementias related to

- Parkinson's disease
- Huntington's disease
- HIV
- Crutzfeldt-Jakob disease
- Korsakoff syndrome



DEMENTIA AFFECTS INDIVIDUALS DIFFERENTLY

- Progression
- Types of dementia
- Individual factors
- Personal history



IMPORTANCE OF TIMELY DIAGNOSIS

- Early intervention
- Planning and support
- Quality of life
- Education and training

DOWN SYNDROME
NEW SOUTH WALES



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DOWN SYNDROME & DEMENTIA



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DOWN SYNDROME
NEW SOUTH WALES 

DEMENTIA AND DOWN SYNDROME

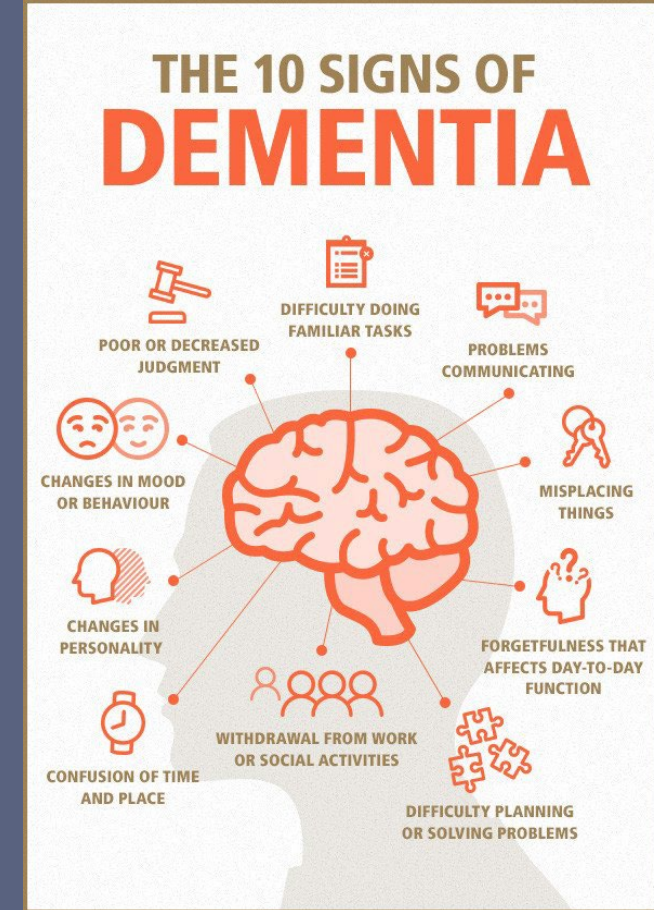
- The link between Down syndrome and dementia is well-established, particularly regarding Alzheimer's disease.
- Significantly higher risk of developing Alzheimer's disease, often at a much younger age compared to the general population.
- This increased risk is primarily due to the presence of an extra copy of chromosome 21, which carries the gene for amyloid precursor protein (APP).

DEMENTIA AND DOWN SYNDROME

- <40 years of age: Symptoms of Alzheimer's disease are uncommon
- By 40: Nearly all individuals with Down syndrome have amyloid plaques in their brains, although not all will develop clinical dementia.
- By 60: Approximately 50-70% of individuals with Down syndrome will have been diagnosed with Alzheimer's disease or another form of dementia.
- >60 years of age: 75% diagnosed

EARLY SIGNS

- Memory loss
- Changes in behaviour and personality.
- Communication difficulties
- Decline in daily living skills
- Confusion and disorientation.
- Decline in cognitive function
- Changes in sleep patterns
- Loss of interest on Social Interaction



UNIQUE CHALLENGES

- Early onset
- Diagnosis
- Communication barriers
- Behavioural changes
- Health comorbidities



STRATEGIES FOR SUPPORT AND CARE

- Early and regular screening
- Person-centred care
- Specialised training for caregivers
- Multidisciplinary approach
- Support networks



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WHAT CAN BE DONE?

- Currently, no cure for Alzheimer's disease, nor do we know how to prevent it.
- Some studies suggest that we may lower the risk by:
 - A healthy diet
 - Being physical active
 - Good sleeping habits
 - Promoting Mental Health
 - Challenging our brain
 - Staying socially engaged



EMOTIONAL SUPPORT

Emotional Impact on Families

- Importance of support
- Shock and grief
- Stress and anxiety
- Guilt and self-doubt
- Social isolation
- Emotional fatigue

Available Support Networks and Resources

- Support groups
- Professional counselling
- Respite care
- Educational resources
- Financial and legal assistance
- Community programs

WHERE TO FROM HERE?

- What are your key issues / concerns / keep you up at night thoughts?
- What practical resources / workshops / services / supports would help, be specific, what, who, how, when, etc.?
- Whilst we may not be able to provide direct services and supports in all the areas identified, knowing this information will enable us to create appropriate referral pathways.

Additional Resources

- Down Syndrome NSW – Ageing Well Initiative
- [Ageing Well Initiative \(downsyndromensw.org.au\)](http://downsyndromensw.org.au)

- Adult Down Syndrome Centre - Dr Brian Chicoine
- [Families and Caregivers - Resources | Adult Down Syndrome Center \(advocatehealth.com\)](http://advocatehealth.com)

- Dementia Australia - www.dementia.org.au
- The National Dementia Helpline - 1800 100 500



www.downsyndromensw.org.au



www.instagram.com/downsyndromensw/



www.facebook.com/DownSyndromeNSW



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