Healthy Minds, Healthy Brains
Part 1

A/Professor Julian Trollor
Chair Intellectual Disability Mental Health
University of New South Wales
What should I hear about in this talk?

- Why is ageing important?
- What happens to the brain as we age?
- What is dementia?
- What is the difference between normal ageing and dementia?
What should I hear about in this talk (continued)?

• How does dementia affect a person with ID?
• If I am concerned what should I do?
• Are there things I can do to make dementia less likely?
• Questions?- later on the panel
The World is Ageing
Some will go to extraordinary lengths..............
Ageing and ID

• The general population is ageing
• The number of older people with ID is also increasing
• This is a good thing
  – better medical and social care

• But:
  – life expectancy varies with disorder and level of ID
  – Most people with milder ID will live to the same age as people without ID
WHAT HAPPENS TO OUR BRAINS AS WE AGE?
What happens to the brain as we age?

- We hit our peak in our 20’s and early 30’s
- After that the brain shrinks slowly
- We slow down a bit
- But: most of our brain functions well
Some changes as we age: brain shrinkage
Some changes as we age: strokes
Some changes as we age: blockage of small deep blood vessels
Ageing and ID: What does it mean for people with ID and their carers?

• For the first time in history, many people with ID can expect to outlive their parent carers

• Carer needs may increase
  – older carers may have care needs too

• Issues of loss and grief may be encountered

• A small change in thinking skills can result in a large change in function
Ageing and ID: What does it mean for services?

- Aged-care Services need to be prepared to help people with ID
- Health care workers need to know about ageing and ID
- We need to decide whether to support people to ‘age in place’ or ‘age in mainstream’.
New estimates of numbers of people with dementia worldwide

Marc Wortmann and Michael Lefevre

2008: 30 million
2030: 59 million
2050: 104 million
What is Dementia

- A syndrome
- With several causes
- Change (decline) in some thinking skills
- Most often but not always affects memory early
- Person’s general abilities to live and function decline
- It is not a normal part of ageing
WHY IS DEMENTIA IMPORTANT FOR PEOPLE WITH ID?
Dementia in ID

- Dementia is more common in people with ID than the general population
- For people without Down syndrome
  - the risk is about 2-3 times the general population
- For people with Down syndrome
  - The risk is about 3-4 times the general population
Down Syndrome & Dementia

• Dementia in Down syndrome
  – About 1 in 5 people with Down syndrome aged 45+
  – About 1 in 2 people with Down syndrome by 60-70 years
• The most common type of dementia in Down syndrome is Alzheimer’s disease
Why is Dementia More Common in Down Syndrome?

- There are lots of reasons
- One of the main ones relates to types of protein which get stuck in the brain
- This protein is called amyloid and it damages the brain
- The gene for amyloid is on chromosome 21, which is the same gene which causes Down syndrome
- People with Down syndrome have 3 copies of this gene and they have more of this protein
Why is Dementia More Common in Down Syndrome?
WHAT IS NORMAL FOR AGE?
# Normal and Abnormal Ageing

<table>
<thead>
<tr>
<th>Normal Ageing</th>
<th>Abnormal Ageing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occasional forgetfulness</td>
<td>Forgetting whole experiences</td>
</tr>
<tr>
<td>Some slowing down of thinking skills</td>
<td>All thinking skills affected</td>
</tr>
<tr>
<td>Decision making OK</td>
<td>Major trouble with decision making</td>
</tr>
<tr>
<td>Knows surroundings to usual extent</td>
<td>Not knowing familiar surroundings</td>
</tr>
<tr>
<td>Recognises loved ones and carers as usual</td>
<td>Lack of recognition of loved ones or familiar carers</td>
</tr>
<tr>
<td>Good mental health</td>
<td>Hearing voices, seeing things that aren’t there</td>
</tr>
<tr>
<td>If loss of skills, this mainly relates to health conditions</td>
<td>Loss of skills</td>
</tr>
</tbody>
</table>
IF I AM CONCERNED WHAT SHOULD I DO?
Ask for an Assessment

- Start with your GP
- Specialist clinics
Assessment of Possible Decline in an Older Person with ID

- What was the person’s best level of ability?
- What changes have been noticed?
- Are there any physical or mental health issues causing a change?
- Is the change noticed in different places?
- Does the person need a detailed assessment of cognitive function?
- Long-term observation usually required
Assessment of Cognitive Decline in an Older Person with ID

- Detailed history
- Physical health assessment
- Blood tests

- Specialists may then order:
  - Brain scans
  - Tests of thinking skills (memory, problem solving, language, construction skills, etc)
  - Tests of every day abilities
HOW DO I KEEP MY BRAIN HEALTHY?
Keeping mentally active

- Mental activity during life protects against dementia later
- Get stuck into life
- More complex activities are probably better
Keep physically active 1

- Dementia more likely in inactive people
Keep physically active 2

- Exercise increases memory
Keep physically active 3

- Exercise protects against brain shrinkage
Look after your general health

- risk factors for dementia include:
  - Smoking
  - Diabetes
  - High blood pressure
  - High cholesterol
  - Strokes and mini strokes
  - Obesity (in mid life)
Look after your mental health

- Dementia risk is increased by having a mental health problem such as depression
AN ADVERTISEMENT
The Successful Ageing in Intellectual Disability Study (SAge-ID)

• We are asking for people with ID over the age of 40 and their carers to be in a study.
• The study aims to
  – Look at the health and mental health of people with ID as they age
  – Understand the experience of carers of older people with ID
  – Look at ways to improve services
  – See if there are ways to prevent dementia
Expression of Interest for the SAge-ID study

If you are interested in participating in the Successful Ageing and ID study, or want some more information about the study, please complete this form and return it to us in the reply envelope. Once we receive this form, we will contact you to give you more information about the study and answer any questions you might have. The call will take around 5 minutes. Please indicate the best times we might be able to call you (e.g. mornings/afternoons/evenings). Any information you give us will be treated as confidential. If you have questions, you can call the study coordinator on (02) 9385 3993.

☐ Please send me more information about the SAge-ID Study

Name..................................................................................................................................................
Conclusions

- People with ID are living healthy, active lives
- As we all age we may develop problems with our health and thinking skills
- It is important for services and doctors to be able to plan for the support needs of people with ID as they age
Healthy Minds, Healthy Brains
Part 2

A/Professor Julian Trollor
Chair Intellectual Disability Mental Health
University of New South Wales
What should I hear about in this talk?

- How common are mental health problems?
- How and why do they affect people?
- What’s this about Intellectual Disability and mental health?
What else should I hear about in this talk?

- Are there things I can do to improve my mental health?
- How do I get help?
- How can I help a person with a mental health problem?
- Questions? - later on the panel
HOW COMMON ARE MENTAL HEALTH PROBLEMS?
How Common are Mental Health Problems?
General Population

- About 1 in 10 of us in a month

2007 National Survey of Mental Health and Wellbeing
How Common are Mental Health Problems?

General Population

- About 2 in 10 of us in a year

2007 National Survey of Mental Health and Wellbeing
How Common are Mental Health Problems? For people with ID

- About 4 or 5 out of every 10 people in a year

Cooper et. al., 2007
How Common are Mental Health Problems?
For carers

- About 3 out of every 10 people in a year

Savage and Bailey, 2004
“The ringing in your ears— I think I can help”
What are some common mental health problems?

- Depression or mood problems
- Anxiety Disorders or worrying problems
- Drugs and alcohol
- Personality problems
- Schizophrenia
- Bipolar disorder
- Cognitive
- Developmental problems such as ADHD
- Behavioural disorder or challenging behaviours
Why do people have mental health problems?
It’s a fine balance

Good for mental health

Not so good for mental health
It’s a fine balance: things we can’t change
It’s a fine balance: things we can’t change
It’s a fine balance: things we may have to deal with

Trauma and abuse
It’s a fine balance: things we may have to deal with

Family Conflict
It’s a fine balance: things we may have to deal with

Stress and worry
“I’m learning how to relax, doctor — but I want to relax better and faster! I want to be on the cutting edge of relaxation!”
It’s a fine balance: things we may have to deal with

Losing a job or a role
It’s a fine balance: things we may have to deal with

Loss and grief
It’s a fine balance: our thinking and communicating

Sensitivity to criticism
It’s a fine balance: our thinking and communicating

Communication difficulties
It’s a fine balance: our thinking and communicating

Who am I?
It’s a fine balance: our thinking and communicating

Being a perfectionist
It’s a fine balance: our thinking and communicating

Social anxiety
It’s a fine balance: our health
It’s a fine balance: our health

Chronic pain
It’s a fine balance: our health

Strokes and small blood vessel blockage
It’s a fine balance: our health

Head injuries
It’s a fine balance: our health

Epilepsy
It’s a fine balance: our health

medications
It’s a fine balance: things we can’t change
It’s a fine balance: things we can’t change
It’s a fine balance: things we can work on

Harmonious family
It’s a fine balance: things we can work on

Stimulation across the lifespan
It’s a fine balance: things we can work on

Healthy diet
It’s a fine balance: things we can work on

No drugs; less alcohol
It’s a fine balance: things we can work on

Exercising your brain
It’s a fine balance: things we can work on

Being able to relax
It’s a fine balance: things we can work on

Dealing with problems
It’s a fine balance: things we can work on

Good social networks
It’s a fine balance: things we can work on

Staying physically active
It’s a fine balance: things we can work on

Being able to say no
It's a fine balance

Good for mental health

Not so good for mental health
Tips for Good Mental Health

• Look after stress levels
• Improving how we cope
• Look after mind and body
  – Exercise
  – Eat well
  – Being mentally active
  – Less alcohol and other recreational drug use
• Dealing with a problem early
• Asking for help
• Letting someone else help
• Learn how to help someone
"Looking good!"
Men Versus Women

• More common in women:
  – Depression
  – Anxiety
  – Problems after childbirth

• More common in men
  – Alcohol abuse
  – Substance abuse

• Equally common
  – Bipolar disorder
  – Schizophrenia
Mental Health later in life: some good news

• Less:
  – Depression
  – Anxiety
  – Severe schizophrenia
  – Behaviour problems
Mental Health later in life: some ‘not so good’ news

• More:
  – Dementia and other cognitive disorders
  – Illness triggered by health problems e.g. after stroke
More about carers and mental health

• Caring role has an impact
• The following may be particularly important in carer wellbeing:
  – The type of disability
  – The degree of disability
  – The proximity
  – The type of relationship
  – The presence of behavioural problems
  – Financial resources
  – Social support
  – Coping strategies, self esteem
• Carer supports very important
People with Mental Health problems have trouble getting help

• For people without ID:
  – only about 1/3 of people who need it actually get a mental health service
• For people with ID:
  – this figure is much worse
Why is it harder for some people with ID to get help?

- Services: limited
- Services: lack expertise
- Some people with ID find that:
  - It is hard to know when to ask for help
  - It is hard to push for something to be done
  - It is hard to say what’s wrong
Why is harder for some people with ID to get help?

• Support person may sometimes:
  – not know what to look for
  – not know how to access help

• Disability workers, GPs and mental health workers sometimes:
  – Don’t know what to look for
  – Don’t have enough training
Why is harder for some people with ID to get help?

• It can be hard to coordinate mental health supports across settings (e.g. Disability and Health)
• Diagnostic difficulties
• Treatment can be more complicated
Sometimes the mental health problem can present differently

- With more severe ID, or when there are communication problems:
  - Behavioural change can be the main sign that something is wrong
  - This can be confusing for support people and for professionals

- Sometimes changes in thinking and behaviour can be mistakenly considered as ‘normal’ for a person with ID
  - Where there is high level challenging behaviour
  - Where there are communication problems
  - Where the person assessing is inexperienced
Sometimes what looks like a mental health problem is something different

• Symptoms of mental health problems sometimes have other causes:
  – Pain
  – physical illness/disorder
  – medication side-effects,
  – response to stress or change
Treatment for most Mental Health Problems involves........

- The person coming first
- A whole person approach
- Respect and engagement in decision making
- Recognising and addressing the triggers and background factors which have contributed
- Persistence and patience
- In particular, in a disability setting, work across multidisciplinary teams
Treatment for Mental Health Problems may involve........

- Education
- Psychological approaches
- Changes to social situations
- Providing increased support
- A detailed assessment and approach to behaviours
- Medications
- Other physical therapies
When medication is used

- A thorough assessment of physical health should take place first
- They should be part of the approach not the whole approach
- Consent should be obtained
- The medication should be started gradually
- The effectiveness should be reviewed regularly
- The side effects should be reviewed regularly
Organisation of mental health supports

- Your GP
- Specialist psychiatrist
- Psychologist
- Other mental health professional e.g. mental health team or nurse
Choosing a Good GP

• Ask around
• Be prepared to book ahead
• See the same GP over a period of time so he/she can be get to know you
• Find someone whose style suits you and whom you feel you can trust
• If you do not feel that your concerns have been taken seriously, go to a new GP
Finding a Psychologist or Psychiatrist

- Ask your GP
- Psychologist: ring the Australian Psychological Association Referral Service 1800 333 497
- Psychiatrist: Ring the New South Wales Branch of The Royal Australian and New Zealand College of Psychiatrists (02) 9352 3600
“Whoa—way too much information!”
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Name...........................................................................................................................................................................
Tell us what you thought......

We would like to know what you thought of this event. We want to know what worked and what did not work.

Please circle one of the answers for each sentence:

<table>
<thead>
<tr>
<th>The talks were helpful</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could understand the talks</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>I could ask a question if I wanted to</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>The building was easy to find</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>It was easy to get into and move around inside the building</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>The paper hand-outs were helpful</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
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<td>Neutral</td>
<td>Disagree</td>
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</tr>
<tr>
<td>The food and drink was ok for me</td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
</tbody>
</table>
Thank you
In conclusion

- Mental health issues are important for all of us.
- Some carers and people with ID can be more likely to experience problems in this area.
- Knowing about mental health is important.
- Knowing about mental health helps us get the help we need.
- Disability and health services are find new ways to work together to help someone with a mental health problem.
DEPRESSION
So we all get moody- when should I get help?

• If the mood doesn’t go away

• If the mood impacts:
  – Work
  – Relationships
  – Activities
  – Ability to enjoy things
So we all get moody - when should I get help?

• Where there are changes in:
  – Energy levels
  – Appetite
  – Sleep
  – usual activities
  – Concentration

• Where there are thoughts of:
  – Guilt
  – Hopelessness
  – That life is not worth living
Bipolar Disorder

- A disorder of mood with extremes of high and low mood.
- Highs and lows in mood usually last weeks-months.
- Sometimes highs and lows last only hours or days.
Bipolar Disorder

• Highs and lows come back unless treated.
• Sometimes they are so severe that the person’s thinking and perceptions are altered (psychosis)
  – Hallucinations
  – delusions,
  – disorganisation of thoughts
Bipolar Disorder

Mania or ‘High’ mood

Hypomania

Depression or ‘low’ mood
Bipolar disorder: Mania

- John, aged 30, has a mild ID and lives at home with his parents. Has been loud and angry for the past two weeks.
- In the last week, he has been up all night playing his music.
- He is getting into arguments, talking very fast and has lots of plans for the future which seem ‘over the top’.
- He normally is careful with his money but recently has been giving away $50 notes at his workplace.
- Even though he is usually shy with girls he has been asking women at the bus stop if they want to go out with him.
ANXIETY DISORDERS
Anxiety disorders

• Generalised anxiety disorder
  – ‘the constant worrier’

• Panic disorder (with or without agoraphobia)
  – repeated severe episodes of anxiety, often without trigger; avoidance of feared situations e.g. buses, trains, shopping centres

• Obsessive compulsive disorder
  – ‘the constant checker’; intrusive unwanted thoughts; repeated actions to reduce anxiety associated with thoughts e.g. checking, counting, washing +++

• Social anxiety disorder
  – Marked concern about one’s appearance or being embarrassed in social situations

• Post traumatic stress disorder
  – Triggered by situations where life or security is dramatically threatened.
  – Intrusive recollections or unwanted re-experiencing of traumatic memories and emotions, emotional numbing, overanxious.
SCHIZOPHRENIA
Key Symptoms of Schizophrenia

- **Psychotic Symptoms**
  - delusions
  - hallucinations
- **Disorganised speech, thoughts and behaviour**
- **“Negative” symptoms**
  - Amotivation, flattening of emotions, social withdrawal, reduced speech
- **Usually longstanding**
Schizophrenia

- A 30-year-old man who has been hospitalised several times in the past for treatment of a mental illness begins to withdraw from his friends. He has been noted to be behaving oddly by his flat mates who say that he talks to himself, appears suspicious and has been accusing them of stealing his possessions. He misinterprets events he sees on the television and thinks that somehow he is connected with what’s happening on the news. It emerges that he has not been taking his medication for several months.
Schizophrenia: Treatment

• Early intervention is preferable
• Combination of:
  – Education
  – Medications
  – Cognitive therapy
  – Socialisation, activities
• Outcome depends on severity