

Support for Older People with Intellectual Disability in Group Homes:

A Manual for Group Home Staff

MANAGER'S GUIDE



Authors

Barbara J. Bowers, PhD, RN

Kimberly Nolet, MS

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

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, Sigam Hartley and He Yu, *University of Wisconsin-Madison*

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

Erika Schoot, *MPA University of Wisconsin, Madison*

Design:

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

Special thanks to:

Fiona Sparrow, *Australian Catholic University, 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

Wisconsin, USA

1-608-263-5189

bjbowers@wisc.edu

Kim Nolet

University of Wisconsin-Madison

School of Nursing

Wisconsin, USA

1-608-262-8146

kanolet@wisc.edu

U.S. Publication Year: 2013

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. Support was also provided by the Clinical and Translational Science Award (CTSA) program, through the NIH National Center for Advancing Translational Sciences (NCATS), grant UL1TR000427. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH. Funding for this project was also provided by the UW School of Medicine and Public Health from the Wisconsin Partnership Program."

Table of Contents

INTRODUCTION.....	1
Where should I begin?.....	1
Chapter 1: Normal Changes as a Person Ages.....	2
Chapter 2: Building Successful Partnerships.....	2
Chapter 3: Decision Making: Advocating for Individual Involvement.....	3
Chapter 4: End of Life Care.....	4
Chapter 5: Understanding, Communicating and Managing Common Symptoms.....	4
Chapter 6: Understanding and Managing Common Conditions.....	6
Chapter 7: Accessing Resources.....	6
TIPS FOR WORKING WITH STAFF	7
The Role of the Supervisor in Developing Staff Skills.....	7
Support from Direct Supervisor.....	7
Support and Acknowledgement of Management.....	8
Organizational Policy Development.....	8
CASE STUDIES FOR STAFF DEVELOPMENT	9
Maggie: Constipation (Staff Handout).....	10
Maggie: Constipation (Training Aid).....	11
Joseph: Falls and Difficulty Walking (Staff Handout).....	13
Joseph: Falls and Difficulty Walking (Training Aid).....	14
Nicole: Obesity (Staff Handout).....	16
Nicole: Obesity (Training Aid).....	17
Marie: Dementia (Staff Handout).....	19
Marie: Dementia (Training Aid).....	20
Stella: Arthritis (Staff Handout).....	22
Stella: Arthritis (Training Aid).....	23
Dominic: Confusion (Staff Handout).....	25
Dominic: Confusion (Training Aid).....	26
Grace: End of Life (Staff Handout).....	28
Grace: End of Life (Training Aid).....	29
Frank: Diabetes (Staff Handout).....	32
Frank: Diabetes (Training Aid).....	33
Steve: Heart Disease (Staff Handout).....	35
Steve: Heart Disease (Training Aid).....	36
Thomas: Normal Aging (Staff Handout).....	38
Thomas: Normal Aging (Training Aid).....	39

Please note that a CD is included on the inside back cover of this document.

This CD provides an electronic copy of the
 Manager's Guide and copies of all the case studies.

INTRODUCTION

This Manager's Guide is designed to help you work with your staff members as they learn to use *Support for Older People with Intellectual Disability: A Manual for Promoting Health*. We hope it will help you to assist your staff to support residents who are experiencing health problems. The Manager's Guide can be used to help orient new staff, to initiate conversations with current staff about residents with health conditions and to assist staff who might be concerned or anxious about resident health conditions. This Manager's Guide has several components:

- Suggestions for using the *Support for Older People with Intellectual Disability: A Manual for Promoting Health* (Manual).
- Case studies that will walk staff through problems commonly experienced by older people.
- Suggestions on how to best support residents.

The case studies are based on real experiences of people living group homes. Each has two parts:

- A case study for support staff that includes questions to think about, and
- A manager's version of the case study that includes questions and suggestions to guide you in your discussions with staff.

Where should I begin?

Supporting people with chronic health problems can be very challenging. When everyone is working together, things go much more smoothly. Sometimes there is inconsistency across the levels of the organization, or even among staff in a single home, about what the policy is and what can be done to help support residents with health conditions. Lack of clarity about what the options are, what the commitment is and who is responsible for what can make this difficult to achieve. Discussions between support staff and the managers/supervisors could include the following questions.

- What is the organization's commitment to people who are aging?
- What needs to be done to fulfill this commitment?
- What is the role of support staff, managers and supervisors and the organization?
- How confident are staff members in supporting residents with health conditions?
- Do staff members have the knowledge needed to support people to age at home?

One way to get started is to review one chapter at a time with staff. You might ask staff members to read the first section of the Manual on normal changes as a person ages and talk about whether they see some of these changes and how the changes might be experienced by current residents. Each of the first four chapters is very short, only a few pages, so they can be read quickly. You might even consider reading a chapter out loud at a meeting. Ask staff members to think about specific residents and what these age related changes might mean for them. It's probably best to discuss only one chapter at a time. What is most important is discussing how staff can use the information to help individual residents.

Chapter 1: Normal Changes as a Person Ages

Understanding the effects of aging is important for many reasons. First, much can be done to support people experiencing age-related changes to make the changes easier to live with. For example, people with age-related changes in their vision could benefit greatly from modifications to the environment and visual aids. You might want to start by asking staff to use the Manual to address the following questions.

1. What are some changes that occur as people age?
2. What are some difficulties created by age related changes to vision, hearing, skin, muscles, bones, stomach and intestines?
3. What are some things that support staff can do to help people experiencing age-related vision changes?
4. How often should older people have vision and hearing tests?
5. What would you do if the family or primary care provider (PCP) did not think a vision or hearing test was necessary, but you felt there was a problem? *Ask staff to identify when they would advocate for further assessment of a resident's vision or hearing changes.* What would you do if one of the residents had a sudden change in vision? Hearing?
6. How can you help prevent falls in older people? Are there any people in your home who might be at risk of falls?
7. What are some things that you can do for people who are having trouble sleeping?
8. What screening tests are important for older people?

Learning will be enhanced if staff members can apply what is in the description of normal aging to some of the residents they know well. Encourage staff members to think about these changes in relation to individual residents and to identify some things they can do to help a particular resident. Learning and more permanent changes to how staff members approach residents, is much more likely if they have the opportunity to apply the information to residents they know personally.

There are many tips listed in this chapter. The most effective way to use the Manual is to think about residents who have experienced some of these changes and discuss how some of the tips might be helpful for specific residents already living in the home.

Chapter 2: Building Successful Partnerships

This section draws on many resources and research studies. The best way to use this section with the staff is to apply it to a resident. Discuss with staff members whether they have had any difficulties communicating with health professionals or family members and what might have happened to residents who were hospitalized. Health care delivery environments can be frustrating and confusing. This section provides some tips on making visits with health professionals a better experience for everyone, which is more likely to result in good care for the resident with intellectual disability (ID). Ask staff to discuss:

1. What happens when you have to wait for long periods of time in a doctor's waiting room?
2. What are some things that would help the visit go more smoothly e.g. if only the people in the office would listen to you?
3. What happens when family members take residents to appointments and you don't really know what happened?
4. What would you do if recommended screening was not being done at a resident's annual PCP appointment or if some, but not all, screening was being done?
5. What will you do to ensure that the family conveys correct and comprehensive information to the PCP and that the family brings back information that support staff needs to know?

Hospital admissions are particularly stressful for many people with ID. They are often stressful for family and support staff as well. The suggestions included in the section on building partnerships have been shown to reduce the stress experienced by everyone and to lead to better outcomes for residents who spend time in hospitals. The following questions can be used with staff when reviewing the section on building partnerships, particularly when someone is being admitted to the hospital.

1. What happens when support staff and families don't agree on what should be done?
2. If you know that a resident will be admitted to the hospital next week for elective surgery, what will you do to prepare?
3. What might prevent you from preparing for the hospital admission? What could you do in this situation?
4. What are some of the things that you can do to prepare for bringing a resident home after a hospital admission?
5. Who has legal rights to decide what treatments a resident might have in the hospital?
6. Think of a resident who has been in the hospital and discuss some of the things that could have been done to make the time less stressful.
7. What can you do to prevent having the resident return home with care requirements that the support staff cannot manage?
8. Where might you go for help if someone is sent back home with treatments that the support staff cannot manage?

Chapter 3: Decision Making: Advocating for Individual Involvement

People with ID are often left out of decision-making. Sometimes this is because the professionals do not believe the person has the capacity to understand. Sometimes it is because the professionals are in a hurry and do not want to spend the time it takes to include the person with ID. Often a resident is considered not competent and left out of decision making when he or she could be involved in at least some of the decisions. The following questions can be used with staff when reviewing the section on decision-making and advocacy.

1. What are some of the ways that people with ID can be involved in important decisions about their medical care?
2. What role can support staff play in helping residents to understand the decision that has to be made?
3. How can you determine whether residents with ID should be involved in a decision about their care and treatment?
4. What role can support staff play in promoting the resident's participation in decision making?
5. What would you do if the health professionals failed to include the resident with ID in decisions or failed to inform the resident with ID about what was happening and what sort of treatment they were going to have? Would you feel confident advocating? How specifically would you do this?

Think of residents who have had a serious illness or condition where important decisions needed to be made about their care. How were they included? What else might have been done to include the resident more in decision-making? What role might support staff have played in achieving more involvement? How might the outcome have been different if the resident had been involved?

Chapter 4: End of Life Care

Supporting someone to remain at home with a terminal medical condition sometimes creates great anxiety for staff. Staff members might fear not being able to provide sufficient support and comfort to the resident. Staff might fear not knowing what to say to the resident who is dying, or to other residents. Many people become quite anxious about the thought of being with someone when they die. Very few support staff have used hospice services and many are uncomfortable with the idea of someone dying at home.

Some questions for discussion include:

1. What can people with ID understand about dying? Would someone with a mild or moderate ID be likely to understand that they are dying?
2. What do you think about talking to the resident who is dying? What are some of the ways you can approach the resident and talk to them about their illness?
3. How much information should you give residents about their prognosis (expected outcome of the illness)? What is likely to happen?
4. What are some strategies you could use to find out how much the resident knows about their condition and prognosis?
5. What would you do if:
 - a. The resident with the terminal illness is asking questions about what is happening?
 - b. You are not comfortable giving the resident information?
 - c. The family has requested that the resident “not be told”?
6. What is the policy of your organization/home regarding supporting residents with an ID to die at home?
7. What specific resources are available to you for supporting residents to stay in their homes at the end of their lives?
8. Do residents have a right to stay “at home” when they are terminally ill?
9. What do you need to find out from the PCP in order to support residents to stay home?
10. What resources might you access to help you care for the resident at home?

Chapter 5: Understanding, Communicating and Managing Common Symptoms

This chapter provides a brief description of each symptom including how it generally appears, whether it is normal for an older resident and possible causes of the symptom. This information should alert staff to the importance of determining the underlying cause and conveying when a symptom might indicate serious underlying medical problems that need attention. Each symptom comes with an Information Gathering Worksheet that can guide staff to collect the information that the resident’s PCP will need.

Completing the Information Gathering Worksheet will probably require input from several staff members and possibly family members. One suggestion is to select a symptom that one of the residents is currently experiencing. See if the staff is able to complete the Information Gathering Worksheet related to the symptom. Remind staff that PCPs need all this information to accurately diagnose and treat health conditions. The sooner this can be done, the less distress the resident will experience.

The Information Gathering Worksheets can be used in several ways. If a resident is having a problem, the Worksheets could be used to initiate a discussion at a staff meeting. Having staff together when the problem is discussed will create an opportunity to collect information from multiple people who may be able to fill in gaps in the Information Gathering Worksheet. The Worksheets can also be used to communicate with family members about some of the difficulties the resident is experiencing. Finally, and most importantly, the Worksheets were specifically designed to include the information that PCPs are likely to need to make the correct diagnosis. So whoever is going to the medical appointment should take the Worksheet along and make sure the PCP or other health professional receives the information.

Learning is most likely when the real life experiences of the learner can be used as part of the learning process. Therefore it would be most effective if staff could use the Worksheets with current residents.

Questions that could guide the discussion include:

1. When will you use the Information Gathering Worksheets?
 - a. Some of the symptoms are very obvious, such as falls or choking. Others might not be so clear, such as fatigue or confusion.
 - b. Because many symptoms occur in clusters, you may also be seeing more than one symptom, so it probably doesn't matter where you start. Although there will be considerable overlap in the Information Gathering Worksheets, you may want to fill out more than one.
2. When should I use the Information Gathering Worksheet?
 - a. The Information Gathering Worksheets are particularly useful with new symptoms. So if you are seeing something for the first time, it will be important to complete the Worksheets that are relevant.
 - b. The Worksheets can also be used when symptoms become worse or more frequent, or if the symptom has gone away and returned. This is particularly important since the same symptom can indicate many different conditions. The Worksheets will help the PCP sort out whether the symptom is related to the same condition as before or something new.
3. Isn't this going to be a lot of work?
 - a. The Information Gathering Worksheets have been kept brief to minimize the workload burden. In short, it doesn't take much time to fill them out, particularly if staff works together.
 - b. This will be good information to have and could be quite useful in the future. So be sure to put the date on the Information Gathering Worksheets. This is important information for the PCP.
4. Who should start gathering the information?
 - a. Anyone can start gathering information. It doesn't matter where or when you start.
 - b. It is quite important that the staff member with the most direct knowledge provide the information. For example, the staff member who was present when the event (fall, choking, aggression) occurred. Second or third hand information is notoriously inaccurate. Don't guess. If no one knows the answer to a question on the Worksheet, don't fill it in.
5. What do you do when you only have part of the information?
 - a. Find out who was actually there and ask them for details.
 - b. Take the Worksheet to a staff meeting with other staff who can help fill in the information.
 - c. Talk to staff at shift changes.
 - d. What other ways can you think of?
6. Should you still fill out the Worksheet if you think you already know what the problem is?
 - a. Absolutely! Most symptoms are associated with several different conditions. It is the collection of symptoms, the particular combination of symptoms that will suggest a particular underlying problem. For that reason it is important to fill in the Worksheet even if you have seen this symptom before. It is often caused by something quite different from a previous occasion or from the same symptom in another resident.
 - b. Remember, any one symptom can be associated with many different medical problems. Assuming

a symptom means the same thing it did in the past can lead to delays in diagnosing and treating a new problem.

- c. Sometimes staff is reluctant to share information with other staff, believing that it is an invasion of privacy for the resident. Support staff has a “duty of care” for residents and are responsible for making sure they receive the professional health care they are entitled to and need. Working with other support staff to make sure this happens is not an invasion of privacy.

7. When should the manager/supervisor be consulted?

- a. This is a question that needs to be worked out within each organization.
- b. Most group homes have instructions for determining when something is an emergency and needs immediate intervention however there is less guidance on how to deal with chronic or less serious problems.

Chapter 6: Understanding and Managing Common Conditions

The chapter on common conditions is intended to provide a brief description of conditions that occur in older adults that we found to be quite common among people aging with an ID. It is included because many of the support staff we talked to commented that they knew very little about the conditions residents had been diagnosed with. In particular, they had little information about what their role might be in relation to the health condition. This chapter outlines what staff should be alert for, what might need to be reported to the PCP and some tips to help work with residents who have these conditions. At the end of each short section are some suggested resources. We have tried to include both local resources to call and web addresses that provide more general information about each condition.

Chapter 7: Accessing Resources

The final section of the Manual includes resources that staff can use to find additional information on each of the conditions and some of the symptoms. It is organized into two sections. The first section briefly describes the major supports for health problems e.g. the Aging and Disability Resource Centers and long-term care options. The second lists local resources by topic areas.

TIPS FOR WORKING WITH STAFF

The Role of the Supervisor in Developing Staff Skills

Managers and supervisors of support staff are the key to helping staff work more effectively with residents who have developed health conditions. It has been repeatedly documented that providing information *is not sufficient* to change the way people do things. Providing a guide on responding to health conditions, even if it includes instructions on what support staff can do to help residents, is unlikely to influence what staff actually do. We have learned from research and practice that nothing is as important as the supervisor in moving staff from “knowing what to do” to “actually doing it”. There are many reasons for this. Helping people with ID to age-in-place in their homes will only happen if managers and supervisors are directly involved. The following section outlines some principles of staff development and practice change, focusing on what the supervisor can do.

1. It has been well documented that less than 10% of new learning is actually used in practice. This is true across industries and work settings. Continuing education rarely leads to practice change or improvement.
2. Even when people are able to apply what they have recently learned, there is only a small chance that they will sustain the new practice over time. People often revert back to old ways of doing things, even though they have learned a new and better way.
3. The likelihood of using new learning is related to the staff person’s motivation to use the information when returning to work.
4. Staff motivation is directly related to supervisor involvement.

Although the personality and interest of the individual staff member is important, the supervisor’s actions are highly influential on staff motivation or willingness to do something differently. Talking to staff members about why they are learning something, how their new learning could affect a resident and helping them actually practice the new way of working has a tremendous effect on motivation. So, in this instance, helping staff to understand how learning about health issues and gathering information for the resident’s PCP will affect the quality of the residents’ lives is essential. Clearly understanding the role they will play in achieving this, will likely affect the motivation of individual staff. Being motivated, they will learn more and retain more and will be more likely to at least attempt to put their new learning into practice.

The work climate is also important in determining whether new learning will be put into practice. In particular, work climate influences the sustainability of changes. Even the most motivated staff member is unlikely to sustain any changes in an unsupportive environment. The most important components of a supportive environment are:

1. Visible, ongoing, direct support from the staff member’s direct supervisor.
2. Support, or at least lack of resistance, from peers.
3. Acknowledgement and appreciation from management.
4. Removal of obstacles to change.

Support from Direct Supervisor

Motivation to change the way something is done starts with understanding why the change is important and how the change being made will alter the outcome of something that is important. Support staff is generally very concerned about the well being of residents and are quite happy to work toward improving this. Showing them the relationship between their actions and improved well being is vital e.g. demonstrating how the information from the Information Gathering Worksheet can decrease residents’ suffering by preventing delays in diagnosing medical problems.

For some residents, having correct and more comprehensive information can also prevent unnecessary or premature moves to a nursing home if used effectively. This means that whenever information gathered by the staff leads to a good outcome i.e. diagnosis and treatment that is helpful to a resident, it is important for the supervisor to make sure that all staff understand what happened and how their input helped lead to the outcome. As simple as this sounds, failing to tell staff about how important their actions were and specifically how their actions were helpful, is one of the most common complaints of direct care staff and a very common reason for leaving their jobs. Supervisors make a difference.

Achieving effective and lasting change is also highly dependent on having an opportunity to practice the new skills or use the new knowledge. Once again, supervisors are in a key position to make this happen. In the case of homes where people with ID have additional support, the supervisor can initiate the use of the Manual and provide an opportunity for staff to complete Information Gathering Worksheets or to consult the Manual about health conditions.

Making sure that changes become part of everyday practice is also highly influenced by what happens when someone tries to use what they have learned. In this case, it would be important for supervisors to work with staff as they use the Manual, to see where they might be having difficulty, to identify barriers to using the Manual and to problem solve with them about how to adapt to the current situation. This means that the manager/supervisor must work closely with staff as they try something new. *Simply providing the information and assuming it will be done rarely works. One of the most important things to consider is that failure to implement new procedures or approaches is more often related to the environment and to the actions of the supervisor than to anything about individual staff.*

Support and Acknowledgement of Management

Upper level managers and program directors often see their role as primarily providing resources. They leave the direct feedback and involvement in actual program development to middle level managers. Research tells us that support staff members are highly affected by interest from upper level management. This may be as simple as an upper level manager saying “How is the _____ program going?” or “I hear you have all started to _____. How is it coming along?” These seemingly casual comments have been shown to have a tremendous impact on sustainability of program changes. Conversely, failing to ask the staff directly involved in the effort about how the new initiative is progressing can have an undermining impact on staff motivation and confidence. Not being aware of a new initiative, should this become apparent to the staff involved in the implementation, also undermines staff motivation to continue. Supervisors are in an excellent position to inform and involve the upper level managers. The impact is well worth the effort.

Organizational Policy Development

Barriers to implementing new practices and approaches in the work setting are often related to organizational policies that are not consistent with the new approach. Sometimes there are policies that are actually at odds with a new practice. Sometimes no policy exists at all where one is needed. Sometimes there is a policy but no corresponding forms or systems to support it. Supervisors are in a key position to identify policies that need to be changed or developed and the systems that need to be created to support these policies. In this instance, it would be important for an organization to have policies that guide staff in preparing residents for visits to PCPs and hospital admissions. In order to be effective, staff should be provided with written guidelines for such preparation, including what needs to be done, the timing of activities, resources available, etc. Supervisors are in an excellent position to see what policies are needed and, with input from support staff and upper management, to organize the development of the needed policies and documents.

CASE STUDIES FOR STAFF DEVELOPMENT

The following pages include case studies which represent many of the conditions your staff are likely to see in residents as they begin to age. These case studies can be used to assist with training of both existing and new staff and are designed to help staff as they learn to use the Manual and develop confidence in supporting people who are aging and developing health conditions. The case studies are designed to be used in discussions amongst staff, perhaps at staff meetings. They can be considered individually or together as a longer training session as desired.

Each case study is presented in two formats, i.e.

- Staff Handout – presents the basic facts and highlights some potential issues and questions.
- Training Aid – for use by the “trainer”, this version includes additional questions and issues to assist managers in guiding discussion. All the information on the Staff Handout is shaded on the Training Aid version allowing you to see at a glance the information and questions provided to staff.

When the term “Manual” is used in the case studies, it refers to the document, *Support for Older People with Intellectual Disability: A Manual for Promoting Health*.

Case Study Table of Contents

- *Maggie: Constipation*
- *Joseph: Falls and Difficulty Walking*
- *Nicole: Obesity*
- *Marie: Dementia*
- *Stella: Arthritis*
- *Dominic: Confusion*
- *Grace: End of Life*
- *Frank: Diabetes*
- *Steve: Heart Disease*
- *Thomas: Normal Aging*

Maggie: Constipation

Staff Handout

Maggie is a 62-year old woman living in your group home. She is taking medication for chronic back pain. She is a very stoic woman and will rarely complain or ask for help, even when she is having problems. Lately, she has been going to the toilet frequently. She will not tell you why. You are reluctant to go with her to the toilet as you think this is a real invasion of privacy.

- What can you do?
- How can you find out how much difficulty Maggie is having and what the problem might be?

One of the staff members learns from Maggie that she is having difficulty with constipation. She goes to the toilet frequently but is unable to have a bowel movement or passes only tiny hard stools.

- What are some symptoms of constipation that you might look for?

Maggie visits her primary care provider (PCP) with the information the staff has gathered. The PCP starts her on a laxative to help. He tells you to “improve Maggie’s diet and exercise” which will help with her constipation.

- What are some things Maggie can eat or drink to help her constipation?
- What are some other things we could do to help prevent constipation with Maggie?

The laxative seems to work well. Maggie is feeling pretty good.

- What should you do now?

Maggie: Constipation *Training Aid*

Maggie is a 62-year old woman living in your group home. She is taking medication for chronic back pain. She is a very stoic woman and will rarely complain or ask for help, even when she is having problems. Lately, she has been going to the toilet frequently. She will not tell you why. You are reluctant to go with her to the toilet as you think this is a real invasion of privacy.

- What can you do?
- How can you find out how much difficulty Maggie is having and what the problem might be?

Discuss with staff:

- What are the concerns in this situation? Help staff recognize going to the toilet frequently is often a sign of a health problem.
- Why might Maggie be reluctant to share information? Is she embarrassed? Does she not have the right words to explain the problem? Talk through with your staff the challenges of gathering information about the health of residents when this requires intimate information or what feels like a breach of privacy. There is no one correct approach to this challenge, but it is important not to just ignore the problem. Maggie is dependent on the staff to help her get what she needs and to help relieve her discomfort.
- What can you do or say to make Maggie feel comfortable talking about her problem? Is there someone she feels more comfortable talking to (family, certain staff person)? Are there specific questions you can ask that only require a yes, no or other easy answer? Exploring the next question might help with this answer.

Have staff look at the *Table of Contents* in the Manual. Do they have other ideas for what might be wrong after looking at the list of symptoms and conditions in Chapters 5 and 6?

- Consider urinary and bowel problems. You might have the staff fill out both Information Gathering Worksheets (urinary frequency and constipation) from Chapter 5.

One of the staff members learns from Maggie that she is having difficulty with constipation. She goes to the toilet frequently but is unable to have a bowel movement or passes only tiny hard stools.

- What are some symptoms of constipation that you might look for?

Have staff find constipation in Chapter 5 of the Manual. Review the section together. Discuss symptoms of constipation Maggie could be hiding.

Symptoms of constipation include really straining when trying to have a bowel movement and a stool that is dry and hard. People may also say they don't feel completely "emptied" after having a bowel movement. Pain, a distended stomach and throwing up are also signs of constipation.

Discuss the importance of documenting these symptoms and the need for each staff person that cares for Maggie to take part in the documentation.

Remind staff to think about medication side effects if it is not mentioned. Staff should see if constipation is a side effect of Maggie's medication for back pain. If they cannot find this information, they can contact the pharmacist or PCP. If it is a listed side effect, they should let the PCP know Maggie is experiencing constipation.

Maggie visits her primary care provider (PCP) with the information the staff has gathered. The PCP starts her on a laxative to help. He tells you to "improve Maggie's diet and exercise" which will help with her constipation.

- What are some things Maggie can eat or drink to help her constipation?

Eating fiber and limiting low fiber foods like milk, eggs and meat can help prevent constipation. Foods that are high in fiber include fruits, vegetables and whole grains (wheat bread, brown rice, etc.).

- What are some other things we could do to help prevent constipation with Maggie?

Maggie can exercise thirty minutes a day to help prevent constipation. Certain types of pain medication can cause constipation. Ask her doctor if the medication she is taking is one of them as he could then order something like a stool softener or laxative to help counteract the constipation and the pain the medication is causing. It is also important to tell Maggie that she shouldn't ignore the urge to have a bowel movement.

The laxative seems to work well. Maggie is feeling pretty good.

- What should you do now?

Looking at the section on constipation in Chapter 5, think about how to prevent this in the future, or from becoming a chronic problem.

Ask staff: Can you keep Maggie on laxatives indefinitely? The chapter on constipation identifies long-term laxative use as a *cause* of constipation. It is important to get Maggie off laxatives or you are just creating a bigger problem for the future. Problem solve with the staff other things that can be done to help Maggie.

FURTHER DISCUSSION

Two weeks go by and Maggie is showing some of the signs of constipation mentioned above. She is also crying and says the last time she had a bowel movement was the last time we talked to her about constipation two weeks ago.

- What should you say or do since she hasn't had a bowel movement in over two weeks?

If someone hasn't had a bowel movement in two weeks, it is important to inform their PCP. Something serious could be going on and she needs to be checked out.

Joseph: Falls and Difficulty Walking

Staff Handout

Joseph is a 67-year-old man with Down Syndrome and congestive heart failure. He has been living in your group home for the past 17 years. He has two brothers who visit him occasionally and have commented that Joseph seems unsteady and has even been bumping into things that are right in front of him. He has also gradually stopped attending daily activities provided by your group home. His balance appears to be getting worse and he has been using handrails whenever they are available to keep him steady. Yesterday he had a fall. He said he was getting up to go to the bathroom and “everything got dizzy and it got black.” His brothers are very concerned and have scheduled an appointment with his primary care provider (PCP). They plan to go with him to this appointment.

- How will you respond to the brothers’ concerns?
- Should the staff assure the brothers that Joseph has been that way for quite a while so there is nothing to worry about?
- Is it natural for people to start losing their balance and bump into things as they age?
- Is this a behavior change that is likely to indicate dementia?
- What else might be going on with Joseph’s health that is causing him to fall?

Joseph goes to his PCP. His appointment goes well and the PCP decides to lower his daily dose of a medication that sometimes causes dizziness when someone stands up. He also went to the ophthalmologist and he now has glasses because of his newly diagnosed presbyopia, an eye condition that makes it difficult to see things up close, more common as people age. This is explained in the section on Normal Changes as a Person Ages.

- Now that his medication has been adjusted and he has new glasses, what can you do around Joseph’s home to make it safer for him in regards to:
 - Lighting?
 - Walking better?
 - Layout of things in his home?
- Are there any other experts who might be able to help Joseph?

Joseph: Falls and Difficulty Walking *Training Aid*

Joseph is a 67-year-old man with Down Syndrome and congestive heart failure. He has been living in your group home for the past 17 years. He has two brothers who visit him occasionally and have commented that Joseph seems unsteady and has even been bumping into things that are right in front of him. He has also gradually stopped attending daily activities provided by your group home. His balance appears to be getting worse and he has been using hand rails, whenever they are available to keep him steady. Yesterday he had a fall. He said he was getting up to go to the bathroom and “everything got dizzy and it got black.” His brothers are very concerned and have scheduled an appointment with his primary care provider (PCP). They plan to go with him to this appointment.

- How will you respond to the brothers’ concerns?
- Should the staff assure the brothers that Joseph has been that way for quite a while so there is nothing to worry about?
- Is it natural for people to start losing their balance and bump into things as they age?

Have staff read Chapter 1 - Normal Changes as a Person Ages and Chapter 2 - Building Successful Partnerships. You can have them do this ahead of time, as the chapters will take some time to read.

- Brainstorm with staff about what normal aging changes could be influencing Joseph’s walking, balance and dizziness. See if staff can identify some things that might be causing Joseph to bump into objects, particularly things that might occur slowly over time. It could be that Joseph needs to get his vision checked and, if so, he should be referred to an ophthalmologist. Cataracts, macular degeneration and glaucoma are all eye problems that occur earlier with people with ID. It could be that his problems are related to an undiagnosed eye problem. Have the staff look up dizziness. What other ideas do they have about next steps?
- Sometimes family members will notice things that the staff does not notice. This can occur when the change is slow and the staff, seeing the resident every day, does not notice the change. In this situation it is easier for someone who does not see the person regularly to notice changes. It is important that staff do not minimize the problem since “it’s been happening for a long time”. It might still indicate a medical problem that needs attention or a change in vision that could be corrected.
- Ask staff what things they think may be of concern to the brothers and how the brothers may be feeling. It is likely they are concerned about Joseph’s health and safety and are worried the support staff might not be able to watch Joseph closely enough to prevent him from falling. Have staff practice specific responses to the brothers.
- Have the staff read the heart disease section? Could Joseph’s fall be related to his heart problem?
- Is this a behavior change that is likely to indicate dementia?

Have staff read the section on dementia in Chapter 6.

Discuss with staff:

- Does this sound like dementia? What is one of the most common reasons for changes in both physical and mental functioning in older people? Staff should always look at new medications as a possible cause for any changes. Joseph is currently on medications for heart problems, depression and seizures. Even when someone has been on a medication for a long time, they can develop new problems related to the medication. Although he is only taking four different medications, he may need a dose change. Current recommendations for the older population to prevent falls include having less than four medications. Side effects from the type of drugs Joseph is on might include dizziness and loss of balance.

What else might be going on with Joseph’s health that is causing him to fall?

- Have staff review the Table of Contents for Chapter 5. What symptoms do they think they might review to help understand what is happening to Joseph? Have them briefly review those sections.
- If it is not mentioned, ask if Joseph has any health problems that suggest he might be on medication. Tell staff Joseph is on a water pill for his heart problems. Water pills will make him go to the toilet more often, increasing his chance of a fall. Knowing the risks associated with these medications can help give you a better idea of how to work with Joseph.
- What Information Gathering Worksheets in Chapter 5 will they fill out? Why did they pick those?

Joseph goes to his PCP. His appointment goes well and the PCP decides to lower his daily dose of a medication that sometimes causes dizziness when a person stands up. He also went to the ophthalmologist and he now has glasses because of his newly diagnosed myopia, an eye condition that makes it difficult to see things up close, more common as people age. This is explained in the section on Normal Changes as a Person Ages.

- Now that his medication has been adjusted and he has new glasses, what can you do around Joseph's home to make it safer for him in regards to:
 - Lighting?
 - Walking better?
 - Layout of things in his home?

Brainstorm the questions above with staff. Provide the following suggestions:

- Appropriate lighting. To make his home a safer environment it is important to have adequate lighting. Because he is on a drug that makes him go to the toilet more frequently, he is at a higher risk for falls, especially at night when it is harder for him to see. Providing adequate light will help him get to the bathroom and around the rest of his home more safely by helping him see objects such as end tables, lights, etc. that he might not see in the dark, especially with his vision declining.
- Consider having Joseph assessed for an assistive device (walker). A walker might help him, especially since he has been grabbing hand rails and other things for balance. If this continues, he could grab something unstable or something on wheels. That could result in another fall. You can explain to him that the walker does not necessarily have to be permanent but could be used just until his balance gets better.
- Clearing the house of clutter also helps to prevent falls. Get rid of things that are low to the floor that he may not see and trip on. Make sure that there are no loose rugs to trip on. If the home has wood floors or another type of floor that could be slippery, think about how to modify the surface. Joseph could also have poorly fitting shoes, which can affect his balance and also make him not want to be as physically active as he may have been before. Ask staff what might be important about his footwear and provide suggestions about making sure shoes fit and laces are not untied. Another solution to slippery floors could be getting him non-slip socks or slippers with good traction on the bottom.

- Are there any other experts who might be able to help Joseph?

There are suggestions in the section on falls.

- A balance clinic might be very helpful for Joseph. Physical activity (that is safe) will also help Joseph gain strength in his legs, which can help prevent falls.
- Having an occupational therapist evaluate the home is an excellent idea. OTs are trained to spot hazards you may have missed.

Nicole: Obesity

Staff Handout

Nicole is 40 years old. She moved into your home a couple of weeks ago from another group home. Her family requested the move because they wanted her closer to them so they could have more contact. Nicole has had a smooth transition with no problems. Her family comes to you because they are concerned about her eating habits and weight. They feel she has gained weight and are wondering what can be done.

- How will you respond to the family?

The staff schedules a discussion with Nicole and her family. It is decided to make an appointment for Nicole with her primary care provider (PCP). Nicole's family takes her to the appointment. When they come back from the appointment her family reports that she has gained weight and her PCP is labeling her as "obese". Her family brings back information on low-calorie diets given to them by the PCP.

- How will you use this information?
- How will you plan meals?
- What about other residents?

Nicole's PCP would also like her to increase her physical activity. The PCP suggested walking, swimming or an exercise bike.

- How could activities be incorporated into Nicole's life?

Looking ahead twenty years, what other health problems might Nicole encounter if her weight is not controlled? How will this impact her quality of life?

Nicole: Obesity *Training Aid*

Nicole is 40 years old. She moved into your home a couple of weeks ago from another group home. Her family requested the move because they wanted her closer to them so they could have more contact. Nicole has had a smooth transition with no problems. Her family comes to you because they are concerned about her eating habits and weight. They feel she has gained weight and are wondering what can be done.

- How will you respond to the family?

Staff should understand that it is important to report concerns to a manager, supervisor or designated personnel. Since the concern is about an issue that could be health related, what should be done and who should make these decisions? Ask staff how they would decide what to do.

It is important to have a system in place for family concerns and ensure that staff know the policy and are comfortable using it. Will it be one person who deals with concerns (e.g. house manager)? How will that person handle the concern? How will that person communicate the outcome back to staff and/or the family?

The staff schedules a discussion with Nicole and her family. It is decided to make an appointment for Nicole with her primary care provider (PCP). Nicole's family takes her to the appointment. When they come back from the appointment her family reports that she has gained weight and her PCP is labeling her as "obese". Her family brings back information on low-calorie diets, given to them by the PCP.

- How will you use this information?
- How will you plan meals?
- What about other residents?

Discuss with staff:

- It is important that any information from health care appointments is shared among all staff and will be followed by all staff members.
- If not already in place, your organization should design a process for reviewing and implementing suggested dietary changes. If a resident needs a different diet who will decide how it will be dealt with or if the changes can be made? Is your facility able to meet these needs and, if not, what would be done? Staff should participate in designing these policies and procedures to ensure they are easy to follow and are communicated clearly.

Nicole's PCP would also like her to increase her physical activity. The PCP suggested walking, swimming or an exercise bike.

- How could activities be incorporated into Nicole's life?

Brainstorm with staff how to achieve the following:

- Identify Nicole's preference for activities. How will you learn about what she would like to do? Talking to Nicole about what she might like is important. Use pictures if that might help her understand. You can also ask her family or friends what she has enjoyed in the past.
- Anticipate potential challenges Nicole or staff might encounter in starting/maintaining an exercise routine. Think about how you will respond if she tries something and doesn't like it or has trouble sustaining her exercise program. Most of us can think of times we have tried to begin an exercise program and quit after a period of time. What were the challenges? What might help prevent these challenges, or what might help when they occur? How can this be built into the house routine?
- How you will track progress and encourage Nicole. Keeping a visible log of activity can be encouraging. How will it get recorded? Who will be responsible for doing this? Avoid food as a reward. Talk to Nicole about other rewards that might be appealing. Encourage others to talk to Nicole about her activities and give her positive feedback and encouragement. Everyone needs to be working together on this.
- What are some organizations that could support Nicole's exercise? Are there others in the home that might like to join Nicole in some of her activities? Are there classes that are low cost or free? Would the family be willing to help participate in activities and who will have this discussion with the family?

Looking ahead twenty years what other health problems might Nicole encounter if her weight is not controlled? How will this impact her quality of life?

Have staff read the section on obesity in Chapter 6 and other related sections.

- Ask staff to discuss the consequences of obesity for older adults.
- What can the staff do to prevent future problems for Nicole?

Marie: Dementia

Staff Handout

Marie is a 68-year-old woman with Down Syndrome. She has lived in your group home for the past 15 years and has minimal family contact. She was living with her parents until they passed away and now has one brother who has occasional contact with her. Over the past several months she has stopped doing activities that she normally enjoys, is waking up in the middle of the night and is unable to fall back asleep. She is not eating as much as she used to and she appears to be frustrated and to need more assistance with activities of daily living (getting dressed, showering, etc.).

- Do you think Marie should continue living in the group home? Why or why not?
- How do you make this decision?
- What should be done first?

An appointment has been made with her primary care provider (PCP) because of these changes. One of your staff members is going with Marie to this appointment.

- What information would be useful to gather to take to the PCP?

Marie goes to her PCP appointment with one of your staff members. The PCP reviews the Information Gathering Worksheets, does some additional testing and says she is developing dementia.

- What are your goals for Marie?

Marie is started on a medication that may increase her function. We know that there is no cure for dementia but there are several things that caregivers and families can do to help.

- What might be helpful to Marie?

Marie: Dementia Training Aid

Marie is a 68-year-old woman with Down Syndrome. She has lived in your group home for the past 15 years and has minimal family contact. She was living with her parents until they passed away and now has one brother who has occasional contact with her. Over the past several months she has stopped doing activities that she normally enjoys, is waking up in the middle of the night and is unable to fall back asleep. She is not eating as much as she used to and she appears to be frustrated and to need more assistance with activities of daily living (getting dressed, showering, etc.).

- Do you think Marie should continue living in the group home? Why or why not?
- How do you make this decision?
- What should be done first?

Discuss with staff:

- It is normal to feel overwhelmed when a resident begins to get older and things begin to change. It is normal to feel that you, as staff, are not prepared or are too understaffed to help Marie. It is important, however, to put yourself in Marie's shoes. Would moving her to aged care improve her situation? How do you think she would react to such a move?
- With some thinking and help, does staff feel like they could help Marie continue living in the home? Identify staff perceptions about what the organization can provide/not provide and their understanding of outside services that might be useful. What makes staff feel uncomfortable about people with dementia in the home? Are there misconceptions about policies or what happens as people age? Do they doubt their own abilities? How can you help support staff?
- Do you have enough information to make a decision about where Marie should live? Talk about how this decision should be made. Who has the opportunity to give input? Who should be consulted? Make sure staff are aware they should consult professionals (PCP) first, as some of the problems you are seeing could be resolved. Remember, many medical problems present as dementia-like symptoms. It is important that a health care provider evaluate the person whenever there is a change in function or behaviors.

An appointment has been made with her primary care provider (PCP) because of these changes. One of your staff members is going with Marie to this appointment.

- What information would be useful to gather to take to the PCP?

Have staff look at the Table of Contents for Chapter 5 of the Manual. What Information Gathering Sheets could be used for this patient to help the PCP understand what is going on?

- Confusion - It appears Marie is having more problems with activities of daily living. We do not know why she is having these problems.
- Fatigue - Since Marie is suffering lack of sleep and appears to have a lack of appetite it is important to assess fatigue and for the PCP to be aware of change in sleep patterns as well as the change in the ability to care for herself.
- Loss of Daily Living Skills - Marie is now having a more difficult time dressing and showering, showing a change in her ability to care for herself. It is important to document all of the changes on the Information Gathering Worksheet.

Marie goes to her PCP appointment with one of your staff members. The PCP reviews the Information Gathering Worksheets, does some additional testing and says she is developing dementia.

- What are your goals for Marie?

Have staff review the dementia section of Chapter 6 in the Manual.

Discuss with staff:

- Ensuring the best physical and mental function for the resident. It is important to continue to discuss how this can be achieved so that Marie can continue to care for herself as much as possible. It would also be helpful to work with staff and healthcare professionals to find activities that Marie may enjoy doing despite her current challenges.
- Identify and manage behavioral symptoms. It is very important to be able to document changes to share with the PCP. This may be achieved by using the Information Gathering Worksheets or working with the PCP to identify symptoms. It would also be important to continue to document whether Marie's changes worsen or if new changes appear. Having good communication between staff members regarding what works and doesn't work when managing behavioral symptoms, and being consistent, is very important. It may also be helpful to review the resources listed in the Manual for additional tips and ideas to help support Marie.
- Identify and treat other health conditions that might worsen dementia. With Marie it is important to bring her to all recommended healthcare appointments and to ensure that she always has an up-to-date medication and health problems list so that the PCP has the necessary information.

Marie is started on a medication that might increase her function. We know that there is no cure for dementia but there are several things that caregivers and families can do to help.

- What might be helpful to Marie?

Refer to the dementia section in Chapter 6 of the Manual.

Discuss with staff:

- Limiting noisy environments. It may be possible that Marie is not eating as well as she used to because being with a large group increases her confusion. It may be helpful to have her eat with fewer people to see if there is a change in the amount that she eats.
- Limiting items that may be a tripping hazard or may cause her to fall. Since she has been getting out of bed in the middle of the night she is at a greater risk for falling.
- Using effective communication strategies to make sure there are limited distractions when helping her complete tasks. It is also important to explain things that you are doing or that you would like her to do in easy to follow steps.
- Break tasks into easy to manage segments.
- Contacting any of the listed resources in the Manual would also be helpful in customizing a plan and activities that may help Marie maintain as much function as possible.

Stella: Arthritis

Staff Handout

Stella is a 62-year-old woman who lives in the group home where you work. Stella has been slowing down gradually over the past year and not participating in activities she used to enjoy. Stella can be challenging sometimes. She is strong willed and determined and likes to have her own way. She occasionally has disputes with other residents over the television and can become quite upset when she is served a meal that she does not really like. Stella goes to work each day for six hours. She has been resisting lately. Stella can speak fairly well but has difficulty sometimes saying what is bothering her. You notice she is frequently rubbing her knees and has been limping when she walks. She has been taking pain medication for joint pain, as advised by her primary care provider (PCP). Lately Stella has been having problems with constipation which she finds very distressing. Her PCP decided to change her pain medication to help the constipation.

When you talk to other staff about Stella's behavior, one of your co-workers says that not much can be done. The supervisor has already spoken with the PCP who does not want to put her back on the other pain medication because of the constipation. You are convinced that Stella is in quite a bit of pain. You don't believe the PCP understands how much pain she has since she is very quiet during visits to the PCP and says she is fine when the PCP asks her about the pain.

- What will you do first?
- Pain may be difficult to assess in residents who aren't able to say they have pain or describe symptoms well.
- What are some of the things you can do to identify pain in someone like Stella?
- What information can you gather that might provide Stella's PCP with a more accurate understanding of the pain Stella is experiencing and how much it is affecting her life?
- What are some other strategies that you might use to help Stella? What can you do to reduce Stella's pain and help her continue to participate in activities she enjoys?

Stella: Arthritis Training Aid

Stella is a 62-year-old woman who lives in the group home where you work. Stella has been slowing down gradually over the past year and not participating in activities she used to enjoy. Stella can be challenging sometimes. She is strong willed and determined and likes to have her own way. She occasionally has disputes with other residents over the television and can become quite upset when she is served a meal that she does not really like. Stella goes to work each day for six hours. She has been resisting lately. Stella can speak fairly well but has difficulty sometimes saying what is bothering her. You notice she is frequently rubbing her knees and has been limping when she walks. She has been taking pain medication for joint pain, as advised by her primary care provider (PCP). Lately Stella has been having problems with constipation which she finds very distressing. Her PCP decided to change her pain medication to help the constipation.

When you talk to other staff about Stella's behavior, one of your co workers says that not much can be done. The supervisor has already spoken with the PCP who does not want to put her back on the other pain medication because of the constipation. You are convinced that Stella is in quite a bit of pain. You don't believe the PCP understands how much pain she has since she is very quiet during visits to the PCP and says she is fine when the PCP asks her about the pain.

- What will you do first?

Discuss with staff:

- Have staff identify what the two problems are (constipation and arthritis). Staff should then review the arthritis section in Chapter 6 and the constipation section in Chapter 5 of the Manual.
- Ask staff how these problems appear to affect Stella's life. Participating in activities, working and simply walking are all things that have become challenging for Stella. If left untreated, she might become depressed and isolate herself.
- Ask staff what might happen to Stella if the pain is untreated. If she is not moving as much, more health problems can occur such as increased joint stiffness, muscle pain in other parts of her body, weight gain, falls and balance problems and even incontinence because she has trouble getting to the toilet quickly.

It would be helpful for staff to collect information on how much pain Stella is having, when the pain occurs and how much it is interfering in her life. This can be valuable information to use in convincing the PCP to take action.

- Pain may be difficult to assess in residents who aren't able to say they have pain or describe symptoms well.
- What are some of the things you can do to identify pain in someone like Stella?
- What information can you gather that might provide Stella's PCP with a more accurate understanding of the pain Stella is experiencing and how much it is affecting her life?

Role play with staff. Ask one of them to pretend to be Stella and to think about how she might communicate that her knees hurt. Have the other staff ask "Stella" questions or describe techniques they could use with "Stella" to identify how much pain she is experiencing.

Find the Faces of Pain Scale in the Health Manual and make sure there is a copy in the house for staff to use (refer Page 83 of Manual).

Discuss with staff:

- One of the most important things that can be done for Stella is for the PCP to understand the amount of pain she is experiencing. It might be helpful to review the chapter on Building Successful Partnerships and the Health Care Provider Tips Appendix. Does Stella need an advocate? How might you be an advocate for Stella? Documenting information over a period of time (morning, afternoon and night for a few days is often enough) regarding Stella's pain will help in advocating for more effective pain control. Using the Faces of Pain is a reasonable way to describe the pain if Stella has difficulty describing her pain.

- Asking Stella specific questions during the appointment can help. If the PCP does not ask, the person accompanying Stella can ask her to tell the PCP what she does not like to do when she is in pain. Stella might want to share that she doesn't like to go to work or leave her bed when she has a lot of pain. If nobody is in the room with Stella during the appointment, staff can talk to Stella about this ahead of time and write a note, in Stella's own words if possible, to give to the PCP during the appointment.
- In addition to recording the amount of pain Stella is having, there are other things that could be useful to the PCP. Review the Pain Information Gathering Worksheet in Chapter 5 of the Manual and discuss how you might collect this information. Watch for signs of pain like rubbing, crying, irritability, furrowed brow, screaming or limiting activities or movement. Record these signs, and when they occur, to give to the PCP.
- What are some other strategies that you might use to help Stella? What can you do to reduce Stella's pain and help her continue to participate in activities she enjoys?

Discuss with staff:

- Discuss what staff would do to find help for Stella despite the PCP not taking action. Collecting information to give to the PCP is important but it would also be useful for the staff to talk among themselves, with family and with managers/supervisors to problem solve about how to help Stella.
- After reading the sections on arthritis and pain, does staff have ideas about how to help Stella? Is there someone else to contact for help?
- People experiencing pain may not want to move, but it is important for someone with arthritis to continue moving to maintain function and help decrease overall pain. Encouraging and assisting with gentle exercise and stretching can help to maintain functioning and decrease pain. Providing music the resident likes or other forms of distraction can be helpful in reducing pain.

Dominic: Confusion

Staff Handout

Dominic is a 64-year-old man who lives in the group home where you work. He is a very friendly man and has always been pretty easy to work with. He enjoys watching birds and talking to the staff. Although he sometimes has difficulty remembering things, he knows his housemates and the staff very well, and knows where he lives. However, in the last few days he has seemed a bit confused about who he is talking to, is acting a bit oddly and has even been asking for people who left the home a long time ago. Today he refused to eat breakfast or lunch and started banging his cup on the table. You are very concerned about Dominic and after talking with the house supervisor you have decided to take him to his primary care provider (PCP) as soon as you can get an appointment.

- What information will you collect to prepare for Dominic's visit to his PCP?
- How will you make sure the information is accurate and as complete as possible?

Dominic sees the PCP later that week. The PCP decides that Dominic is dehydrated. The PCP recommends that Dominic increase his fluid intake immediately by drinking more water, juice or tea so he is better hydrated.

- Now that you know that Dominic is prone to becoming dehydrated, what are some things you can do to help prevent Dominic from becoming dehydrated again?
- What will you keep a watch out for in order to identify the signs of dehydration early next time?

While attempting to encourage Dominic to drink a glass of water, he just shakes his head and grabs his jaw. You bring this up to another staff member and she says he has also noticed that Dominic still does not want to eat or drink anything. He seems upset whenever you try to get him to eat or drink.

- What could be contributing to Dominic's resistance to eating or drinking?

Dominic: Confusion *Training Aid*

Dominic is a 64-year-old man who lives in the group home where you work. He is a very friendly man and has always been pretty easy to work with. He enjoys watching birds and talking to the staff. Although he sometimes has difficulty remembering things, he knows his housemates and the staff very well, and knows where he lives. However, in the last few days he has seemed a bit confused about who he is talking to, is acting a bit oddly and has even been asking for people who left the home a long time ago. Today he refused to eat breakfast or lunch and started banging his cup on the table. You are very concerned about Dominic and after talking with the house supervisor you have decided to take him to his primary care provider (PCP) as soon as you can get an appointment.

- What information will you collect to prepare for Dominic's visit to his PCP?

Ask staff to look at Chapter 5 of the Manual. Discuss with staff:

- Have them list which sections of the Manual might be important to read.
- Which one do they think they should look at first?

Since Dominic is showing some signs of a change from his usual self, including signs of confusion, start by looking at the Information Gathering Worksheet on confusion in Chapter 5 of the Manual. The worksheet helps you to think about other recent changes or symptoms that may not seem to be related to confusion, but are vital for the PCP to determine the source of the confusion.

- How will you make sure the information is accurate and as complete as possible?

Discuss with staff:

- Who might have helpful information to contribute to the Information Gathering Worksheet?
Note that it is important to ask staff across shifts. Family or others that recently spent time with Dominic might have noticed important things too. Collaborating with others while going through the worksheet will give a more accurate and complete representation of all the changes that Dominic is experiencing. Discuss how you would like to see staff use these worksheets.

Dominic sees the PCP later that week. The PCP decides that Dominic is dehydrated. The PCP recommends that Dominic increase his fluid intake immediately by drinking more water, juice, or tea so he is better hydrated.

- Now that you know that Dominic is prone to becoming dehydrated, what are some things you can do to help prevent Dominic from becoming dehydrated again?

Have staff turn to the section on dehydration in Chapter 6 of the Manual and read the contents. What are their ideas for helping Dominic?

It is vital to encourage Dominic, and all older adults, to drink plenty of fluids every day to prevent dehydration. As people age, the sense of thirst diminishes, which can often lead to not drinking enough fluids. It is important to remind older adults of the need to drink fluids in order to stay healthy and avoid dehydration.

- What will you keep a watch out for in order to identify the signs of dehydrating early the next time?

Go to the section on dehydration in Chapter 6 and find the symptoms to watch for. It is also good to keep in mind that Dominic now has a history of being confused when he is dehydrated. If he shows signs of confusion in the future, look to see if he has other signs of dehydration to see if this is again the cause of his confusion. Ask staff to list the signs of dehydration.

While attempting to encourage Dominic to drink a glass of water, he just shakes his head and grabs his jaw. You bring this up to another staff member and she says he has also noticed that Dominic still does not want to eat or drink anything. He seems upset whenever you try to get him to eat or drink.

- What could be contributing to Dominic's resistance to eating or drinking?

Since Dominic is resisting eating or drinking, it might be a good idea to look at the section in Chapter 5 of the Manual on resistance to care. Review the Information Gathering Worksheet. You will notice that one of the items on the worksheet is pain. Ask staff if they think Dominic is showing signs of pain.

Have staff to turn to the section on pain in Chapter 5 to read signs and symptoms of pain to be aware of. Ask staff to discuss ideas for how they could find out if Dominic is indeed in pain.

Grace: End of Life

Staff Handout

Grace is a 68-year-old woman who has lived in your group home for the past 15 years. A year ago she was diagnosed with cancer and has been receiving treatment for her cancer since then. Recently Grace was seen by her primary care provider (PCP) for evaluation of her cancer and it was discovered that, despite treatment, her cancer has continued to spread. At her PCP appointment her sister was told that Grace's cancer was terminal. Grace's sister (who accompanies her to appointments) and the PCP have decided to stop the cancer treatments and instead focus on making Grace comfortable.

Grace knows that she is ill but does not know that she is dying. She does not want to leave her home and says she is afraid of being in hospital. The group home staff is very fond of Grace and is quite distressed about her diagnosis. Grace's sister wants her to remain in the group home as long as possible.

- What do you think is the best thing for Grace?

Most of the staff really wants to keep her in the group home but many are quite frightened about what might happen, whether they can handle it and how it might disrupt the other residents and make them emotional. A few staff members have expressed a fear of being alone in the home when Grace dies and are really worried about what this would be like. There is clearly a high level of staff anxiety over the situation.

- How do you feel about this?
- What are your concerns about your ability to care for Grace at the end of her life?
- What needs to be considered in deciding how to support Grace?
- What are some of the most important things you can do for Grace?
- What will you do if some staff members are afraid of caring for Grace?
- How will you talk to other residents? What will you tell them? How much will you tell them?
- How will you talk to Grace? What are the most important things to remember when talking to Grace?
- How will you decide the best way to work with the family?

Grace now understands that her cancer is terminal and she comes to you with questions about what is going to happen.

- How can you best handle the questions that Grace may have as her illness progresses?

Grace has made many close friends at your group home who are witnessing changes in Grace and realize that something is wrong. As other residents know or understand more fully what is happening, it is expected that emotional and behavioral responses will be varied. Grief and end of life transitions can be challenging.

- What can you do to provide support and information to the other residents?

Grace: End of Life *Training Aid*

Grace is a 68-year-old woman who has lived in your group home for the past 15 years. A year ago she was diagnosed with cancer and has been receiving treatment for her cancer since then. Recently, Grace was seen by her primary care provider (PCP) for evaluation of her cancer and it was discovered that despite treatment her cancer has continued to spread. At her PCP appointment her sister was told that Grace's cancer was terminal. Grace's sister (who accompanies her to appointments) and the PCP have decided to stop the cancer treatments and instead focus on making Grace comfortable.

Grace knows that she is ill but does not know that she is dying. She does not want to leave her home and says she is afraid of being in hospital. The group home staff are very fond of Grace and are quite distressed about her diagnosis. Grace's sister wants her to remain in the group home as long as possible.

- What do you think is the best thing for Grace?

Letting go of what we believe is best for someone can be difficult. Encourage staff to think about this from Grace's point of view.

Discuss with staff:

- Ask staff if they think Grace might want to stay in the group home for as long as possible and why.
- Ask staff to share ideas about how they could get Grace's input. It might be difficult for Grace to understand her choices and the impact of those choices. Asking Grace what is most important in her life, and what is most important about where she lives, is a good place to start to help staff understand Grace's point of view.

Most of the staff really want to keep her in the group home but many are quite frightened about what might happen, whether they can handle it and how it might disrupt the other residents and make them emotional. A few staff members have expressed a fear of being alone in the home when Grace dies and are really worried about what this would be like. There is clearly a high level of staff anxiety over the situation.

- How do you feel about this?
- What are your concerns about your ability to care for Grace at the end of her life?

Encourage staff members to talk about their hopes, fears, and concerns. If some say they are scared about being the one in the house if she is in pain, or enters the final moments of her life, drill further and ask staff "Why." This can give you important information about what you need to do to help educate and prepare staff.

- What needs to be considered in deciding how to support Grace?

Have staff prepare for this scenario by reading the chapter on End of Life Care in the Staff Manual. There are good tips about decision making related to end of life. Staff should recognize, again, that Grace's wishes are most important. A second concern is about the home's ability to collaborate with other organizations to assess needs and provide end of life care.

- What are some of the most important things you can do for Grace?

Ask staff to identify some things they can do to begin to help Grace. They should:

- Consider collaborating with other resources such as palliative care teams.
- Recognize Grace might be scared and might need some time to talk about her fears.
- Ask the PCP about any special diets or other needs they can implement to help Grace.
- Think about how to monitor Grace's pain.
- Consider learning about any of Grace's religious or cultural beliefs or wishes.

This is also a good time to ask staff members about what positive skills and attributes they may bring to the equation. Is there someone that has gone through end of life with a resident before? Can he or she share what was learned during that experience? It is good to help staff members understand their knowledge of the resident and compassion are two of the most important things to a resident at the end of life.

- What will you do if some staff members are afraid of caring for Grace?

Assure staff members that they will be supported when needed and discuss the type of support available to them. As an organization, think about how you will specifically help those who are afraid. Where can you list emergency phone numbers if Grace begins to have significant problems? Can a hospice organization provide education and “practice” for certain scenarios? What will you do if a staff person may not want to be in the house alone if Grace is sharply declining? Having staff input into this process is valuable.

- How will you talk to other residents? What will you tell them? How much will you tell them?
- How will you talk to Grace? What are the most important things to remember when talking to Grace?
- How will you decide the best way to work with the family?

Grace now understands that her cancer is terminal and she comes to you with questions about what is going to happen.

- How can you best handle the questions that Grace may have as her illness progresses?

Have staff review the section on End of Life Care in the Manual. It has some suggestions for talking to people with intellectual disability who are dying. One of the first things you and the staff might want to do is to find out how much Grace understands about her illness and what she wants to know more about. Brainstorm about how to phrase questions to Grace in easy to understand language.

Experts suggest that information works better and is received better when it is presented in small pieces, checking to make sure the resident understands what they are being told each time. It is also a good idea to stay with the resident for a while after information is given or after a discussion has occurred to make sure they have emotional support. In this case, it would be important to check in with Grace regularly as her illness progresses, to make sure she understands what is happening and that she is getting the support she needs. Consider that this type of discussion is not only hard for Grace but also for staff; discuss ways that staff can be supported and made comfortable through the end of Grace’s life. There are also people who are experts in the care of someone who is dying who might be called on to help. Discuss with the staff what resources might be sought. Think about what conversations are important for the staff, the family and Grace.

Ask staff what they might do if a distant family member arrives and begins to complain that staff isn’t paying enough attention to Grace. Remind staff that family members are often only concerned about their loved one’s well-being, particularly at this fragile stage of the resident’s life. Distant family members may be upset they have “lost time” with the resident and this unfortunately might lead to them taking out anger on staff. It might be effective to role-play this scenario with staff and to make sure staff understand what they are to do when there is a family complaint.

Grace has made many close friends at your group home who are witnessing changes in Grace and realize that something is wrong. As other residents know or understand more fully what is happening, it is expected that emotional and behavioral responses will be varied. Grief and end of life transitions can be challenging.

- What can you do to provide support and information to the other group home residents?

Ask staff to brainstorm ideas about how to inform, support and comfort other residents. Have them review the information in the End of Life Care Chapter of the Manual.

Asking Grace what she would like the other residents to know about her situation is important. Being with Grace and other residents as they express their feelings and ask questions will allow people to process what is going on, to begin grieving and to show support to Grace. It may be that Grace needs some time first, before others know and begin to ask questions. The staff should all be aware of Grace's wishes and have a consistent response to other residents to prevent confusion.

Also be aware that many residents might want to be part of Grace's memorial service or have their own remembrance and celebration of Grace's life.

Frank: Diabetes

Staff Handout

Frank is a 53-year old man who has been living in your group home for five years now. His brother and sister-in-law were taking care of him for several years before his move to the group home. As they began to experience their own health problems they found it difficult to manage Frank's needs. One of Frank's health problems is his diabetes. It was pretty easy to deal with when Frank first moved in since he was only on pills and only needed finger sticks once each day. You and other staff are quite comfortable doing a finger stick to test his blood sugar. So that's not been a problem. Lately Frank's diabetes seems to be getting worse and the pills were changed to better control his blood sugars. The primary care provider (PCP) says that Frank needs to be watched more closely now since he is on higher doses of his diabetes medication.

- What are some important things to consider about keeping Frank safe and well cared for?
- What are some ways to prevent problems with Frank's blood sugar?
- What role does support staff play in keeping Frank's blood sugar in a normal range?
- What are some things to consider when the group goes on day-long outings?
- What are the risks associated with increasing Frank's diabetes medication?
- What are the signs that Frank's blood sugar is getting too low?
- List five symptoms of low blood sugar that would be important to watch for.
- What would you do if you thought his blood sugar was too low?
- What plan should you have in place in case Frank's blood sugar goes dangerously low? How will you know what level is dangerously low?

The PCP increased Frank's finger sticks to three times a day. Frank used to be fine with the finger sticks but now seems to be upset by them and is increasingly resisting. Frank has an appointment with his PCP next week and one of the staff will be going with him.

- What information will you need to send to the PCP?
- How will you get this information?
- You are a bit concerned that you will not be able to give the PCP all the blood sugar information she wants since Frank has not been cooperating. What do you think is most important for her to know about Frank?

Frank's brother takes him to the PCP appointment. When they return, the brother tells you that Frank is now on insulin injections for his diabetes.

- What needs to be done for Frank? What do you think?
- What resources will you need?
- What kinds of things should be monitored?
- Will Frank now have to move to a nursing home?

Frank is normally cheerful, pleasant and talkative. He is normally able to get out of bed and get dressed on his own. He wakes up one morning and appears confused and is having trouble getting out of bed.

- What would you do?

Frank: Diabetes *Training Aid*

Frank is a 53-year old man who has been living in your group home for five years now. His brother and sister-in-law were taking care of him for several years before his move to the group home. As they began to experience their own health problems they found it difficult to manage Frank's needs. One of Frank's health problems is his diabetes. It was pretty easy to deal with when Frank first moved in since he was only on pills and only needed finger sticks once each day. You and other staff are quite comfortable doing a finger stick to test his blood sugar. So that's not been a problem. Lately Frank's diabetes seems to be getting worse and the pills were changed to better control his blood sugars. The primary care provider (PCP) says that Frank needs to be watched more closely now since he is on higher doses of his diabetes medication.

- What are some important things to consider about keeping Frank safe and well cared for?

Have staff prepare for this scenario by reading the diabetes section in Chapter 6 of the Manual.

Blood sugar readings are the most important thing to track when working with a resident who has diabetes. It is important to find out what range of blood sugars the PCP wants Frank to stay within and what to do if sugars are outside this range. Although direct measurement of blood sugar is the best way to monitor blood sugars, there are many signs of high and low blood sugar. Timing of these symptoms and noting what food consumption and activities precede the symptoms and, whether the food and activity are different than usual for this resident are important things for staff to monitor and record.

- What are some ways to prevent problems with Frank's blood sugar?
- What role does support staff play in keeping Frank's blood sugar in a normal range?
- What are some things to consider when the group goes on day-long outings?

Have staff brainstorm about ways to help Frank such as adjusting his diet and making sure healthy snacks are available. Assuring Frank takes his medication as prescribed will also be important for staff to monitor. When Frank's schedule is altered, or he is outside the home for an extended period, plan for meals and snacks and make sure his medications are available.

Staff should note any medication change for residents with diabetes. Some medications that are used to treat other conditions can affect blood sugar. You might want to ask when any new medication is prescribed if it will affect blood sugar.

- What are the risks associated with increasing Frank's diabetes medication?

It is important whenever a diabetic's medication is increased or changed that you watch for signs and symptoms of low blood sugars (hypoglycemia). More frequent blood sugar checks may be required with new medications so it is important to ask health care providers how often blood sugars should be checked.

- What are the signs that Frank's blood sugar is getting too low?
- List five symptoms of low blood sugar that would be important to watch for.

Have staff review the symptoms of low blood sugar in the diabetes section in Chapter 6 of the Manual and list them. Ask staff what would help them remember signs of low blood sugar. Consider posting these in a common area where staff can see daily them as a reminder of what to watch for.

- What would you do if you thought his blood sugar was too low?

Have staff review recommendations in the diabetes section in Chapter 6 of the Manual for low blood sugar. The most important thing to remember is that low blood sugar can be life threatening. This can happen if someone takes insulin or their diabetes pills and then does not eat or if they exercise more than usual. There is a particular danger of this if a resident becomes ill, is nauseous or vomiting.

- What plan should you have in place in case Frank's blood sugar goes dangerously low? How will you know what level is dangerously low?

As an organization, you should have a procedure for staff to follow in the case of very low blood sugar. This will help Frank stay out of the hospital and may reduce further damage to Frank's health. A policy will also help staff feel more confident and secure in caring for residents. It helps to have staff give input into the procedure and recommend how to make that procedure accessible to staff.

"Normal" ranges of blood sugars vary by person. It is important to consult with the PCP to determine what is "normal" for each resident and what is considered "low" and "dangerously low".

The PCP increased Frank's finger sticks to three times a day. Frank used to be fine with the finger sticks but now seems to be upset by them and is increasingly resisting. Frank has an appointment with his PCP next week and one of the staff will be going with him.

- What information will you need to send to the PCP?
- How will you get this information?
- You are a bit concerned that you will not be able to give the PCP all the blood sugar information she wants since Frank has not been cooperating. What do you think is most important for her to know about Frank?

Ask staff to look at the Table of Contents in the Manual and identify any "symptoms" in Chapter 5 that might be useful to consider.

Highlight "resistance to care" and "pain". Sometimes an area can become very sensitive to repeated finger sticks and the resident might feel pain. Review the Information Gathering Sheets for these symptoms and ask staff to think about how you can collect information. Have staff share ideas about how staff across shifts can fill in the information and what to do with the information once it is collected. Staff should identify that it is important to consult with Frank's PCP once the information is collected. The PCP may have suggestions such as alternatives for where finger sticks can occur on Frank, the type of needles or equipment used, or he or she may identify other issues that need attention.

Frank's brother takes him to the PCP appointment. When they return, the brother tells you that Frank is now on insulin injections for his diabetes.

- What needs to be done for Frank? What do you think?
- What resources will you need?
- What kinds of things should be monitored?
- Will Frank now have to move to a nursing home?

Be certain about whether prior medications should be continued when a new one is added. A common mistake is to add a new medication and forget to discontinue the old one. This could also happen if communication between the PCP and the support staff is not clear, for example, if a relative takes the resident to their appointment or if the staff person does not have an opportunity to talk with the PCP.

Frank is normally cheerful, pleasant and talkative. He is normally able to get out of bed and get dressed on his own. He wakes up one morning and appears confused and is having trouble getting out of bed.

- What would you do?

With any diabetic patient it is important when there are any sudden changes in energy levels or changes indicating confusion. Immediately think about changes in blood sugars. This can be a life-threatening situation. First check to see if the blood sugar is too low. If the resident's blood sugars are below the range given by the PCP, the resident will need a quick source of sugar to raise the blood sugar level. If the resident is conscious and able to swallow, 4oz. of juice, a glucose tablet or a sugary snack should be given. The resident's PCP should be able to give you clear instructions on when to do this and what blood sugar level requires sugar. This sugar source should be kept in a place where they are certain to be available when needed. It is also important to recheck the blood sugars after giving the sugary snack to make sure their blood sugar increases to the minimum level. Some people may require their blood sugars to be checked more frequently if they tend to fluctuate. It is also important that these episodes are reported to the house manager/supervisor every time they occur. Find out from the PCP what level of blood sugar is an emergency.

Steve: Heart Disease

Staff Handout

Steve is a 59-year-old man who lives in your facility and has recently had an appointment with his primary care provider (PCP). His sister, who went to the appointment with him, tells you that Steve's PCP believes that Steve has heart disease and that his recent slowing down is due to a heart condition. Steve is an overweight man who enjoys eating, especially foods like soft drinks, cookies, chocolate and chips. He enjoys watching television, socializing with other residents and playing games but does not like being active or exercising. The instructions Steve's sister gives you from his PCP about what needs to be done for Steve include changes to his diet, increasing his daily exercise and taking some new medications. The PCP has also said that Steve should be watched to see how he responds and to let the PCP know if there are any changes in Steve's symptoms.

- Where can you find the information you need to be helpful to Steve?

Three weeks later you notice that Steve is tiring much more easily than he used to. He is getting up later, taking naps during the day and resisting activities that require him to walk for any distance, including things he used to really enjoy. What will you do?

- What are some of the things you might see if Steve is experiencing increasing fatigue but is unable to tell you?

Steve sees his PCP about the fatigue and it is decided that it is probably due to a medication he has started to take. The PCP is not concerned but suggests that he be watched closely for any additional signs of heart problems. He gives you a list of these signs. About a month later, you hear from other staff in the group home that Steve is having trouble sleeping at night. He has been waking frequently, bothering other people in the house and walking around during the night. What will you do now?

- Steve does not speak well enough to describe any symptoms he might be having. How will you know if he is having any pain, such as chest pain?
- Is there anything the support staff can do to help slow the progression of Steve's heart disease?
- Are there any house routines, organizational policies, job demands that might make it difficult to carry out your plan?

Steve has an appointment with his PCP. You are the staff person going along with him. You know that Steve gets very anxious about seeing the PCP. He doesn't like to wait. He is uncomfortable around people he doesn't know. He is always afraid that he will be given an enema since he had one in the PCP's office three years ago. How will you help Steve get through the appointment and make sure that he gets the attention he needs to figure out what's wrong?

Steve: Heart Disease *Training Aid*

Steve is a 59-year-old man who lives in your facility and has recently had an appointment with his primary care provider (PCP). His sister, who went to the appointment with him, tells you that Steve's PCP believes that Steve has heart disease and that his recent slowing down is due to a heart condition. Steve is an overweight man who enjoys eating, especially foods like soft drinks, cookies, chocolate and chips. He enjoys watching television, socializing with other residents and playing games but does not like being active or exercising. The instructions Steve's sister gives you from his PCP about what needs to be done for Steve include changes to his diet, increasing his daily exercise and taking some new medications. The PCP has also said that Steve should be watched to see how he responds and to let the PCP know if there are any changes in Steve's symptoms.

- Where can you find the information you need to be helpful to Steve?

Discuss with staff:

- Any information that has come from Steve's PCP.
- The section in the Manual on heart disease.

The section on heart disease in the Manual outlines the symptoms to look for and report to the PCP such as fatigue, changes in activity levels, changes in breathing, chest pain and ankle swelling.

Three weeks later you notice that Steve is tiring much more easily than he used to. He is getting up later, taking naps during the day and resisting activities that require him to walk for any distance, including things he used to really enjoy. What will you do?

- What are some of the things you might see if Steve is experiencing increasing fatigue but is unable to tell you?

Since you know he has heart disease, you might want to refer to the section on heart disease to see whether fatigue is listed as a symptom of heart disease. You could also go to fatigue in Chapter 5 of the Manual and read the description of fatigue. Fill out the Information Gathering Worksheet on fatigue, with input from others as needed. This might be other staff or family members. It is important to point out to staff that fatigue can be caused by many conditions. This might indicate a worsening of the heart disease but it might also indicate another condition. Filling out the Information Gathering Worksheet on fatigue will help the PCP determine which of these is more likely.

Steve sees his PCP about the fatigue and it is decided that it is probably due to a medication he has started to take. The PCP is not concerned but suggests that he be watched closely for any additional signs of heart problems. He gives you a list of these signs. About a month later, you hear from other staff in the group home that Steve is having trouble sleeping at night. He has been waking frequently, bothering other people in the house and walking around during the night. What will you do now?

Go back to the section on heart disease to see if "trouble sleeping" is a symptom of heart disease. Go to the section on sleep problems in Chapter 5 and begin filling out the Information Gathering Worksheet. This information will be important for Steve's PCP. Staff members should identify how they will collect the information, make sure it is direct observation rather than hearsay, and make arrangements for Steve to see his PCP. Since the symptoms would likely be observed on different shifts, it is important to gather information from all shifts while putting the whole picture together. Discuss with staff how they will gather the information.

- Steve does not speak well enough to describe any symptoms he might be having. How will you know if he is having any pain, such as chest pain?

You could discuss with staff how they will fill out the Information Gathering Worksheets to ensure the information is comprehensive and takes into account what happens across shifts and on different days? Refer to the section on pain in Chapter 5. Discuss how they might determine whether Steve is having chest pain.

- Is there anything the support staff can do to help slow the progression of Steve's heart disease?

Diet and exercise are important for people with heart disease. Steve should be encouraged to eat fruits and vegetables and lean meats. It would also be helpful to reduce salt in his diet and for Steve to lose some weight. The staff might consult the local Aging and Disability Resource Center to identify a dietitian and physiotherapist to get Steve started on a diet and exercise program.

Are there any house routines, organizational policies, job demands that might make it difficult to carry out your plan?

The section on heart disease in Chapter 6 of the Manual has a brief description of some things that can be done to help slow the progression of heart disease. There are many other resources regarding heart disease. The American Heart Association has literature online related to diet and exercise. Support staff might want to discuss the impact on staff and other residents of changing food and exercise for Steve. Changing his diet means that staff will have to shop for different foods and learn to prepare different foods. Other residents might object to the new diet which will actually be healthier for everyone but not necessarily welcome. How will they deal with this? An exercise program might also require other staff and residents to change activities. It is always challenging to change routines, particularly when it involves many people. Other staff may be as difficult to convince as residents. Routines will need to be changed for everyone.

Steve has an appointment with his PCP. You are the staff person going along with him. You know that Steve gets very anxious about seeing the PCP. He doesn't like to wait. He is uncomfortable around people he doesn't know. He is always afraid that he will be given an enema since he had one in the PCP's office three years ago. How will you help Steve get through the appointment and make sure that he gets the attention he needs to figure out what's wrong?

You might suggest that staff look through the chapter of the Manual on Building Successful Partnerships. Discuss with them what can be done prior to an appointment, how to prepare Steve and what should be communicated to the PCP and office staff. If support staff have had bad experiences in the past, help them problem solve about what they might be able to do differently this time. A bad experience in the past will often discourage staff from even trying.

Thomas: Normal Aging

Staff Handout

Thomas is a very friendly, 56-year-old man with a moderate intellectual disability. During the past year, Thomas has been diagnosed with gastro-esophageal reflux (GORD) and osteoarthritis. He has needed more and more help to do things and seems to be generally slowing down.

- What do you know about the conditions Thomas has?
- In relation to Thomas's health conditions, what will you need to observe about Thomas in the future?
- What specifically do you need to watch for and record?
- Are there things that staff on other shifts should be watching for? How will you communicate with them?
- Osteoarthritis often causes pain. Sometimes it can be quite severe. If Thomas is unable to tell you he is experiencing pain from his arthritis, how will you know if he is having pain? What will you look for?
- What can the support staff do to help slow the damage to Thomas's joints and the progression of his arthritis?

Lately Thomas seems to be confused quite a bit, often not seeming to understand what you are saying. At times he has difficulty communicating with others. This is new for Thomas. In the past he has been very good at communicating with staff and other residents.

- What do you need to know about the confusion to provide good information to Thomas's primary care provider (PCP)?
- How likely do you think it is that Thomas has developed dementia?

Lately Thomas has had a few other problems as well and you are becoming quite worried. For example, last week he tripped twice on an outing to the zoo. He didn't hurt himself but you are worried that he will have a bad fall and injure himself. He saw the PCP three months ago.

- What can you do to help Thomas?
- Do you think Thomas should be seen by his PCP?
- If you decide to send him, what information would be important to send with him?
- What will you do if a family member is taking him?

A month later, after talking with Thomas, you find out there are a few other things that have been bothering him lately. He complains of having difficulty falling asleep at night, as well as having to urinate more frequently, sometimes even during the night.

You discuss these issues with your supervisor and it is decided that Thomas's PCP will be contacted. An appointment is scheduled and, after assessing Thomas, the PCP suspects that Thomas's inability to fall asleep and night time awakenings are signs of uncontrolled pain, possibly an indication that his arthritis is worsening. She prescribes a medication for his pain and also a stool softener to prevent Thomas from becoming constipated.

A few weeks later, you are talking to Thomas about his sleeping problems. He says he is still waking up and the night staff reports that he has been roaming the house during the night. They have also heard the toilet flush frequently.

- Do you send him back to the PCP or assume that the PCP already knows and there is no point in sending Thomas again with the same problem?
- If you send Thomas back to his PCP, what information might you gather to help the PCP figure out what is going on with Thomas?
- Which Information Gathering Worksheets will you take to the PCP?
- What will you do to make sure that all the information is gathered?
- What have you learned about GORD that might account for Thomas's night waking?
- What about the frequent toilet flushing?

Thomas: Normal Aging *Training Aid*

Thomas is a very friendly, 56-year-old man with a moderate intellectual disability. During the past year, Thomas has been diagnosed with gastro-esophageal reflux (GORD) and osteoarthritis. He has needed more and more help to do things and seems to be generally slowing down.

- What do you know about the conditions Thomas has?
- In relation to Thomas's health conditions, what will you need to observe about Thomas in the future?

In order to help Thomas, to make him comfortable and be alert for changes that need to be referred to the PCP, staff should know a bit about the health conditions. Look these up in Chapter 6 of the Manual and discuss what is important for the staff to be aware of and to keep track of for each of the conditions.

- What specifically do you need to watch for and record?

Go to the sections on GORD and arthritis to see what the staff should be watching for and what they should be thinking about to make Thomas more comfortable. Is there someone currently in your home with either of these conditions who the staff could use the Information Gathering Worksheets with?

- Are there things that staff on other shifts should be watching for? How will you communicate with them?

What are the things that might be occurring on other shifts that should be observed and recorded? What if one of the staff members feels this is an invasion of Thomas's privacy and that it is not appropriate to be "observing" Thomas and recording things about him.

- Osteoarthritis often causes pain. Sometimes it can be quite severe. If Thomas is unable to tell you he is experiencing pain from his arthritis, how will you know if he is having pain? What will you look for?

In Chapter 5 there is a section on pain. This provides some tips on how to tell if someone is in pain when they are unable to tell you. Pain is one of the most common reasons for aggressive behavior and other behavior changes in people with ID.

- What can the support staff do to help slow the damage to Thomas's joints and the progression of his arthritis?

Refer to the arthritis section of Chapter 6 and the resources listed for arthritis. There are also many tips on the arthritis website. OTs and physios are great resources for helping people with arthritis.

Lately Thomas seems to be confused quite a bit, often not seeming to understand what you are saying. At times he has difficulty communicating with others. This is new for Thomas. In the past he has been very good at communicating with staff and other residents.

- What do you need to know about the confusion to provide good information to Thomas's primary care provider (PCP)?

You might start with the Confusion Information Gathering Worksheet. Also, reviewing Chapter 1 – Normal Changes as a Person Ages might lead staff to consider the possibility of either hearing or vision changes being behind some of Thomas's problems. Changes in both vision and hearing can both appear as confusion. Declining hearing and vision are common in older age and are often missed and misinterpreted as confusion. These are even more common and more often missed in people with ID than they are in the general aging population.

- How likely do you think it is that Thomas has developed dementia?

Confusion can be caused by many things. The section on confusion in the Manual lists some of these. Unfortunately, it is often assumed that confusion, particularly in someone with ID, indicates the development of dementia. Assuming it is dementia will delay treatment for underlying conditions that are causing the confusion. The Information Gathering Worksheet on confusion should provide some of the information needed by the PCP to determine the actual cause of a resident's confusion. However it is vital for staff to understand that confusion, particularly when it comes on quickly, is usually not dementia but is caused by something that can be treated.

Lately Thomas has had a few other problems as well and you are becoming quite worried. For example, last week he tripped twice on an outing to the zoo. He didn't hurt himself but you are worried that he will have a bad fall and injure himself. He saw the PCP three months ago.

It might be helpful to consult the falls and difficulty walking section in Chapter 5 and to fill out the Falls and Difficulty Walking Information Gathering Worksheet. It should be apparent that many different things could be causing the falls. The falls could be related to Thomas's osteoarthritis or an underlying problem that is causing his confusion. They could also be related to a problem with Thomas's vision as Thomas may be experiencing vision changes related to aging. This might explain why Thomas has fallen and is appearing to be uncooperative. Hearing decline, much of which is preventable, can also lead to apparent confusion.

- What can you do to help Thomas?
- Do you think Thomas should be seen by his PCP?

At this point, the staff hopefully realizes the complexity of Thomas's problems. He has many symptoms which could be caused by any one of a number of underlying problems. They might be related to each other and they might be several completely separate conditions. Thomas really needs to see the PCP.

- If you decide to send him, what information would be important to send with him?

It is particularly important to provide as much information as possible in a situation that is complex like this one. Having the Information Gathering Worksheets filled out will be very helpful to the PCP.

- What will you do if a family member is taking him?

The section on Building Successful Partnerships includes a discussion of working with families. It would be important for staff to make sure that the information they have been collecting actually reaches the PCP. They might negotiate going to the appointment with the family member. Some group homes have a policy of staff always going with a resident. Another possibility is to work closely with the family to ensure that there is a good flow of information in all directions; that the family is aware of the information gathered by the staff, appreciates the importance of passing it on and takes it to the appointment. It is important that staff work with families so that everyone understands and is in agreement with how information will be communicated. This would, of course, include bringing information back to the staff so they are prepared to be as helpful and supportive as possible to Thomas.

A month later, after talking with Thomas, you find out there are a few other things that have been bothering him lately. He complains of having difficulty falling asleep at night, as well as having to urinate more frequently, sometimes even during the middle of the night.

You discuss these issues with your supervisor, and it is decided that Thomas's PCP will be contacted. An appointment is scheduled and, after assessing Thomas, the PCP suspects that Thomas's inability to fall asleep and night time awakenings are signs of uncontrolled pain, possibly an indication that his arthritis is worsening. She prescribes a medication for his pain and also a stool softener to prevent Thomas from becoming constipated.

A few weeks later, you are talking to Thomas about his sleeping problems. He says he is still waking up and the night staff report that he has been roaming the house during the night. They have also heard the toilet flush frequently.

- Do you send him back to the PCP or assume that the PCP already knows and there is no point in sending Thomas again with the same problem?
- If you send Thomas back to his PCP, what information might you gather to help the PCP figure out what is going on with Thomas?
- Which Information Gathering Worksheets will you take to the PCP?
- What will you do to make sure that all the information is gathered?

The inability to fall asleep shortly after going to bed is sometimes experienced as a normal part of aging. However it can also indicate medical problems that need treatment. The section on sleep problems in Chapter 5 suggests other possible causes that need to be considered. What other Information Gathering Worksheets might be helpful to fill out and take to the PCP?

- What have you learned about GORD that might account for Thomas's night waking?

Night waking can be caused by reflux of stomach juices into the esophagus, causing a burning sensation. Putting the head of the bed on blocks can alleviate this condition. There are also medications that can help with reflux. Collecting information about the time of waking and whether Thomas is experiencing any burning or a bad taste in his mouth can help the PCP sort out what is causing Thomas to wake during the night. It is particularly important that staff do not go immediately to thinking this is a "behavior problem" or "dementia." If they do this, the real diagnosis will be missed or delayed resulting in Thomas suffering unnecessarily and the house being disrupted.

- What about the frequent toilet flushing?

Sometimes night time toilet flushing is interpreted as confusion or a behavior problem. However, it may be that Thomas is having urinary frequency which can indicate several possible medical problems that need attention. Have the staff move from the Information Gathering Worksheet on sleep problems to the Information Gathering Worksheet on urinary frequency.

