

FOCUS Conference

Caring for People Aging with Intellectual Disability
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Trends Over Time: The Good News

- International phenomenon
- Life expectancy increases
- Projected population increases
- Relocation to nursing homes

Implications for People with ID

- Increased burden of illness
 - Disability related and life long conditions
 - Disability related to external factors
- Premature relocation to aged care
- Suffering for person with ID/ difficulty for caregiver

What's Different for People with ID?

- Less likely to be screened
- Less likely to be diagnosed
- Less likely to be treated
- Untreated illness often irreversible

Background: Insufficient Information

- Diagnosis primarily based on history, what patients can tell you (80%)
- Some people with ID are unable to describe their symptoms
- People with ID who can talk about symptoms are less able to distinguish and describe symptoms
- Health professionals are often not knowledgeable about ID and the risks
- Inability to describe symptoms

Why so Many Unidentified?

- Caregiver misinterpreting symptoms as age or behavior problem
- Caregiver not noticing symptoms
- Change in caregiver
- Assumptions that PCP can see the problem
- Assumptions that screen will not be tolerated
- PCP unfamiliar

Common Illnesses

- Same as all older adults
- Higher than others
 - Respiratory (leading cause of death)
 - Diabetes (obesity, inactivity)
 - Gastrointestinal
- Increasing
 - Cancer (GI, testicular)
 - Arthritis
 - Less likely to treat
 - Heart disease
 - Related to disability
 - Obesity
 - Inactivity

Gastrointestinal Conditions: An Example

- *Much* higher rate
 - Constipation up to 70% (meds, inactivity)
 - Reflux 50% (vs 7%)
 - Bowel and GI cancer
 - Hepatitis and H Pylori (institutional exposure)
- *Highly associated with behavioral changes*
- *Even with speech, unable to articulate symptoms*

Take Home Messages

- Beware of sudden changes
- Be mindful of slow changes over time, baseline
- Don't assume 'its just getting older'
- Behavior change is common indicator of illness
- Ask the most familiar person or people
- The same symptom can be many things
- Sometimes there is more than one thing

- What happens to people ageing in group homes?
- How do staff and family respond?
- What leads to relocations of people to residential aged care?
- What is the aged care experience for people with ID?

Study of Aging With an ID

What we Found

- There were many accounts of delays
 - Delays in identifying a change
 - Delays in seeing the change as problematic
 - Delays in seeking help once a problem had been identified
- Screening different than others

N=17	
Impaction	12
Behavior	12
Incontinence	9
Confusion	8
Falls	8
Heart	7
Choking	7
Arthritis	5
Seizures	5
Slowing down	5
Night waking	4
Infections	4
Cancer	4
Hearing	2
Vision	3

Delayed Identification: Invisible Signs

- Older residents who did self care
- Accidental discoveries of physical changes not visible to staff
- Discovered during unrelated exam
- Individual rights/privacy/dignity/self care

Working With Health Care Providers

- Double appointment time
- Familiar person
- Decrease the wait time
- Accompany throughout
- Explain services at group home

- *“..an elderly man independent with all his own personal care, he, so the staff never went to the bathroom with him....and it turned out he had cancer that, of the testicle, and it was massively enlarged but because the staff had never been in the bathroom with him, they’d never seen it and his mum had never seen him naked either....*
- *..and it’s only that he broke his arm and his mum then had to help him with a bottle to urinate and his mum noticed this massive testicle and took him off straight to the doctor and they found out it was cancer.”(Group home staff)*

Delayed Identification: Invisible Conditions

- Many conditions not visible (heart, GI, Requires symptom description
- Unable to provide description or history
- Often subtle changes that go unnoticed or attributed to something else, slowing down, less cooperative, more fatigued
- thyroid, etc)

- *“Because a disability, he ’s got cerebral palsy, he ’s deaf, he ’s getting older ... and I know there was a problem he had for quite a while which we didn ’t ever click on and that was his heart, which we all clicked on now. Strictly speaking a doctor should have spotted that a lot, lot earlier...” (Family Member)*

Delay: Just Aging

- Normal aging versus treatable condition
- Acceptance of decline
- Focus on ability to function

Just Aging: Focus on Function

- Oh, well he's probably, might have cataracts, and he doesn't see very well, but he obviously, he knows the jobs that he does so well, ... he can do it blindfolded pretty much. But I've noticed that he is, oh possibly with his age, you know he's a year older and he's, he's a bit slower but he, yes he still gets the job done, and he does, you know, it in his own pace, yes. (Group home staff)

Delay: Irreversible

- Things related to ageing are irreversible
- Irreversible changes:
 - Accommodate
 - Move on/relocate

Delay: Same Old Problem

- Problems that looked similar to past
- Recurrent, altered, more frequent
- Expect similar outcome
- Expect similar treatment/support
- Fail to question source or cause

Delay: Expecting Dementia

- High expectation for dementia in all residents
- Slow or sudden onset not distinguished
- Often professionals concur
- Behavior changes seen as confirmation of dementia and accepted

Expecting Dementia

- *"A lot of times he's just going to the toilet and I don't believe that he really wants to go to the toilet I think it's just he wakes up and thinks 'oh I'm awake I'll go to the toilet' and he has the falls." (Group home staff)*

Delay: Protecting

- Accommodating and protecting
- Irreversible changes accommodated as long as possible (supportive)
- Protecting person from relocation

Confidence and Decision Making

- Link between confidence and remaining at home
- Link between confidence and training
- Link between confidence and support

Screening Rates for Australia and Residents

Test	General Population	Residents	Don't know
Hearing	N/A	51%	27%
Breast (mammogram)	57%	63%	13%
Cholesterol	54%	76%	16%
Blood Sugar	N/A	77%	18%
Blood Pressure	95%	95%	3%
FOBT (Faecal Occult Blood Test) ★	38%	19%	34%
Pap ★	61%	15%	8%

average age of residents was 55 (range 41-78)

Organizational Policies

- Common
 - Diabetes care
 - Emergencies
 - Medications
- Missing
 - Post discharge
 - Relocation
 - Prevention

Lessons

- Misinterpretation of signs and symptoms
- Failure to identify health conditions
- See age related conditions as irreversible
- Inability to communicate symptoms
- Conflict with rights and focus on independence/choice
- Protecting person from anticipated consequences

Where did the Manual Come From?

- Following people ageing with an ID for 4 years
- Many interviews with group home staff
- Interviews with families of people with ID
- Interviews with residential aged care staff
- Long time to diagnosis
- Premature relocation
- Irreversible relocation

Components of the Staff Guide

- Basic Information, knowledge, tips (brief)
 - Normal ageing
 - Building successful partnerships
 - Decision making/advocating
 - End of life care: keeping people home
 - Common symptoms
 - Common conditions
 - Resources

Working with Families

- Shared decision making
- Changes in level/type of involvement
- Information sharing
- Differences and disagreements

End of Life Care

- Working with the person who is dying
- Talking to other residents
- Keeping people home
 - Supporting staff
 - Finding resources
 - Working together

Communicating about Symptoms

- What is a symptom?
- Why is it important to document?
- ‘Behavior problems’
 - Aggression
 - Confusion
 - Daily living skills
 - Resistance to care
 - Screaming
 - Sleep problems

Resources Available

- Manual
- Managers' Guide
- Survey

- https://charge.wisc.edu/care/items.asp?cat_id=95
