

# Supporting Older People with an Intellectual Disability to Age at Home:

A Manual for Support Staff and Carers

Queensland, Australia (2014)



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**Much of the material contained in the Manual and accompanying Manager's Guide was prepared as part of a project funded through the Australian Research Council (ARC) Linkage Program. The Project's partners were Catholic Homes, Gill Family Foundation, National Disability Services Victoria, Office of the Public Advocate (Vic), St John of God Health Care and Wesley Mission Melbourne. The researchers were R. Webber (Australian Catholic University), B. Bowers (University of Wisconsin-Madison) and C. Bigby (LaTrobe University).**

**The development and production of the Queensland version of this Manual was jointly funded by Endeavour Foundation, Cerebral Palsy League, UnitingCare Community, Life Without Barriers, Centacare, Multicap and National Disability Services (Queensland)**

## NOTICE

This is an information gathering and resource Manual to be used in conjunction with a GP or specialist. It is not intended for diagnosis, treatment or as a substitute for medical advice.

Before starting a diet or exercise plan consult with a health care professional.

If there is a situation which is not an emergency but could be serious, Queensland Health has a telephone line **13 HEALTH (13 43 25 84)** for all Queenslanders to help take the worry out of health concerns.

**If it is an emergency ring 000.**

### Why should I bother with this Manual? I have enough to do!

The information in this manual can help you support ageing people with an intellectual disability to remain in their own home. It is designed to help you find information very quickly.

### We don't provide nursing care here. This is supported accommodation.

The tips found in this Manual are not meant to turn you into nurses! The information is intended to help you act as a more effective health advocate for the residents you support, to better identify when medical attention is necessary and to assist you to gather the type of information needed by GPs and allied health professionals.

### Shouldn't I just call an ambulance for medical problems?

You should always call an ambulance for a medical emergency. Your organisation has policies for responding to emergencies. This Manual is never to be used in a medical emergency. It is to help you provide useful information to GPs so that the residents you support will receive a timely diagnosis and treatment.

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## How staff can use this Manual

### Using this Manual

The purpose of this Manual is to help staff support people with an intellectual disability who are ageing, to keep them active despite the development of health conditions, to prevent disability and discomfort and to keep people in their own home as long as possible. It provides tools to help staff understand common symptoms and conditions and will help staff to communicate with health care professionals, to advocate for care and to comfort supported accommodation residents.

The Manual is arranged as follows:

- Section 1: Normal Changes as a Person Ages
- Section 2: Building Successful Partnerships with Health Care Providers and Families
- Section 3: Decision Making: Advocating for Individual Involvement
- Section 4: End of Life Care
- Section 5: Understanding, Communicating and Supporting Residents with Common Symptoms
- Section 6: Understanding and Supporting Residents with Common Conditions
- Section 7: Accessing Resources
- Appendix: Tips

### Getting to know the Manual for new and existing staff:

Explore the Table of Contents

- Read the Introduction
 

Understand that this Manual is **not to be used for emergency situations**. This is to be used to help you understand issues that are common in older adults with an intellectual disability (ID) and to prepare you to find help as health issues arise.
- Read Chapters 1 to 4
 

Read these chapters and then come back to them as specific issues arise with residents in your supported accommodation.
- Browse Chapters 5 and 6
 

Look at the list of symptoms in the Table of Contents. Think about symptoms you might have seen some residents exhibit in the last month. You can come back to this chapter for tips on what to do when you see a symptom. Make extra copies of the Information Gathering Worksheets as you need them (copies can be printed from the CD on the back cover). Now think about which conditions residents have been diagnosed with. Read those sections (Chapter 6) carefully. Consider making a copy of relevant pages and sharing them with other staff.
- Browse the Resources Chapter
 

Make a list of the things that would be helpful to you right now. Come back to this chapter as needs arise in your home.
- Look at the Appendix
 

Is there anything here that is helpful to you now? If yes, make a copy. If not, remember these resources in case they might be helpful later.
- Pick up this Manual and review the contents periodically.

## When a resident exhibits a symptom:

- If this is an emergency, use the correct emergency procedures for your home.

## If this is not an emergency:

- Read about symptom(s) in Chapter 6.
- Make a copy of the relevant Information Gathering Worksheet (from CD in back cover).
- Talk to other staff who may have information that you don't have about the resident.
- Plan next steps with your manager or supervisor.
- Make sure information goes with the person taking the resident to his/her next health care appointment.
- If the symptom is not listed in this Manual, talk to your manager or supervisor about what to do and where to go for help.
- See the Resources (see Chapter 7).

## When a resident is diagnosed with a condition:

- Read about the condition and any related conditions and/or symptoms. Talk to your manager or supervisor and other staff about what to watch for as you and the resident manage the condition on a daily basis. Ask the resident's GP any questions you have.

## *Normal changes as a person ages*

People with intellectual disability are living longer than ever before. Advances in medical technology, social support and health care programs for people with intellectual disability have increased life expectancy. Consequently, it is now common for people with intellectual disability to live well into old age.

## Health and intellectual disability

People with intellectual disability have higher rates of certain medical conditions than would be found in the general population. Higher rates of brittle bones, cancer, heart disease and vision/hearing loss make ageing difficult for people with intellectual disability and for their carers. People with certain types of intellectual disability may age prematurely. For example, those with Down syndrome develop age related conditions at a much earlier age than most other people.

## Where older people live

As people age, they usually remain in their home as long as they are able, often with support from health and community services and family members. People with intellectual disability are less likely than other older adults to have adult children to help with their care. Parents may no longer be alive and siblings are often unprepared to assume caregiving responsibilities. Older adults with intellectual disability may move into supported accommodation at this point. Others with intellectual disability have been living in supported accommodation since childhood. For both groups, advancing age brings with it the same health concerns that all other older adults experience, in addition to any disability already present. Ageing is accompanied by predictable changes in physical functioning and general resilience. Some conditions can be prevented. Others cannot be prevented but can be treated, resulting in better overall health and better quality of life.

## Challenges for supported accommodation providing care to ageing people

Support staff often feel unprepared to support residents as they develop health conditions. Finding the right resources to help sort out the problem, altering house routines to accommodate changes, managing treatments and providing the most effective support and supervision for people with health conditions is often challenging. Some health conditions can be difficult to manage. Handling multiple medical appointments and understanding the condition and treatment side effects are all issues that supported accommodation staff may feel unprepared for. As a consequence, people with intellectual disability can be prematurely relocated to aged care, resulting in loss of important relationships and likely diminishing quality of life.

### What support staff can do

Support staff play a crucial role in supporting residents to age in place in their supported accommodation. Most important is the role support staff can play in making certain that GPs have the information they need to make the correct diagnosis and begin treatment.

## Aggression

Aggressive behaviour is not a normal part of getting older. Aggression can be physical or verbal and can be directed at another person, object or oneself. It may include hitting, kicking, biting, insulting, accusing or threatening. These behaviours commonly occur during routine caregiving, physical examinations, social interactions with others or even when there is no apparent trigger for the aggression.

Signs that someone may become aggressive include:

- Changes in language (e.g. repetition, louder or faster speech).
- Changes in behaviour patterns (e.g. cannot focus on an activity, rocking, resisting care).
- Increased fidgeting (e.g., rocking, pacing, beating hands on legs or table).
- Increased repetition of a word or phrase, noises, movements or other actions.
- New or increased restlessness.
- New suspiciousness or paranoia.

### What are possible causes of aggression?

Aggression can be a normal response to an upsetting or threatening situation. In someone who is unable to communicate verbally. Aggression can be a symptom of physical discomfort, pain or the onset of illness. This should always be considered first. It can also be a symptom of a mental health condition, including dementia. Health problems that can be signalled by aggressive behaviour could include:

#### Physical conditions

- pain or other discomfort
- constipation
- illness
- medication side effect
- changes in vision or hearing
- seizures
- stroke/CVA/cerebral infarction
- fatigue or sleep disruption
- dehydration

#### Situational conditions

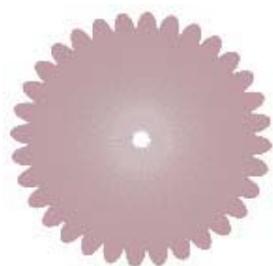
*(may not be health related)*

- fear/anxiety
- need for attention
- desire for power or control
- fatigue
- unmet sexual desires or frustrations
- environment (too large, cluttered, busy, loud, unfamiliar surroundings, not enough structure)
- tasks that are too confusing or complicated

#### Mental conditions

- depression
- dementia

### What should I do if I am noticing an increase in aggression?



If this is an emergency, follow proper emergency procedures for your workplace. If this is not an emergency, one important thing you can do is to collect information and document your observations. This can assist the GP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident and discuss with your house manager/supervisor how to proceed.

- If the aggression has been assessed by a practitioner in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for managing the aggression.
- If the aggression is *new, increased in frequency or has not been assessed by a GP*, please notify the resident's medical practitioner and bring the worksheet to the resident's next appointment.

### What are my resources?

Dealing with combative behaviour. Wellington Parc.

[http://www.wellingtonparc.com/Dealing\\_With\\_Combative\\_Behavior.pdf](http://www.wellingtonparc.com/Dealing_With_Combative_Behavior.pdf)

Queensland Department of Communities, Child Safety and Disability Services

<http://www.communities.qld.gov.au/disability/key-projects/positive-futures/changing-lives-through-positive-behaviour-support>

Understanding Intellectual Disability and Health. Behaviour Management

<http://www.intellectualdisability.info/mental-health/behaviour-management>

In depth reading on dual diagnosis (intellectual disability and mental illness)

[http://www.som.uq.edu.au/media/197709/sand\\_in\\_society.pdf](http://www.som.uq.edu.au/media/197709/sand_in_society.pdf)

A challenging behavior information sheet

<http://www.cddh.monash.org/assets/chabev.pdf>

### Related sections of Manual

- Depression
- Resistance to Care

## Information Gathering Worksheet: Aggression

If a resident is becoming aggressive (see previous page), please complete this worksheet to assist with information gathering in order to present helpful data to the medical practitioner.

Information to Collect	Yes/No	Observations: Also ask anyone else who may have information (such as staff on other shifts or family members)
Describe the aggressive behaviour. Be specific.		
Is aggression unusual for this resident?		
When did you first notice the aggressive behaviour? What was happening immediately prior to the aggression?		
Was the resident exhibiting any signs of nervousness or anger prior to the aggressive act? What were those signs?		
How quickly did the resident recover from the situation? Was there anything that helped calm the resident?		
Has anything occurred outside of the resident's regular routine, such as a visitor, new resident, a medical procedure, unusual weather that may have affected their comfort or sleep patterns?		
Has the resident shown signs of: <ul style="list-style-type: none"> <li>• pain</li> <li>• headaches</li> <li>• fatigue</li> <li>• trouble sleeping</li> <li>• trouble concentrating</li> <li>• difficulty with hearing or vision</li> <li>• other? (even if unrelated)</li> </ul>		
Have you noticed any speech changes lately? has the resident started to slur words, stop mid-sentence, or become confused about something they were talking about?		

next  
steps

Name:  
Date:  
Action(s):