

Support for Older People with Intellectual Disability:

A Manual for Promoting Health



Authors

Barbara J. Bowers, PhD, RN

Kimberly Nolet, MS

University of Wisconsin-Madison, School of Nursing, Madison, WI, USA

With

Ruth Webber, PhD, *Australian Catholic University, Quality of Life and Social Justice Research Center, Melbourne, Australia*

Christine Bigby, PhD, *LaTrobe University, Department of Social Work and Social Policy, Melbourne, Australia*

Eleanore Stumm, MS, NP, *University of Wisconsin Medical Foundation, Madison, WI*

Contributors

John Chesterman, *Office of the Public Advocate, Melbourne, Australia*

Kristen Czarny, Bo Kim, Jacqueline Nelson, Kristin Pecanac, Kelly Planton,

Katie Stodola, Sigan Hartley and He Yu, *University of Wisconsin-Madison, USA*

Julie Wilmot, *Australian Catholic University, Melbourne, Australia*

Erika Schoot, MPA, *University of Wisconsin-Madison*

Design and Editing:

Erin Curran, Stephanie Bakula and Jennifer Morgan, *University of Wisconsin-Madison, USA*

Special thanks to:

Fiona Sparrow, *Melbourne, Australia*

Alfred Johnson, *Wisconsin Department of Health Services*

Wisconsin Aging with Intellectual Disability Steering Committee

For information:

Barbara Bowers

University of Wisconsin-Madison

School of Nursing

1-608-263-5189

bjbowers@wisc.edu

Kim Nolet

University of Wisconsin-Madison

School of Nursing

1-608-262-8146

kanolet@wisc.edu

2014 2nd Edition

This work is licensed under the Creative Commons Attribution-Non Commercial-No Derivs 3.0 Unported License. To view a copy of this license to understand how this work may be used, visit <http://creativecommons.org/licenses/by-nc-nd/3.0/> or send a letter to Creative Commons, 444 Castro Street, Suite 900, Mountain View, California, 94041, USA

This Manual was prepared as part of a project funded through the Australian Research Council (ARC) Linkage Program, University of Wisconsin-Madison School of Nursing and Gill Family Foundation. The project was supported by the Clinical and Translational Science Award (CTSA) program, previously through the National Center for Research Resources (NCRR), grant 1UL1RR025011, and now by the National Center for Advancing Translational Sciences (NCATS), grant 9U54TR000021. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

This Manual has been designed for a general audience; however, some of the resources provided are specific to the state of Wisconsin.

NOTICE

This is an information gathering and resource Manual to be used in conjunction with a Primary Health Care Provider (PCP) 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.

In case of emergency, call 911.

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

The information in this Manual is designed to help you support aging people with an intellectual disability to remain in their own home. This manual is designed to help you find information very quickly. It should only take you a few minutes to find the information you are looking for. Please note that for persons with physical disabilities, such as Cerebral Palsy and genetic syndromes, support staff will need to discuss the specific symptoms they should be alert for with health care providers. This manual does not address the physical changes that are seen commonly in people aging with physical disabilities.

We don't provide nursing care here.

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 persons you support, to better identify when medical attention is necessary and to assist you to gather the type of information needed by Primary Care Providers (PCPs) and other health care providers.

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

You should always call an ambulance for a medical emergency. This Manual is never to be used in a medical emergency. It is to help you provide useful information to PCPs so that the people you support will receive a timely diagnosis and the best possible treatment.

Table of Contents

iii

Chapter 1 – Normal Changes as a Person Ages	1
Chapter 2 – Building Successful Partnerships	11
– Working with health care providers	
– Screenings	
– Working with persons and their families	
Chapter 3 – Decision Making: Advocating for Individual Involvement	24
Chapter 4 – End of Life Care	29
Chapter 5 – Understanding and Communicating Common Symptoms	35
Aggression	37
Breathing Difficulty	40
Choking/Swallowing Difficulty	44
Confusion	47
Constipation	55
Dizziness	59
Falls and Difficulty Walking	63
Fatigue	68
Foot Problems	72
Loss of Daily Living Skills	76
Pain	79
Resistance to Care	83
Screaming/Vocalizing	86
Sleep Problems	90
Slowing Down	94
Swelling (Edema)	97
Thirst	102
Urinary Frequency	105
Urinary Incontinence	108
Weight Gain	112
Weight Loss	116
Chapter 6 – Understanding and Supporting Persons with Common Age Related Health Conditions	119

Arthritis	120
Cancer	123
Dehydration	126
Delirium	128
Dementia	130
Depression	134
Diabetes	138
Epilepsy/Seizure Disorders	141
GERD (Reflux)	145
Hearing Changes	147
Heart Disease	150
Hypertension	152
Lung Disease	154
Obesity	156
Parkinson's Disease	158
Stroke	160
Vision Loss	162
Chapter 7 – Accessing Resources	165
Appendix – Health Care Provider Tips	171
A My Health Passport: Information to bring to appointments with health care providers to help with communication	
B Medication Information Form: Information to bring to appointments with health care providers to track medication	
C What is a Blood Test?: A visual aid to prepare individuals for a blood draw	
D Hospital Admissions Checklists	
E Fitting Footwear: A manual on how to properly fit shoes in order to avoid foot problems	

Please note that a CD is included on the inside back cover of this document. This CD provides an electronic copy of the Manual as well as master copies of all the Information Gathering Worksheets.

How to use this Manual

Getting to know the Manual:

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 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 health issues arise with persons in your group home.
- Browse Chapters 5 and 6

Look at the list of symptoms in the Table of Contents. Think about symptoms you might have seen some persons 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 persons have been diagnosed with. Read those sections (Chapter 6) carefully. Consider making a copy of relevant pages and sharing them with other staff. (The CD at the back will allow you to run off separate pages.
- 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.

When a person 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 about the person that you don't have.
- Plan next steps with your manager or supervisor.
- Make sure information goes with the person taking the person 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 person 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 person manage the condition on a daily basis. Ask the person's PCP any questions you have.

Normal changes as a person ages

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

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. Advancing age brings with it the same health concerns that all other older adults experience, in addition to any disability already present. Aging 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 group homes providing care to aging people

Group home staff often feel unprepared to support people 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 group home staff may feel unprepared for. As a consequence, people can be prematurely relocated to nursing homes, resulting in loss of important relationships and likely diminishing quality of life.

What group home staff can do

Group home staff play a crucial role in supporting persons to age in place. Most important is the role group home staff can play in making certain that PCPs have the information they need to make the correct diagnosis and begin treatment.

Using this Manual

This Manual is intended to help staff support people as they age. 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 persons, to keep people active despite the development of health conditions, to prevent disability and discomfort and to keep people in their own home as long as possible.

Aggression

Aggressive behavior 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 behaviors 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 behavior 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 particularly 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, or dementia. Health problems that can be signaled by aggressive behavior 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

Mental health conditions

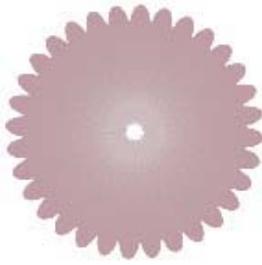
- depression
- dementia

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

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



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 PCP 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 person 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 PCP*, please notify the person's medical practitioner and bring the worksheet to the person's next appointment.

Who can I call for help after the PCP?

Central Wisconsin Center: Short Term Assessment Program (STAP). 1-608-301-9233

<http://www.dhs.wisconsin.gov/cwc/Services/stap/index.htm>

- A service for people who demonstrate challenging behavior. This can include aggressive, self-injuring, anti-social or dangerous behaviors.

What are my resources?

Wellington Parc. Dealing with combative behavior.

http://www.wellingtonparc.com/Dealing_With_Combative_Behavior.pdf

Resnick, B. What is the best approach for managing aggression in older adults?

<http://www.medscape.com/viewarticle/716803>

Behaviour Support Plans. Office of the Senior Practitioner.

<http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/behaviour-support-planning-practice-guide-senior-practitioner>

Understanding Intellectual Disability and Health. Behaviour Management.

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

Behavioural Concerns. Assessment and Management of people with Intellectual Disability.

<http://www.racgp.org.au/afp/2011/april/behavioural-concerns/>

Related sections of Manual

- Depression
- Resistance to Care

Information Gathering Worksheet: Aggression

If a person 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 behavior. Be specific.		
Is aggression unusual for this person?		
When did you first notice the aggressive behavior? What was happening immediately prior to the aggression?		
Was the person exhibiting any signs of nervousness or anger prior to the aggressive act? What were those signs?		
How quickly did the person recover from the situation? Was there anything that helped calm the person?		
Has anything occurred outside of the person's regular routine, such as a visitor, new person, a medical procedure, unusual weather that may have affected their comfort or sleep patterns?		
Has the person shown signs of: <ul style="list-style-type: none"> • pain • headaches • fatigue • trouble sleeping • trouble concentrating • difficulty with hearing or vision • other? (even if unrelated) 		
Have you noticed any speech changes lately? has the person started to slur words, stop mid-sentence, or become confused about something they were talking about?		

next
steps

Person Name: _____

Staff Name(s): _____

Date: _____

Action(s): _____