

Support for Older People with Intellectual Disability:

A Manual for Promoting Health



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

NOTICE

This is an information gathering and resource Manual to be used in conjunction with a Primary Health Care Provider (PCP) or specialist. It is not intended for diagnosis, treatment or as a substitute for medical advice.

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

If in doubt, call 911.

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

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

We don't provide nursing care here.

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

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

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

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

How staff can use this Manual

Getting to know the Manual:

Explore the Table of Contents

- Read the Introduction

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

- Read Chapters 1 to 4

Come back to these chapters as specific issues arise with residents in your home such as a resident with a terminal condition whose life will end soon or a resident seeing a new Primary Health Care Provider (PCP).

- Browse Chapters 5 and 6

Look at the list of symptoms in the Table of Contents. Think about symptoms you might have seen some residents exhibit in the last month. You can come back to this chapter for tips on what to do when you see a symptom. Think about which conditions residents have been diagnosed with. Read those sections carefully. Consider making a copy of relevant pages and sharing them with other staff.

- Browse the Resources Chapter

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

- Look at the Appendix

Is there anything here that is helpful to you now? If yes, make a copy. If not, remember these resources in case they might be helpful later.

- Pick up this Manual and review the contents periodically.

When a resident exhibits a symptom:

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

If this is not an emergency:

- Read about the symptom(s) in Chapter 5.
- Make a copy of the relevant Information Gathering Worksheet.
- Talk to other staff who may have information you don't have.
- Plan next steps with your manager or supervisor.
- Make sure information goes with the person taking the resident to his/her next health care appointment.
- If the symptom is not listed in this Manual, talk to your manager or supervisor about what to do and where to go for help.
- See the Resources (see Chapter 7).

When a resident is diagnosed with a condition:

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

Normal changes as a person ages

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

Health and intellectual disability

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

Where older people live

As people age, they usually remain in their home as long as they are able, often with support from health and community services and family members. People with ID are less likely than other older adults to have adult children to help with their care. Parents may no longer be alive and siblings are often unprepared to assume caregiving responsibilities. Older adults with ID may move into homes with additional support at this point. Others with ID have been living in such homes since childhood. For both groups, advancing age brings with it the same health concerns that all other older adults experience, in addition to any disability already present. Aging is accompanied by predictable changes in physical functioning and general resilience. Some conditions can be prevented and some can be treated, resulting in better overall health and better quality of life.

Challenges for support staff providing care to aging people with intellectual disability

Support staff often feel unprepared to care for residents as they develop health conditions. Finding the right resources to help sort out the problem, altering house routines to accommodate changes, managing treatments and providing the most effective support and supervision for people with health conditions is often challenging. Some health conditions can be difficult to manage. Handling multiple medical appointments and understanding the condition and treatment side effects are all issues that staff may feel unprepared for. As a consequence, people with ID can be prematurely relocated to a nursing home.

What support staff can do

Support staff play a crucial role in assisting residents to age in place in their home. Most important is the role staff can play in making certain that PCPs have the information they need to make the correct diagnosis and begin treatment.

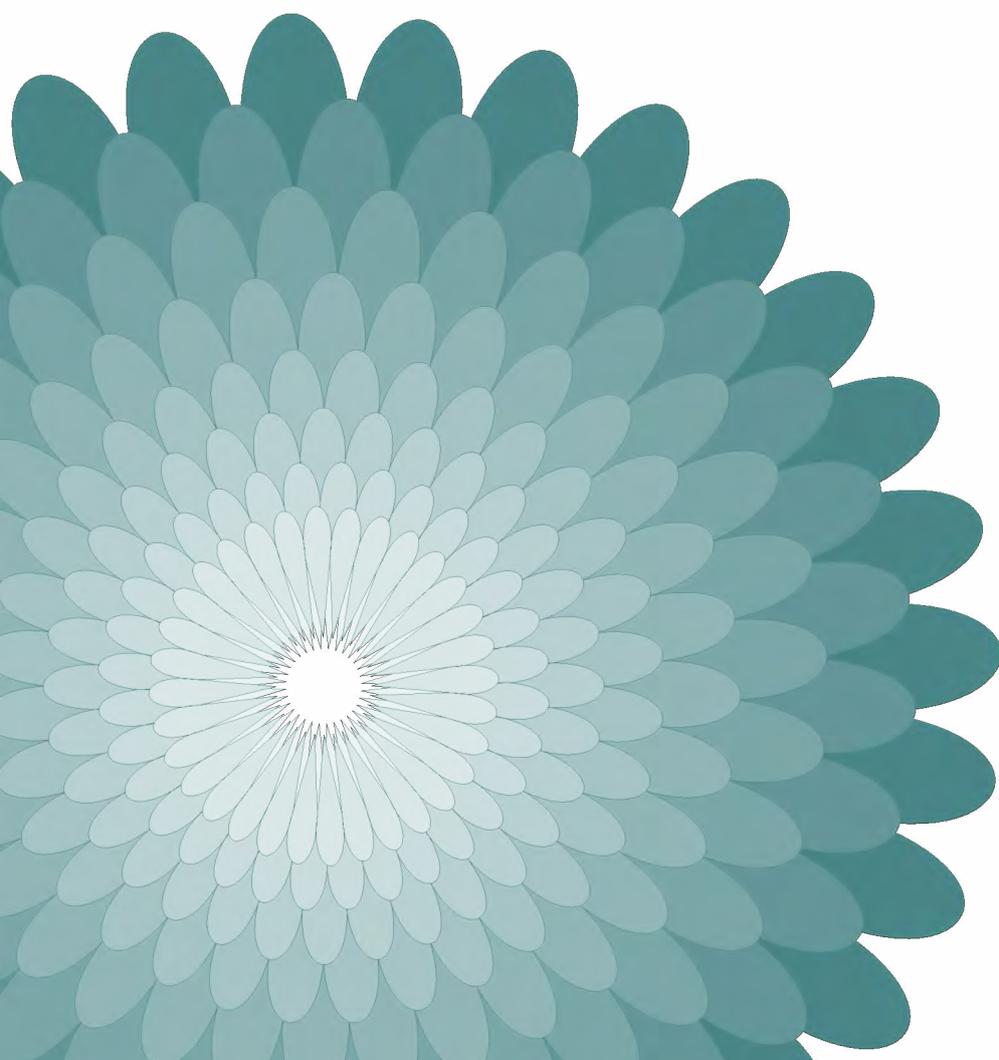
Using this Manual

This Manual is intended to help staff support people as they age. It provides tools to help staff understand common symptoms and conditions and will help staff to communicate with health care professionals, to advocate for care and to comfort residents. The purpose of this Manual is to help staff, to keep people active despite the development of health conditions, to prevent disability and discomfort and to keep people in their own home as long as possible.

The Manual is arranged as follows:

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

Normal Changes as a Person Ages



Normal aging

As people age, they experience many normal and expected physical, emotional and social changes. Some of these might be unwelcome challenges to individuals, but aging also can be a very positive experience for many people. What many people don't realize is that creativity may actually be enhanced in older people and that capacity to learn continues into very old age. As we grow older we develop skills and wisdom that can be brought to new situations.

For example, people living in group homes have often experienced the coming and going of many caregivers. The ability to adjust to such important relationship changes requires a specific set of skills. Many group home residents have developed these skills over time. So, while there is certainly physical decline in later life, the impact on quality of life can be minimized through social engagement, continuation of meaningful activities and development of new interests.

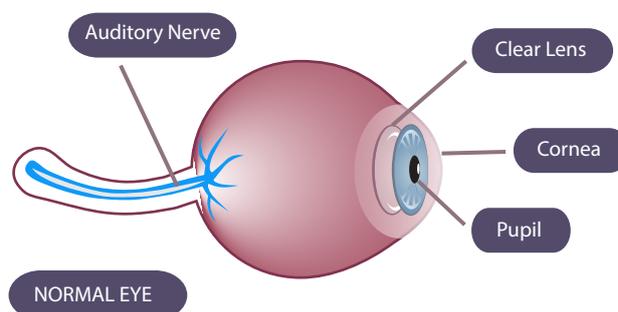
Many changes occur as part of the normal aging process. These changes occur at different rates for different individuals. Sometimes it is difficult to distinguish normal aging from certain illnesses. Sometimes illness is misinterpreted as normal aging, causing delays in identification and treatment of illness and leading to unnecessary suffering. A major and unfortunately common mistake is to assume that things such as vision loss, diminished hearing and other conditions are 'just aging.' This prevents people from getting the treatment they need and undermines their quality of life. Changes should always be considered treatable until proven otherwise.

Vision

Normal vision: How the eye works

The cornea is the outermost layer of the eye. It is a transparent window that allows light to enter the eye. The pupil, which is behind the cornea, controls the amount of light coming into the eye. In bright sun, the pupil constricts to limit the amount of light. In darker settings, the pupil dilates to let more light in. You have probably noticed that it takes time to adjust to both dark and very bright settings. This adjustment is your pupil responding to different levels of light. Without this, it would be difficult to see in darkened rooms or in bright light.

The lens is a clear oval shaped section of the eye. The lens is what allows you to see both near and distant objects clearly. The lens actually changes its shape to bring objects at different distances into focus like a camera. Light passes through the lens to the back of the eye. Once the light passes to the back of the eye, it can be transported through nerves to the brain. This results in vision.



The aging eye

As people age, several things occur that make vision more difficult. The pupil becomes less able to change size to accommodate for changes in light and dark, which means that older people can have difficulty adjusting to changes in light. Accommodation to light changes can take longer and be less effective than in younger people. The lens also changes with age. Two things happen to the lens that interfere with vision. First, the lens becomes less adaptable and cannot change shape as easily to focus at different distances. This often results in 'far sightedness' or presbyopia. The ability to see distant objects may be good, while the ability to see objects that are close up is diminished. This is why so many older people use 'reading glasses' and have difficulty doing things close up.

The lens can also yellow or become cloudy with age. When this occurs, light is blocked from passing through, resulting in fuzziness, blurriness, glare and difficulty discriminating colors. Going from dark to light and light to dark can cause temporary distortions in vision and difficulty seeing. It also means that bright lights can cause glare, making it difficult to see the environment. The best type of lighting for aging eyes is indirect (has a shade, bounces light off ceiling) and uses fluorescent, xenon or halogen bulbs that help correct yellowing. Changes in the eye's ability to see color and contrast can lead to problems seeing objects that are similar in color or tone or seeing an object against a background of the same or similar color. Changes can also occur to the nerves in the eye resulting in problems sending the correct visual message to the brain, which is common in diabetes. Any changes in the eyes, particularly those that occur more in one eye than in the other, can cause diminished depth perception, which increases the risk of falling.

People with age-related vision changes might have difficulty:

- Seeing in the dark.
- Seeing colors.
- Seeing close objects.
- Seeing in brightly lit areas.

You might notice:

- They are squinting.
- They are sheltering their eyes in the sun.
- They seem to trip or fall often.
- They have worsening table manners.
- They have a new sloppy or messy appearance.
- They are withdrawing from social activities.
- They appear confused.
- They have difficulty recognizing people.

Tips:

- Shine additional light on close up work materials.
- Use color to distinguish important objects, such as painting the bathroom door bright red so it is easy to find.
- Use lights that have adjustable necks so light can be directed.
- Try reading glasses for close up work.
- Consider motion-sensor lights that turn on automatically when you enter a room.

- Avoid bare bulbs, clear shades and chandeliers without shades that create glare.
- Avoid or cover shiny or highly polished surfaces, especially floors.
- Take caution using stairs. See Conditions: Vision Loss for more tips.

Vision screening

- People with intellectual disability have more conditions affecting vision than the general population.
- Annual vision screening by an optometrist or ophthalmologist.
- Glaucoma screening once before age 40, every 2 to 4 years after age 40 and every 1 to 2 years at age 65 and thereafter.
- Cataract check annually starting at age 30 for people with Down Syndrome, every 6 months for anyone taking antipsychotics, as recommended by physician or ophthalmologist for all others.

People with intellectual disability

People with ID have more vision problems than other older adults. Many experience vision problems at a young age and then experience the additional age-related vision changes as well. Vision problems in people with ID are often undetected and therefore untreated. Sometimes vision problems are not picked up in people with ID who have communication problems because they are unable to participate in the usual vision screening that is done for other people. It is important to know that very good vision testing has been developed for people who have communication problems. It is generally necessary to see a vision specialist for this test. People with Down Syndrome are particularly likely to have vision problems and should be routinely screened.

Eye conditions that occur more frequently in older adults

There are several eye diseases and conditions that are not normal aging but are much more likely to occur in older adults. These include:

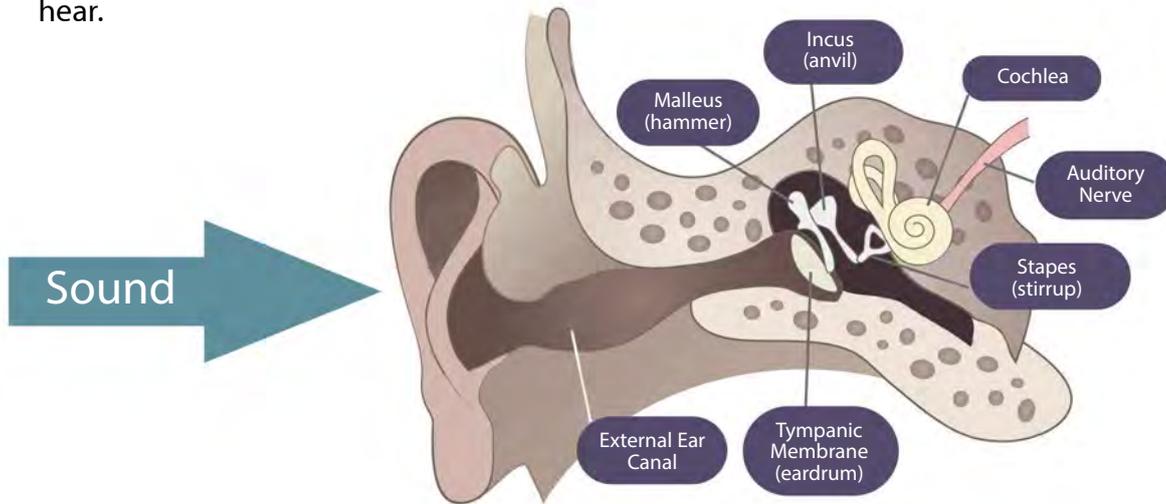
- **Glaucoma:** Glaucoma results from a build up of pressure within the eye. If untreated, glaucoma can lead to irreversible vision loss. Vision loss in glaucoma is peripheral, the vision off to either side. This leads to tunnel vision. Glaucoma is generally painless. The only way to detect it is through a very simple eye examination that can be done quickly and easily by an eye specialist.
- **Cataracts:** Cataracts also occur more frequently in older people. A cataract is a clouding of the lens that results in blurred, fuzzy vision and glare. Cataracts can also affect depth perception leading to stumbling and falls. Many people have cataract surgery to replace the cloudy lens with a new synthetic lens. This is a very simple surgery and results in much clearer vision.

Hearing

Normal hearing: How the ear works

The ability to hear requires that sound be transmitted from the environment into the external ear canal and into the ear drum (tympanic membrane). From the ear drum, sound is sent through tiny bones in the middle ear (malleus, incus, stapes). These bones vibrate with the sound and send waves of sound into the inner ear (cochlea). The inner ear

contains fluid and thousands of tiny hair cells (cilia). Sound comes into the inner ear, travels in waves through the fluid and on to the hair cells. The hair cells cause a reaction that is transmitted through the auditory nerve to the brain. When this happens, we can hear.



Problems with any of these functions can block the transmission of sound. As we age, the tiny bones in the middle ear become stiffer and don't vibrate as well, diminishing the sound transmitted to the inner ear. The hair cells in the inner ear decline in number with age, diminishing the sound transmitted from the inner ear to the brain. These changes result in predictable, gradual loss of hearing. Age-related hearing loss is termed presbycusis and it usually results in:

- The loss of higher frequency sounds. With high frequency loss, women's voices are more difficult to hear and understand than men's voices.
- Difficulty distinguishing sounds or 'extracting' a sound from other sounds in the environment. It is much more difficult for older people to hear (to distinguish sound) when there is background noise such as several people talking at once or television, radios, dishwashers or fans. Increasing volume will *not* make it easier to hear. Eliminating background noise will help.

As hearing loss comes on slowly, people who are losing their hearing often don't realize it. Therefore they can't tell you that they have been losing their hearing. It is not unusual for others to think the resident with hearing loss has become confused as they seem not to understand as well as they used to. Sometimes the resident with hearing loss also believes they have become confused.

People with intellectual disability

People with ID have a much higher incidence of hearing loss, at all ages, than people who do not have ID. Almost 100% of aging people with Down Syndrome have hearing loss. Many people with ID have never had their hearing tested, even as they age. This means that much of their hearing loss remains undetected and untreated. Even when hearing loss in people with ID is known, it is often not treated. It is often believed that people with ID will not tolerate a hearing aid. While difficult to get used to, people with ID can become comfortable with hearing aids if they have the proper support. There are specialized hearing tests for people with ID. These are used effectively for people who have difficulty communicating.

Recommended screening for hearing

- Routine ear examination annually by Primary Health Care Provider (PCP) (particularly check for ear wax build-up).
- Screening (preferably by an audiologist) at age 45 and every 5 years after.
- For adults with Down Syndrome, screen hearing every year.
- People with ID are at greater risk for hearing problems, even at an early age.

[Note]: Specialized hearing tests are available for people who have communication problems.

You might suspect some hearing loss when you see:

- Difficulty hearing with background noise.
- Misunderstanding speech.
- Confusion.
- Withdrawal.
- Anger or irritation.
- Being uncooperative.

Some things you might do to help the resident hear more clearly:

- Decrease the background noise (fans, dishwashers, televisions).
- Get their attention before you start to speak.
- Indicate or gesture to help them understand.
- If they don't understand, change the words or phrases rather than shouting.
- Lower the pitch of your voice, particularly women. This can be learned.

Skin

Skin is a much more important organ than most people are aware of. Skin is involved in controlling body temperature, maintaining your fluid balance and giving you clues about dangers in the environment. With aging the skin becomes thinner, less elastic and less sensitive to the environment. Thinning of the skin makes the skin quite fragile and easily torn or injured. Skin tears, bruising and small bleeds under the skin are common in older people. The fat layer just below the skin which provides padding and insulation also thins. One of the most important consequences of this particular change is the reduced ability to regulate body temperature. This means that older people are less able to accommodate changes in heat or cold. Body temperature will rise or fall with the surrounding temperatures much more quickly than in a younger person. This means older people are more vulnerable to heat stroke and hypothermia than younger people.

As people age, their oil glands also produce less oil, making skin more likely to be dry and itchy. You may have noticed that skin color changes with age as well. This occurs because the number of pigment-containing cells, called melanocytes, decreases, causing the skin to appear thin, pale and translucent. This is perfectly normal unless spots start to change. Because aging skin repairs more slowly than younger skin, wound healing will also be slower than it is in younger people. Finally, changes in skin also lead to loss of sensitivity, particularly in hands. This makes it easier for people to injure themselves and to be unaware of injuries to their skin.

Tips:

- Keep skin moist with lotions that are low in perfume and water content.
- Take care in temperature changes.
- Avoid pulling on skin, especially over the forearms and hands.
- Encourage wearing of shoes and socks so skin is protected.

Musculoskeletal (Muscles and Bones)

With age, there is a loss in bone density. That is, bones are not as thick as before and can become more brittle, making them weaker and more susceptible to fracture. This makes older people more likely to break a bone when they fall. Bone density loss is much easier to prevent than it is to reverse. Bone density loss in women often accelerates at menopause so post-menopausal women should be screened for bone density and have their diet assessed for calcium and vitamin D. Weight bearing exercises such as walking are also very helpful in preventing or delaying bone density loss. Muscles often lose strength and flexibility which may result in a decrease in coordination or balance. As muscle decreases, it becomes replaced by fat. Some of the important consequences are:

- Decreased hand grip strength.
- Stooped posture.
- Difficulty getting up from a chair.
- Problems walking.
- Falls.

While aging cannot be prevented, some of the consequences can be slowed or minimized. For example, regular exercise can maintain muscle mass and function, while loss of muscle function can occur very quickly with lack of use. Loss in muscle mass and function can often be reversed with careful graded exercise. However it is much more effective to prevent loss in the first place.

Important: You must consult the resident's PCP before starting an exercise program.

Tips:

- Encourage residents to participate in activities that promote movement.
- Make sure there are adequate 'grab bars' near steps and in the bathroom.
- Remove tripping hazards such as excess furniture or rugs.
- Watch for signs of pain with movement or weight bearing.

Recommended preventative screening for bone mineral density (Osteoporosis)

- People with ID are at an increased risk of osteoporosis, particularly if they have been taking seizure (anticonvulsant) medications, have poor diets or are generally inactive.
- Bone mineral density should be checked by PCP at the time of menstruation cessation (regardless of the reason for menopause) and then as determined by PCP. For men, at age 40 the physician should consider when testing is recommended given the individual's risk factors.

Sleep

People with ID living in group homes have much greater difficulty sleeping than other older adults. In one study, 15-20% of all group home residents had serious sleep problems. One of the problems discovered by a study of group home residents was that people in group homes were often put to bed when they were not tired and had not had enough exercise during the day. Allowing bedtimes that correspond to the resident's wishes can help residents sleep more effectively. Additionally, adding physical activity to a resident's daily routine will cause fatigue, which also helps residents to fall asleep.

Tips:

- Avoid noisy environments at night.
- Maintain a routine for sleep.
- Avoid napping.
- Exercise regularly.

Stomach/Intestines (GI tract)

As a person ages, digestion becomes slower and less efficient. Less stomach acid enzymes are produced, leading to slower and less efficient use of nutrients. Additionally, a delay in transit of stomach contents into the intestine sometimes causes older people to feel full after eating only small amounts of food. The slower digestion can also lead to constipation, which is a very common and distressing problem. Constipation is not a normal part of aging. Constipation often results from a combination of medication side effects, lack of exercise and inadequate fluids and fiber.

Tips:

- Consider small, more frequent meals, particularly when there is weight loss.
- Avoid drinking large quantities of fluid with meals.
- Drink fluids throughout the day.
- Eat foods high in fiber (fruits and vegetables).
- Get plenty of exercise.

Recommended preventative screening for constipation

- Inquire about side effects of new medications (constipation).
- Increase fiber and fluids and monitor if taking medication known to cause constipation.
- Monitor people for constipation if they have minimal exercise and do not eat fruits and vegetables.

Many other problems that occur in the stomach and intestines are more common as people age. Colon cancer is a relatively common type of cancer that increases with age and can often be prevented. People with ID are much less likely to be screened despite a possible increased risk of colon cancer. People who have lived in an institutional setting at any time during their lives are at greater risk. People who are overweight are also at increased risk. Support staff can play a very important role in making sure people are properly screened.

Recommended preventative screening for stomach and colon cancer

- Faecal occult blood tests (stool tests) should be done annually starting at age 50. Future needs depend on results and family history, but at least every 10 years.

Recommended preventative screening for swallowing problems

Swallowing difficulties occur when the muscles in the esophagus (passage way for food from the mouth to the stomach) are less able to coordinate during swallowing. Swallowing is actually very complex. It requires the coordination of about 50 pairs of muscles and nerves. Many conditions can interfere with swallowing. Sometimes this causes pain and sometimes it leads to choking. People with ID may have genetic conditions making them more vulnerable to swallowing problems. Swallowing problems are also much more common in older people. It is important to observe for signs of swallowing difficulty. One of the most significant results of swallowing problems is 'aspiration'. Aspiration is when food or drink goes into the lungs instead of the stomach. This can cause immediate problems with breathing difficulty, which can be life threatening. More often, it results in small amounts of food or drink in the lungs that causes lung infections. For some people, it may not be very obvious that small amounts of food or drink are going into the lungs, except that they may have frequent lung infections. Repeated lung infections should always raise concern about swallowing problems. People with swallowing difficulty might also become afraid to eat. Dietitians can help identify the specific problem and the foods that are easier to swallow or cause less discomfort. If people are experiencing repeated chest infections, having pain with swallowing or are reluctant to eat, the PCP can refer the resident for 'swallowing studies' and dietitians and speech therapists can advise you on how to reduce choking. Head posture while swallowing can also improve swallowing and decrease choking. More information on swallowing problems can be found later in this Manual (see page 46).

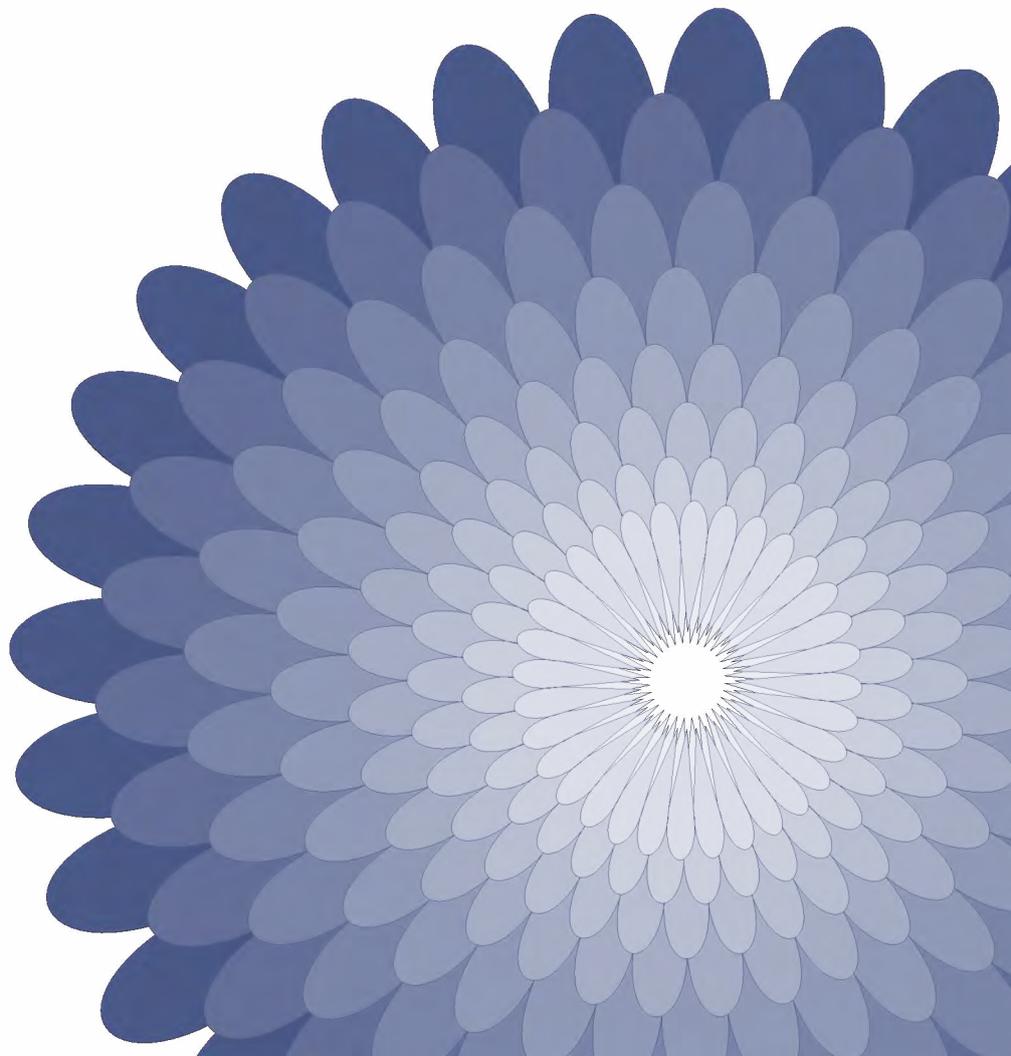
Urinary Changes (Genitourinary)

With aging the bladder becomes smaller and less elastic and, as a consequence, can hold less urine than it previously could. Additionally urine remains in the bladder after urinating, resulting in increased frequency of urination. This can also make older people more susceptible to urinary tract infections. Incontinence is not a normal consequence of aging. It is often caused by bladder infections but can also be caused by other medical conditions. Older men often have enlarged prostate glands which can block the outflow of urine. When this happens, the flow of urine is slower to begin, less forceful and prolonged. It may also lead to frequent urination.

Tips:

- Encourage residents to use the toilet prior to sleep at night.
- Make sure there is a lighted passageway to the toilet at night.
- Alert the PCP about any sudden changes in urination, unusual smelling or appearing urine, incontinence or difficulty urinating.
- Alert the PCP about any prolonged time to empty bladder or frequent trips to the toilet.
- See Symptoms: Urinary Frequency for more tips

Building Successful Partnerships



Working with health care professionals

Appointments with Primary Health Care Providers (PCPs) and other health professionals

People with intellectual disability (ID) experience more health problems than the general population. This is partly due to difficulty communicating about health problems or symptoms, health care providers not sufficiently understanding the needs of people with ID, failure of caregivers to pass on important information and, in some instances, less reliable access to health care services and professionals. As people age, they are more likely to develop health conditions and require appointments with health professionals. An increase in the frequency of clinic visits is common. Support staff are familiar with the resident, their preferences, fears and routines and are often in a good position to communicate key information to health care providers.

Effective communication with health professionals is vital. The PCP and specialists rely on the insights and information provided by support staff in order to help the appointment to go smoothly and to make the correct diagnosis. Staff are in the best position to notice changes that the resident has been experiencing. They can tell the PCP what is usual for the resident and any changes that have occurred. The ability to compare 'what is usual for the resident' to 'what is happening now' is crucial to making the correct diagnosis. This information is often much more important than anything the PCP can learn by examining the resident or doing tests. People with ID are often unable to tell the PCP about the problem they are having. In particular, health professionals often underestimate the amount of pain or discomfort the resident is having if they only speak with the resident with an ID.

It is important to keep in mind that some health care providers (physicians, nurses, or others) may have long-term relationships with a particular resident. As support staff turn over quite frequently, health care providers may know the resident the best. Although they may not be familiar with the details of the person's daily life, the providers may know a lot about the person's history, including life-changing events; what makes the person anxious or afraid; and what has worked well in the past. This knowledge may help support staff provide the best care possible.

People with ID often become confused or anxious when visiting a clinic. Your presence can help the resident remain calm and be less frightened. Clinic visits become very difficult once the resident becomes anxious or afraid, often making effective care impossible. You probably know what tends to cause fear and anxiety and can alert the clinic staff. This will go a long way to making the clinic visit more effective.

Tips for the making the appointment more effective

- It is important for people with ID to have a familiar person accompany them to medical appointments.
- It may be appropriate to advocate for a longer time for the appointment (the last appointment of the day may be useful for those who need longer).
- It may be appropriate to ask for an appointment time when there might be a shorter wait time (e.g. early in the morning) to reduce anxiety and restlessness during the appointment.

Prior to the medical appointment

It is possible that the PCP who is seeing the patient is not familiar with him/her, and might not have experience working with people with ID. As an advocate, it will be important to politely share with the PCP or other professionals tips for communicating effectively with people who have ID. One approach is to give them a copy of these tips prior to the appointment or upon arrival (see the end of this chapter). It is also helpful to request a double appointment to avoid rushing the visit.

Another thing that might help the appointment go more smoothly is to complete the **My Health Passport for Hospital/Clinic Visits** (created by the Florida Center for Inclusive Communities) and **Medication Information Forms** (see Appendix chapter). Share the completed forms with providers prior to the appointment or upon arrival. Ask other staff members and family to help document any tips or concerns on the worksheets.

Before you leave for the medical appointment, gather the following things to bring along:

- **My Health Passport for Hospital/Clinic Visits Form** (see Appendix chapter).
- **Medication Information Form** (see Appendix chapter).
- **Information Gathering Worksheet** for the health problem (found in this Manual and available on CD on the inside back cover of this document) if applicable.
- **Mobility devices** used, such as wheelchair or walker.
- **Sensory devices** used, such as glasses or hearing aids.
- **Health history and information.** If your organization does not require you to use specific templates to document health information, then a personal health record may be useful for keeping medical information. This is a record that contains a cumulative summary of the resident's health care information. It is maintained by the patient, the support person and the PCP and is taken to each consultation with a healthcare provider. A personal health record for people with ID is available from Concordia Plan Services (http://www.concordiaplans.org/graphics/assets/documents/My_Personal_Health_Record.pdf). Examples of useful information:
 - Medication record.
 - Any recent weights, blood sugars, or other data that may be available.
 - Any progress notes or caregiver records.
 - Fears and things to avoid.

If an intrusive (e.g. pap smear) or challenging procedure (e.g. taking blood, breast examination) is planned, it might be useful to ask the PCP's office to **arrange a visit ahead of time to talk about the procedure** and tell the resident exactly what will happen. This often results in things going more smoothly than anticipated.

During the appointment

Staff or family members have an important role during appointments.

- **Decide ahead of time how others will participate in the appointment.** It can be reassuring for the resident to have a trusted person in the room during procedures or examinations, but it is important for the resident to control who is present. If the resident cannot make or communicate these decisions, speak to the appropriate person ahead of time (family, guardian) and decide how others will participate in appointments and examinations. Confirm the resident's comfort with these decisions to the extent possible.

- **Allow the resident to speak on his/her behalf** during the appointment whenever possible. Encourage him/her to show or tell details. Help translate the information to the provider as needed. This may take additional time so you may need to consider asking for double appointments.
- **Communicate facts.** Health care providers rely on a history of the health concern to make many diagnoses. People with ID may have trouble communicating important details. For example, if a resident is having frequent headaches, the PCP will ask several questions about location of the pain, severity, how long the pain has been present, frequency, timing, and other factors such as past injuries or medications. A resident with ID may have difficulty communicating these details. It is important for staff or family members to be prepared with facts during appointments. The Information Gathering Worksheets in the symptoms section of this Manual will help document the important facts.
- **Avoid 'diagnosing'** before letting the PCP examine all the evidence. This allows for more accurate diagnoses and treatment. For most of us, when we have decided what we think is going on, we tend to select the facts that support that conclusion. This is natural. However, it is important to avoid this habit as it is more likely to leave out important information and delay diagnosis and treatment.

Admission to the hospital

Hospitals are scary places for people when they don't understand what is happening around them. People with ID often have a difficult time in hospitals. The majority of staff in hospitals are not trained to work with people with ID. Hospital staff rotate frequently, making it challenging to keep everyone informed about the special needs of people with ID. Having some familiarity with the hospital environment, the staff and the activities will help allay fears. Some things that have been found to be helpful are:

Preadmission

- **Visit the hospital** prior to the stay/procedure with the patient whenever possible. See the unit where the resident will be. Meet the people who will be taking care of him/her.
- **Organize the information that the hospital staff will need** into an information packet. My Health Passport for Hospital/Clinic Visits Form (see Appendix chapter) is a tool that may be used to help a hospital stay go more smoothly.

Contents of Packet

- A. Medical Information: A list of current medications, a list of current medical diagnoses, a list of recent medical events or illnesses.
- B. Past Medical History: If not available, ask PCP for a copy to share with hospital staff.
- C. Social/Behavioral Information: preferences, fears, things that comfort the resident.
- D. Things they need help with: Eating, toileting, etc.
- E. Communication: Whether they are verbal, how they communicate emotions, ability to understand, language skills.
- F. Contacts: Name and contact of support staff in your home or family members.
- G. Any specific forms which your organization requires you to use to provide information to the hospital regarding the resident.

Format

- A. Brevity: Keep information brief, bullet points.
- B. Sequencing: Put information staff will need immediately at the beginning.
- C. Labeling: Bold headings so information is easy to find.
- D. Laminate the information sheet.
- E. Make multiple copies to give out as staff change.

Upon admission

- **Bring information packet** for staff (see previous page).
- If you do not have a **list of medications**, bring the medications.
- Bring **items that are comforting or familiar** to the resident.
- Coordinate with staff:
 - 1) Introduce yourself to the staff on each shift you are there.
 - 2) Offer to work with the staff. They may not be used to caring for people with ID.
 - 3) Explain to the staff how the resident communicates. Give them recommendations that you think will help.
 - 4) Ask if the hospital has someone whose job it is to support people with disabilities while in hospital and make an appointment to meet with them.

During hospitalization

- Check to **see if staff have seen the information packet** (previous page). It is useful to bring several copies of the packet as nursing staff change frequently and there will likely be many different people involved in the care.
- **Make arrangements for consultants/specialists to visit when you (or another support person) are there.**
 - 1) Find out when treatments and tests will be done that might require a familiar support person.
 - 2) Find out when instructions can be given or test results communicated to the patient so that someone else will be there. Request these also be put in writing. Families and support staff should work together on this if they are both involved.
- **Ask to talk to the discharge planner early** to prepare for discharge. Make sure the discharge planner knows what support can and cannot be provided in your home. If there are no discharge planners, ask to talk to someone such as the social worker who can help you plan for the discharge.
- **Encourage support staff and families to talk to each other about post hospital care** and location.
 - 1) Begin discussing early where the resident will go after discharge (temporarily to rehab, permanently to a nursing home, family home or group home).
 - 2) Discuss with discharge planner the support that is available in that setting, what additional support will be needed and how to acquire it.

Upon hospital discharge

- A going home guide, "Taking Care of Myself: A Guide for When I Leave the Hospital", is available from the U.S. Department of Health and Human Services Agency for Healthcare Research and Quality (<http://www.ahrq.gov/qual/goinghomeguide.htm>).

- Make sure you have a **list of medications that will be taken after discharge**. Ask for a list of side effects and make all support staff and others (e.g., family) aware of what to watch for. If possible, complete the **Medication Information Form** (see Appendix Chapter) before you leave the hospital.
- Clarify what should be done about **medications and treatments that the resident was on prior to hospitalization**. Should they be stopped or continued?
- Ensure the hospital arranges appropriate community based nursing and health supports for the resident when returning home.
- Be clear about **what care or treatments will be needed** and who will be doing them. Request help coordinating resources if needed.
- Ask for **clear instructions** about what to be alert for (e.g. slow healing incisions, not eating, pain). Establish a plan to communicate this to all staff (and family members).
 - Find out **who to call if there are problems**. Get contact information.
 - Be clear about the expected **follow up care** or appointments.
 - Consult with local pharmacist about medications added at hospital discharge. The pharmacist can tell you about side effects to watch for as some medication combinations do not work well together and might even be dangerous. Sometimes hospital staff are not aware of the medications the resident is already taking.

Information to share with the providers

Communication Tips for Health Care Providers

People with ID appreciate PCPs who:

- Do not shout.
- Explain what is happening.
- Take time to explore how much they can understand. Communicate in a way that acknowledges this.
- Listen to what they are trying to say.
- Encourage patients to say when they do not understand something.
- Say when they do not understand the patient.
- Allow sufficient enough time for a consultation.

Techniques to assist in clear communication:

- Gain the patient's attention and eye contact if possible by using their name, or with touch. Do this before speaking.
- Use simple words, sentences and concepts.
- Avoid jargon; adopt age-appropriate terminology that is familiar to the patient.
- Expect a response and wait at least 10 seconds.
- Rephrase questions if necessary.
- Supplement speech with body language (e.g. signs, gestures, facial expression, and demonstrations).

Obtaining recommended screenings

People with ID often are not screened for health conditions as often as recommended. However, they are often at greater risk than the general population. Practitioners are sometimes hesitant to screen people with ID because they think the resident cannot manage going through the screening process. This is often not true and may only require a longer appointment time (which you can request) and preparation (talking to the resident and showing the resident exactly what will be done, allowing them to touch and feel equipment as necessary). Support staff play an important role in advocating for residents with ID to receive the screening that they are entitled to. Ask those in your community to identify important allies in advocating and finding providers who specialize in helping people with ID.

Commonly missed conditions in people with intellectual disability include:

- Hearing impairments (sometimes requires specialized tests)
- Vision impairments (sometimes requires specialized tests)
- Dental care
- Pain
- Thyroid problems
- Osteoporosis
- Constipation
- Cancer (e.g. skin, breast, testicular, cervical, colon)
- Over medication (particularly tranquilizers and anticonvulsants)
- Seizure Disorder/Epilepsy
- Depression
- Reflux (GERD)

Recommended preventative screening and immunization frequency for older adults with intellectual disability*

*If a resident is at high risk, more frequent checks may be ordered by the PCP.

| Preventative Screening | Frequency |
|---------------------------------------|--|
| Blood pressure | <ul style="list-style-type: none"> • Every PCP visit (at least annually). |
| Blood sugar | <ul style="list-style-type: none"> • People who are overweight are at increased risk . • Every 3 years until age 45, annually after. • Annually at any age if on antipsychotic medication or with Down, Turner, Prader-Willi or Klinefelter Syndromes |
| Cholesterol | <ul style="list-style-type: none"> • People who are overweight are at increased risk. • At least every 5 years. Discuss frequency with PCP based on resident's risk factors and past results. |
| Faecal occult blood test (stool test) | <ul style="list-style-type: none"> • People who are overweight are at increased risk. • People who have lived in an institutional or group setting are at an increased risk. • Annually at age 50 and thereafter, earlier if at increased risk. |
| Height and Weight | <ul style="list-style-type: none"> • Weight - Every PCP visit (at least annually). |
| Mammograms | <ul style="list-style-type: none"> • Every 1 to 2 years after age 40. |
| Clinical Breast Exam | <ul style="list-style-type: none"> • Recommendations vary, discuss with PCP. Every 3 years is common. |
| Colonoscopy | <ul style="list-style-type: none"> • People who have lived in an institutional or group setting are at an increased risk for colon cancer. • Every 10 years after age 50 (discuss alternative tests with PCP. |
| Depression | <ul style="list-style-type: none"> • Annually. |
| Pain | <ul style="list-style-type: none"> • A change in behavior suggests the possibility of pain and needs medical review. |

| Preventative Screening | Frequency |
|------------------------|---|
| Oral Health/Dental | <ul style="list-style-type: none"> • At least annually, preferred every six months. • Include oral cancer screening. |
| Pap Smears | <ul style="list-style-type: none"> • Pap smears are necessary if women have <i>ever</i> been sexually active. • Every 2 to 3 years over age 30. Discuss sedation with PCP if necessary. • After age 65, if previous three tests were negative, talk to PCP about discontinuation. |
| Prostate exam | <ul style="list-style-type: none"> • At physician discretion; ask for recommendation. |
| Thyroid | <ul style="list-style-type: none"> • Every 3 years. • Recommendations vary from 1 to 3 years for high-risk groups, such as people with Down Syndrome. |
| Vision | <ul style="list-style-type: none"> • People with ID have more conditions affecting vision than the general population. • Annual vision screening (by optometrist), including cataract after age 45; glaucoma every 2 to 4 years at age 40; and every 1 to 2 years at age 65. • Cataract check at age 30 for those with Down Syndrome and every 6 months for those on antipsychotics. |
| Hearing | <ul style="list-style-type: none"> • People with ID are at great risk of hearing problems. • Annual auditory screening by physician, particularly checking for ear wax. |
| Diet | <ul style="list-style-type: none"> • Annually discuss with PCP. |
| Medication Audit | <ul style="list-style-type: none"> • Review supplement needs annually with PCP (calcium and vitamin D are often ordered). • Review medications at every PCP visit. • Review with pharmacist any time a new medication is added. |

| Preventative Screening | Frequency |
|-------------------------------------|--|
| Constipation | <ul style="list-style-type: none"> • Assess risk with new medications. • Assess risk at least annually, by dietitian or PCP, particularly for those with immobility, medications such as anticonvulsants, tranquilizers or for those exhibiting food refusal. |
| Bone Mineral Density (Osteoporosis) | <ul style="list-style-type: none"> • People with ID, who are sedentary, take seizure medication or have low vitamin D are at greater risk. • Check with physician for recommendation at age 40, earlier if at increased risk. • Counsel on preventative measures and ways to decrease fall risk. |
| Immunization and Vaccinations | <ul style="list-style-type: none"> • Pneumococcal (Pneumonia): Once in childhood, booster after age 65. • Influenza: Annually. • Tetanus-Diphtheria Booster: Every 10 years. • Hepatitis A and B: Discuss individual status and recommendations with physician. • Zoster (shingles): Once after age 60. • Tuberculosis: Annually unless directed otherwise by physician. |

The above summary is based on the following resources. The screening recommendations are current as of 2012; however, they are subject to change.

- 1) Massachusetts Department of Developmental Services. Massachusetts Department of Mental Retardation health screening recommendations. Boston (MA): Massachusetts Department of Developmental Services; 2007. 2 p.
<http://guideline.gov/content.aspx?id=37906>
- 2) NYS Office of Mental Retardation & Developmental Disabilities. Preventative Health Care Screening Guidelines for People Aging with Intellectual and Other Developmental Disabilities.
http://www.ucp.org/uploads/media_items/preventive-health-care-screening-guidelines-for-people-aging-with-intellecutal-and-developmental-disabilities.original.pdf
- 3) Ohio Department of Developmental Disabilities.
<http://test.mr.state.oh.us/health/documents/HealthScreening.pdf>

Working with residents and their families

Family involvement varies widely. Some residents may not have any close relatives who are involved in their care. Some have family members who are very involved. Some have family members who have intermittent contact or involvement in their lives. This means there can be no single approach to working with family members or how family members will be involved in medical decisions for their relative. The following section encourages you to think about all the ways family members might be involved or want to be involved in medical decisions and includes tips for decision-making and communication that involve staff, residents and families.

Family roles

Parents and siblings can fill many roles. Some of the most important roles are:

Influencing formal care

- Direct and continuous involvement or partnership with medical decisions.
- Intermittent involvement in medical decisions.
- Primary contact with medical professionals.
- 'Step in' or 'take over' as needed.
- Advocate and negotiate when they don't like the way things are going.

Some family members are highly involved with their relative but less involved in medical decisions, seeing this as the staff's responsibility. These families might:

- 'Do what we can' to help out.
- Focus on maintaining family connections.
- See their role as companionship and promoting social activities (holidays, visits).
- Provide extra support (financial, transportation or other) when it is needed.

How families help with decision making

- Roles such as with health powers guardian, administrator, next of kin.
- As part of the team, including care workers, that makes service decisions.

A family member's involvement may change over time due to location, his/her own life circumstances and more. As residents age, the roles played by parents are likely to be replaced by a sibling or more distant relative. Usually siblings who take over a parent's role will have a strong and life long relationship with their brother or sister with ID. They may however have little knowledge of the disability service system, expectations of families or the legal issues that surround decision making. Staff and family can explore where support roles may be shared, such as taking the resident to appointments or activities. Some family members may embrace sharing this role and others may wish to leave these responsibilities to staff.

Building partnerships

No matter what kind of involvement a family member has in a resident's life, staff, residents and families can form partnerships to improve caregiving and decision making.

Partners in problem solving

- Families can help staff understand a resident's behavior, needs and wants.
- Families have the resident's history and can often provide important information that is not available in your records, such as involvement in traumatic events and past experience with health care.
- Staff can help families understand a resident's behavior, needs and wants. This is particularly helpful to family members who have not been intimately involved in a resident's daily life.
- Families, staff, the resident, health and social care providers can often solve problems best in a group. This is particularly important when there are serious or complex health concerns and difficult decisions to be made. Often each person knows something different about the individual or knows different techniques and resources that can help solve a problem.

Partners in decision making

- It is important to understand whether, and to what extent, the resident can be involved in making the decision for him or herself, albeit with help from others. It is vital that everyone involved support the resident making the decision whenever possible.
- Understand legal rights for the resident and their family members before making decisions (see 'Advocacy' chapter).
- Think about when it might be necessary to have someone formally assigned to an individual to help make decisions (see 'Advocacy' chapter).
- Remember that the best decisions are often made in partnership with others.
- Focus on what is best for the resident, then work together to figure out how you can achieve the goal or something close to the goal.

Challenges to building partnerships

Sharing information

Most homes do not have clear procedures for gathering and sharing information with health care providers, families and staff. Because there are many staff members looking after each resident, and family members are not seeing the resident day-to-day, important information does not always find its way to the PCP who needs the information. Consider the following scenario, demonstrating what can happen when information is not shared.

Frank's brother takes him to a PCP appointment. Frank's brother drops him off at home after the appointment with a new medication, saying to the staff 'they changed his cholesterol medication and he needs to take it once a day with food like the last one' and 'he has another appointment in three weeks to see if it's working.'

Does that feel like enough information? It might at the time, but if a staff member were to sit in on that same appointment, he/she might recognize other things that are important, such as why the decision was made (was it because it was making his stomach upset or was it because his urine test showed kidney problems?) and what side effects you should be looking for (e.g., nausea, muscle soreness). Having this information could have an important impact on how staff interact with Frank over the next few weeks and what gets reported to the PCP during the next appointment. If the staff do not know what to look for and the resident has a slightly decreased appetite or begins periods of screaming for apparently no reason (which could indicate pain), important information would be less likely to be shared with the PCP. As a consequence, Frank may suffer needlessly from undetected pain or nausea.

If a staff person attends an appointment with Frank, information about the appointment should be carefully recorded and shared with other staff.

- What happens if the staff person forgets to mention that a new medication could cause sleep problems? Frank could be up at night, even fall and injure himself if the staff didn't know to look for sleep disturbance.
- What happens if the staff person forgets to ask the PCP if there is anything that can be done to help Frank if sleep problems occur (for example, avoiding naps)? The problems with night waking could be worse than are necessary.
- Even if this information is shared with staff, what could happen when Frank goes to stay with family for the weekend and they don't know about the new sleep problems? He could forget his surroundings and have trouble finding the bathroom or fall. The family could get angry they weren't prepared or informed.

Tips for sharing information include:

- Use the Information Gathering Worksheets in this manual to record information to share with the health care provider and family prior to appointments. It will help them make the best decisions.
- Develop a form with managers/supervisors to share information with family members and for family members to take to appointments to share information with staff. Involve family members in testing and revising the form as they might have important ideas that will help them use the form effectively.
- Develop a process with managers/supervisors to share information among staff to assure that everyone has the information they need.
- Make sure you find out the side effects of any new medications. Contact the PCP or pharmacist to discuss this if you were not able to do so at an appointment. Share this information with other staff and the family.

Aging family members with health problems of their own

Many family members have cared for sons, daughters or siblings with ID throughout their lives and have difficulty seeing support staff make decisions they have previously made. They worry about the resident's well-being when they can no longer care and advocate for them. Sometimes siblings take over care as a parent ages. Remember the sibling might not have the same outlook as the parent.

Tips for this situation include:

- Understand that parents may have difficulty 'letting go' of the primary caregiver role. Assure them you will become their partner in caring for the resident and looking out for his or her best interests.
- Help the parent feel prepared by arranging for the house manager or supervisor to discuss issues such as financial plans, power of decision making, and the parent's long term wishes for the resident, including wishes about where the resident lives as the resident ages.
- Welcome siblings or other family members into the resident's life and understand they might be having difficulty understanding and assuming this new role and responsibilities.

Disagreeing on what is best for the resident

Sometimes there is tension between families and support staff. Staff might feel they know a resident better than the family. Remember that families often have a long history and family bond with the resident even though they might not have spent much time with them in recent years. Family members may feel like it is their responsibility to advocate for the resident. Many have spent a lifetime in this role and feel they should always question whether the resident is getting the best care possible, assuming they will need to 'fight' for the right decision to be made. Many have had to fight for their loved one in the past. It would be easy in this situation for the support staff to mistake this for an accusation that they do not have the resident's best interests in mind.

Tips for this situation include:

- Let family members know you value their involvement in the resident's life.
- Listen to the family carefully. Do not assume you know why family members feel a certain way or are advocating for something in particular. In a calm, understanding tone, ask them what they want to see happen and why it is important to them.
- Try to reach a shared understanding of the issue and the decision that needs to be made. For example, if there is a decision to stop medical treatment for cancer, does everyone understand the options, the pros and cons, and what that could mean over time for the resident, the staff and the family?
- Understand what decisions the family has the right to make and what decisions the resident has the right to make. Residents should be as involved as possible in decisions. See the 'Advocacy' chapter for more information.
- Think about what you would like to see happen and ask yourself why you feel that way. Is it because it is best for the resident, best for you and other staff or best for other residents? Discuss this with your manager. Sometimes together you can solve the problems that are worrying you.
- Is there a way to 'trial run' a decision, such as to try out an aged care home?

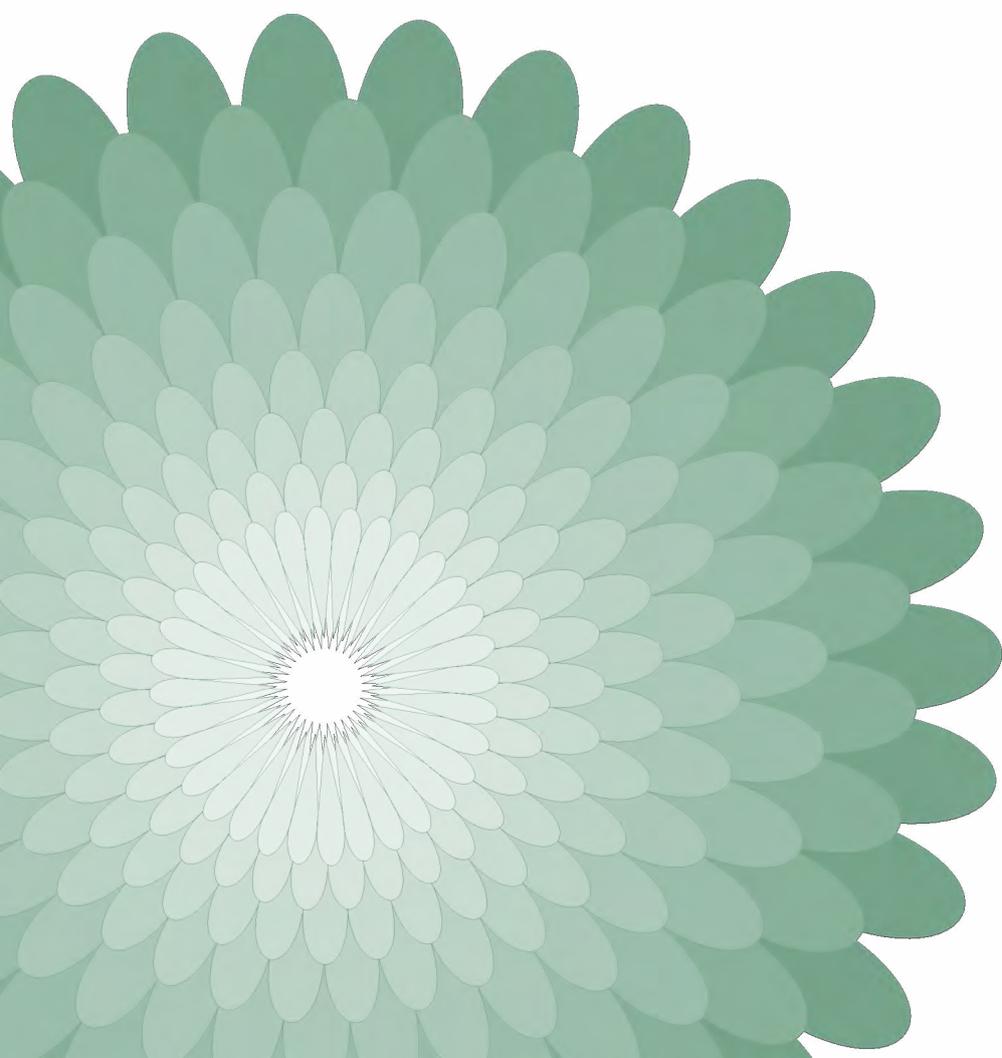
Difficult problems sometimes require quick decisions

Difficult problems, such as rapidly declining health, may push staff and families to make decisions quickly. This often means the people involved are under stress. Examples include the decision to move the resident to a nursing home, to change group homes or to undergo medical treatment.

Tips for these challenging situations include:

- Understand that everyone might be feeling stressed about the situation. This might be the reason for anger and frustration that can affect how you communicate with each other.
- Do not make decisions or confront others while you are highly stressed.
- Have an 'emergency meeting.' Meet with other staff and family to clearly define and understand the problem(s) and discuss multiple solutions. Evaluate each solution as a group. Make sure to get the resident's opinion whenever possible.
- Ask experts to help before any of you make up your minds. What is the opinion of professionals such as the resident's PCP or a dementia specialist?
- See the 'Advocacy' chapter to find resources about legal decision making.

Decision Making: Advocating for Individual Involvement



Advocating for individual involvement

Older people with intellectual disability (ID) are frequently left out of decision making about themselves, such as whether they will go to a nursing home or have a certain medical treatment. It is often assumed that they are unable to understand well enough to participate in the decision. However, people with mild to moderate ID are able to participate in many decisions. They will be able to make some decisions on their own. For other decisions, they will need assistance and support. Some decisions might even have to be made by others, but always with input from the resident with ID. How much input depends on the complexity of the decision, the capacity of the resident with ID and whether others have taken the time to help the resident understand. Several Manuals have been developed for supporting people with ID through decision-making processes.

Everyday decisions such as choosing clothing, choosing among food options, personal and intimate relationships, etc. are choices that people with ID are often able to make without support or guidance. However, health and medical care are generally seen as requiring some assistance and where it is difficult for people with ID to be entirely autonomous. For example, if an older resident with ID has health conditions which make influenza a serious risk (people with heart or lung disease), whether or not to have an influenza vaccine is a decision that should be made with strong input and encouragement from professionals. However, there are many decisions surrounding the vaccine that could be made autonomously by the resident. For example, whether to have a nurse come to the home or go to the clinic, whether to have a familiar person or a stranger give them the vaccine and who takes them to the clinic, are all decisions they should be able to participate in. Also, allowing the resident with ID to have the injection on a day when they are feeling good, not upset or ill, should be supported.

It is also important to remember that people with ID can participate in discussions about what will happen, whether it is about vaccines or other medical procedures. We know that people do much better when they are aware of what will happen, when they have had a chance to ask questions and express concerns, when they have received support for difficult experiences and when they are familiar with the place and the people involved. This is not only true for people with ID. It is true for all of us. Unfortunately, people with ID are often not included in decision-making and do not always have the opportunity to be part of the discussions. One study of people with ID who had scheduled hospital admissions found that the people who visited the hospital, met the staff and saw where they would be and who would be caring for them did much better than those without such an opportunity.

However, if a resident does require someone to provide consent on his/her behalf, then this person's details and what they can provide consent for (e.g. medical/dental procedures, sharing health information) should be clearly documented on the resident's health plan.

Determine, along with others who know the resident well:

- Which decisions the residents can make on their own.
- Which decisions they need support and guidance to make.
- Which decisions the residents can participate in, with others making the final decision.
- How to include people in decisions they are unable to make.

Promote:

- Decision making by the individual whenever possible.
- The resident's ability to make some of the decisions in every situation.
- The resident's participation in discussions, even when someone else will be making the final decision.
- Making the resident familiar with the issue, the decision and the experience.
- Gaining consent from the resident whenever possible for medical decisions.

Guidelines suggest that people with ID should be provided with information on:

- What will happen.
- The benefits to be expected.
- Who will be involved and provide the care.
- Whether there are other options and the benefits of each option.
- The amount of uncertainty about what will happen.
- What will happen if the procedure/intervention is not done.
- What support they will have during and after the procedure.
- Where they will recover and who will care for them during recovery.

Determining capacity to consent to a procedure should include the following questions:

- Does the resident understand the issue (what will happen, the benefits and risks)?
- Is the resident able to retain the information he/she has been given?
- Is the resident able to use the information when talking about the issue and making the decision?
- Can the resident express his/her opinion or communicate their decision?

Involving multiple support people

When decisions are being considered, it is always important to involve support people who are familiar with the resident, who know their daily habits, fears, preferences and modes of communicating. This may require several people, or only a few. It is unusual for any one person to have all the information needed to assist the resident with ID through the decision and the procedures. Having caring, familiar, and supportive people around will maximize the chances that problems and difficulties will be anticipated and prepared for in advance.

Having multiple support people involved can also create challenges as the people involved may not agree on what should be done or how involved the resident with ID should be. While this can be difficult, it is extremely important. High levels of conflict among support staff and other decision-makers can lead to formal processes that remove decision-making from those who are most familiar to the resident with ID. While there are legal routes that can be taken to remove decision-making from the resident with ID, this should only be considered when the involved support people have tried to agree on a decision, but have not come to a mutual understanding. Formal legal processes should be viewed by all as a *last* resort, although they are available when necessary.

Formal processes: Legal decision making capacity

When an adult with an ID is unable to make important decisions and there is a need for someone else to make these decisions, a guardian can be appointed by a county circuit court. A guardian of the estate is able to make financial decisions for an adult with an ID, while a guardian of the person is able to make lifestyle decisions (such as where a resident lives and what health care they receive). In Wisconsin, an individual or a non-profit organization (corporate guardian) may be named to serve as guardian of the estate, guardian of the person, or both. For the guardianship forms required in court proceedings, please go to: <http://www.wicourts.gov/forms1/circuit/index.htm#guard>.

- It is worth noting that people with the legal capacity to do so can themselves appoint others to make decisions for them in the event that they lose the capacity to make their own decisions. This is usually by executing a Power of Attorney for Health Care or a Power of Attorney for Finances (Durable Power of Attorney). For information on powers of attorney, please go to: <http://cwagwisconsin.org/publications/guardianship-support/>.
- If people lose some decision-making ability, the court may grant limited guardianship of the property or person so that the person retains some autonomy. For information on this please see: <http://cwagwisconsin.org/publications/guardianship-support/>.
- When it comes to the authority to make medical treatment decisions (**outside of emergency situations**), if an adult does not have the capacity to make a decision about his/her own treatment, then responsibility for making the decision falls to the Power of Attorney for Health Care or the court appointed Guardian of the Person. The court may appoint a standby guardian at the time of guardian assignment that will serve as guardian if the originally appointed guardian is unable to fulfill the duties. For information on this please see: <http://cwagwisconsin.org/publications/guardianship-support/>.

Resources:

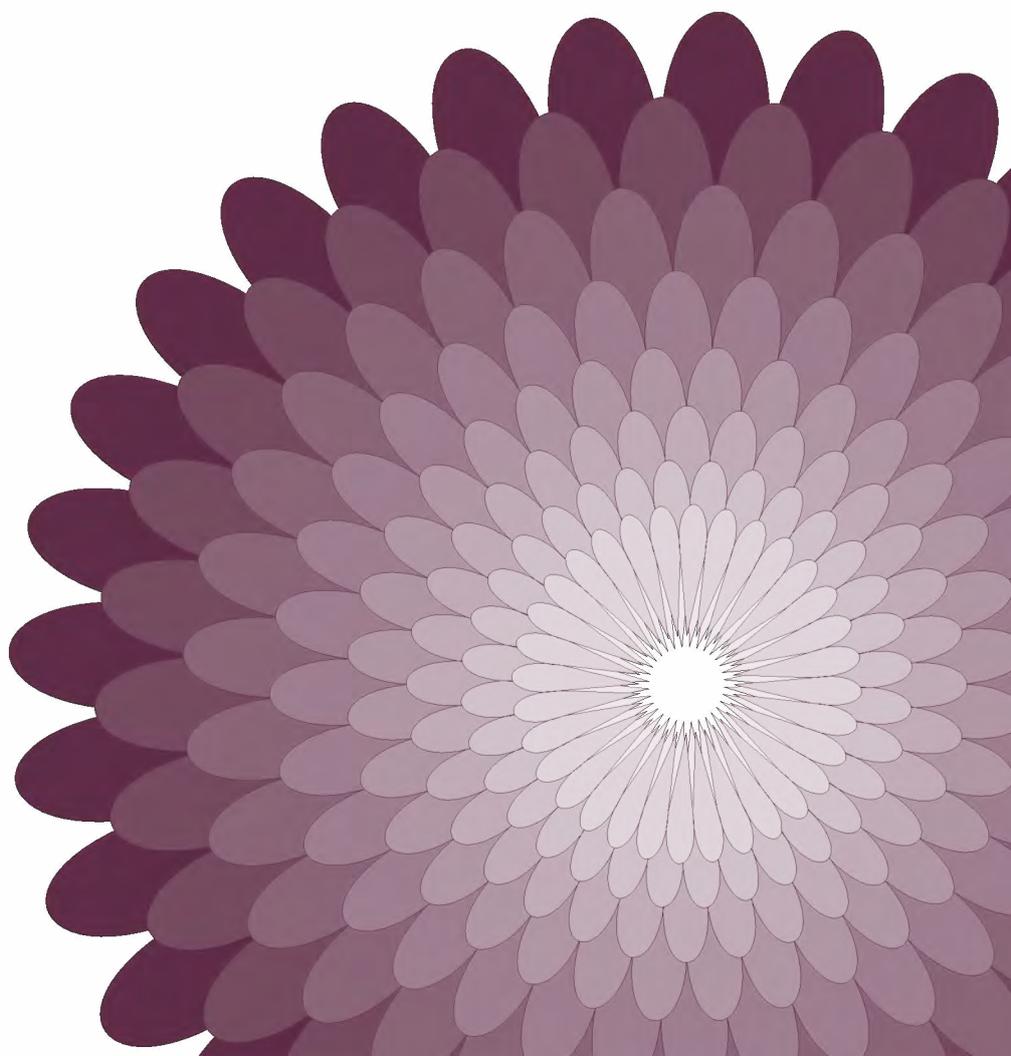
Wisconsin Guardianship Support Center (GSC), Coalition of Wisconsin Aging Groups Elder Law Center. <http://cwagwisconsin.org/elder-law-center/> Phone: (608) 224-0606. *The GSC provides advice and information relating to guardianship, protective placements, conservatorships, Powers of Attorney for Health Care, Powers of Attorney for Finances, Living Wills, and DNR orders. The GSC offers legal resources, consultation, and referrals, but it does not give legal representation or advice or assistance locating a guardian.*

Wisconsin Board on Aging and Long Term Care (BOALTC), <http://longtermcare.wi.gov>. Phone: 1-800-815-0015. *The BOALTC Ombudsman Program provides free information, education, advocacy and resources pertaining to guardianship, advance directives and other end-of-life decisions to adults over the age of 60 who reside in a long term care program in Wisconsin.*

Disability Rights Wisconsin (DRW). <http://www.disabilityrightswi.org> Madison Office Phone: 1-608-267-0214 Milwaukee Office Phone: 1-414-773-4646 Rice Lake Office Phone: 1-715-736-1232. *DRW is an independent, non-profit organization that works to protect the rights and dignity of people with disabilities throughout the state of Wisconsin. DRW provides free advocacy services from three locations across Wisconsin in Madison, Milwaukee, and Rice Lake. You should contact the office nearest to you.*

Guardianship of Adults – A Decision-Making Guide by Roy Froemming and Betsy Abramson, 1997; updated by Roy Froemming, 2010 Wisconsin Department of Health Services. <http://www.dhs.wisconsin.gov/publications/P2/p20460.pdf>.

End of Life Care



Introduction

Residents and support staff in homes often feel like 'family,' and it can be difficult to watch a family member's health decline. It can also be challenging to provide physical care, at home, at the end of life. But caring for someone at the end of life can also be a rewarding experience for staff and residents. Having familiar faces, familiar routines and people who know the resident's preferences and needs can provide a much better end of life experience for any person, but particularly for people with an intellectual disability (ID). As a staff person, this means you will often be in a position to support the resident and their friends and family through the final phase of their life, to comfort them in physical and emotional ways. This chapter will help you prepare for the needs of people at the end of life and learn about resources to help you care for the resident and cope with the experience yourself.

What is end of life?

Some people think of end of life as those few weeks before death, but it can be a much longer journey. The timeframe for end of life care is often from the moment the resident receives a terminal diagnosis. A terminal diagnosis often means a life expectancy of six months or less, but this is only an estimate.

Terminal diagnosis

Upon receiving a terminal diagnosis, everyone will have emotions and questions. Family or staff members are often told about the older resident's terminal diagnosis before the resident knows themselves. There is a common misconception that people with ID cannot understand or cope with knowing they are dying. The reality is that the resident probably knows something is very wrong based on frequency of medical appointments, emotional reactions of family and staff and physically not feeling well. They may have anxiety about this and questions they want to ask. To be prepared for this, family and staff should discuss how to talk to the resident about dying and their diagnosis.

Tips for talking to a resident with an intellectual disability about dying

- Find out what the resident knows. Ask questions specific to the health problem, for example: 'Do you know why you are in so much pain?' or 'Do you know what the lump is?'
- Find out if the resident wants to know more. Clearly ask, 'Do you want to know more about what this means or what is happening to you?' The resident might express not wanting to know any more (or might want to know everything) at first, but it is important to check back as the weeks go on. They might change their mind.
- Tell the resident you are always willing to answer their questions or find the answer to their questions.
- Give information in small pieces. Too much information can be difficult for the resident to understand and emotionally digest. For example, explain what cancer is in simple terms.

- This will often lead to more questions. If the resident doesn't ask questions, try revisiting the topic in a few days and offer new information. This might mean explaining there is not a cure for the condition and attempts to stop the condition from getting worse have not been effective.
- Think about what the resident understands and use examples to explain.
- Do not leave the resident alone after they have been given important news about their health. If they express the desire to be alone, you should respect this, but continue to check in frequently.
- Monitor changes in mood, eating habits and sleeping habits. Small behavioral changes can signal emotional distress. This may be addressed by having open conversations about questions or worries the resident has. However, prolonged problems may require medications, professional counselling or therapies. Speaking to the resident's Primary Health Care Provider (PCP) about what you are seeing (see Symptoms and Conditions sections of this Manual) is important. A hospice care professional can also help staff identify the appropriate treatments.

Planning for care

Physical, emotional and spiritual needs

One of the biggest challenges for support staff is to think about how to keep a resident in their home as long as possible. People with ID often do not cope well with unfamiliar spaces, people and routines. Staff are often their closest relationship and the house is their home. The move to a hospital or nursing home at any stage of life can cause stress, depression, isolation, anger, sadness and more. At the end of life, these issues can become even more intense and make a resident's final days, weeks or months particularly difficult. An end of life care goal should be to make the resident's final stage of life one of peace and comfort. Sometimes, however, movement to a hospital or nursing home is helpful. Sometimes this is needed to control pain. Questions that should be asked:

- Can we allocate more resources to make sure the resident has what he/she needs at end of life? This might mean active 24 hour staffing.
- Can we get staff the training needed to manage the situation as the condition worsens?
- Can we help other residents and their families understand the goal of giving the resident a good end of life by staying home?
- Do experts such as the PCP think a nursing home might be a more appropriate placement? What does the family think? Why can't they be kept at home?
- Does the resident want to stay in the home? If the resident cannot verbalize this, can he/she communicate in other ways to specify where he/she wants to be?
- Be mindful of an appropriate time to ask these questions. The resident may see these questions as you telling them they need to leave and may have strong negative reactions. Or the resident may still be coping with understanding the terminal diagnosis.

- What are the resident's spiritual beliefs? If the resident does not have an expressed religious belief, this might mean he/she does not believe or it might mean he/she has never known about religion or other options for spiritual beliefs. Hospice care teams can help a resident examine spiritual needs and beliefs. It is important not to assume someone will be comforted by the same things which comfort you. If someone is from a culture or religion you are not familiar with, it is important to seek information from the resident, family or hospice care experts.
- What are the organization's protocols for handling end of life? Do you need more help in this area? Involve health care professionals such as the PCP or hospice care team in this conversation.

General resources

It is important to develop a network of professionals to help you and the resident through the end of their life. Support staff do not need to 'do it all' by themselves.

Families

If a resident has family members who have been active in their care and life, you may find yourself forming a natural alliance with the family. You may both be going through similar emotions and have similar questions. The most important thing you can do is to sit down with the family and explore questions, make plans and document how the family wants to be involved in decision making and care throughout the process.

If the resident has family members, but these people have never been very involved with the resident's care or life, it can be challenging for staff. It is common for these family members to 'rally around the resident' who is dying. They may realize the precious time they have missed with the resident or may feel a renewed sense of obligation to help the resident through this difficult time. It is important for staff to support this family involvement, even though staff may feel anger or resentment towards those family members for not being involved sooner. It can be frustrating for staff to 'teach' the family members about their own relative. Staff often feel protective of the resident in this situation. 'Absent' family members may also not know the system. It is important for both the family and staff to discuss the goal each person has: providing the best end of life care to the resident who is dying. Forming an alliance to support each other through this experience can be the most effective way to support the resident.

PCP

The resident's PCP will be an excellent resource for answering your questions and the resident's questions. Questions that might arise include:

- What exactly is (disease)? Can you show us on a picture and use simple terms?
- Why is treatment no longer working or why isn't it an option?
- Can we keep the resident at home instead of a nursing home? If so, what do we need to plan for?
- What problems can we expect as time goes on (e.g., incontinence, pain)? Will the resident get to the point he/she cannot get out of bed? Why does that happen (pain, walking problems)? When is it likely to happen?
- When should we call you? Are there things we should be alert for?
- Are there some things that can happen for which we should call the ambulance?
- What can't we do at the home? Will there be a time the resident MUST move into a nursing home?
- What do we need to plan for in the last days? What can we expect to happen in the final days?
- Are there signs that the end is getting closer?

Hospice Care Teams

Hospice care teams are specialists in dying. They incorporate a wide range of pain management, spiritual, social and psychological care. It is never too early to contact a hospice care team once a resident has received a terminal diagnosis.

Your co-workers and supervisors

As staff, it is important to feel supported by others in the organization. Discussing your own feelings about keeping the resident in the home while he/she is dying, nervousness about death or your ability to answer residents' questions is important. Some questions you might have:

- What are my feelings about caring for someone who is dying? How do others in the organization feel?
- Does anyone here have experience with end of life? What can I expect?
- What if I can't handle it emotionally?
- What if I don't think I can handle the resident's physical needs?
- What do we do when someone no longer wants to get out of bed?
- What happens when the resident can't use the toilet themselves anymore?
- What happens when someone has pain? Does that mean he/she is dying?
- What do we do if we find someone is not breathing?

- What do we tell the other residents in the home as the resident's health starts to visibly decline?
- What do we tell the other residents if someone dies? What if they want to see the body?
- Shouldn't the resident be in a hospital or nursing home when he/she is dying?
- How can we help the resident and others in the house experience a 'good death' to the extent possible?

Conclusion

End-of-life care can be both a challenging and rewarding experience as a caregiver. Although dying often does not go according to plan, by examining your own comfort level and speaking to others in your organization, you can all be more prepared for the experience. Each individual resident will have a different reaction to their terminal diagnosis. There is no 'right way' to react or feel. It is important for staff to be flexible in their approach to exploring the diagnosis and path through the end of life. By asking for help early from professionals, family and others in your organization, you can help a resident die with peace, surrounded by those who are most important to them.

Quick tips:

- Take a terminal diagnosis slowly. Give information in small bits unless the resident asks to hear it all at once. Let the resident guide the pace of the conversation.
- Other residents may need your help understanding someone's health decline when it is happening in front of them. Communicate with the resident about what he/she would like to tell the others.
- Celebrate a resident's life and his/her contributions. Others in the home may find it comforting to participate in this both during the end of life and after the resident has died.
- 'It takes a village.' Involve any family members, even distant ones. Other staff and outside groups such as hospice care organizations can be helpful in making decisions, providing care and comforting everyone involved.

Other resources

Thinking Ahead My Way, My Choice, My Life at the End by the Coalition for Compassionate Care of California.

http://coalitionccc.org/_pdf/Thinking_Ahead_English_web.pdf

This Manual includes information about how staff can facilitate a discussion to help enable people with intellectual disabilities to be involved in their end-of-life decisions.

Supporting People with Disabilities Coping with Grief and Loss: An Easy-to-Read Booklet by Scope Victoria.

<http://www.scopevic.org.au/index.php/site/resources/supportingpeople>

This Manual includes specific information and tips for support staff.

End-of-Life Care. A guide for supporting older people with intellectual disabilities and their families by Last Passages. Last Passages is a joint project of the Volunteers of America, the University at Albany, NYSARC, Inc. and Marist College.

<http://www.albany.edu/aging/lastpassages/manual-entire.htm>

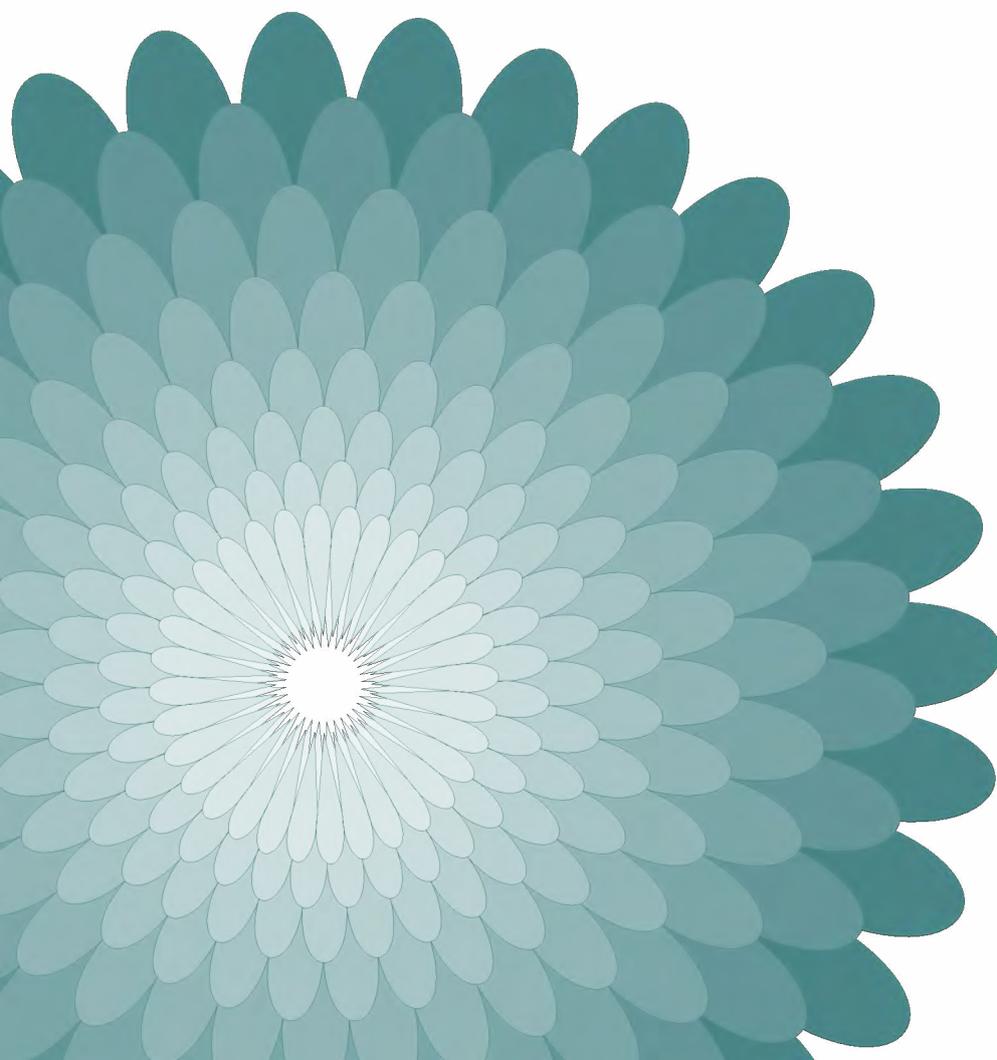
Caring Connections.

<http://www.caringinfo.org/>

This is a program of the National Hospice and Palliative Care Organization that works to improve end-of-life care. This group provides free resources and information to assist people in planning for end-of-life care.

Understanding and Communicating Common Symptoms

If you are concerned about something you observe with an older resident, here is a place to learn about the symptom and learn about what you should do next.



People with intellectual disability often have difficulty describing how they feel

This leads to delays in diagnosing and treating illness, causing needless suffering.

What can I do to help?

Just think about it: When you personally seek medical help, it is generally because you don't feel well. You feel something that is not right, not usual or bothersome. Most of the time it is not because you look different. People cannot generally know what you are feeling by looking at you. When you see your Primary Health Care Provider (PCP), you are asked many questions about what you are feeling. Think about how this would work if you were not able to tell anyone how you felt, what hurt, where it hurt, how long it had been going on or what made it feel better or worse. The PCP would have great difficulty diagnosing or treating you if this were the case. **Up to 80% of diagnoses are made from the information provided by the patient, not based on what can be seen or tests that are done.**

People with intellectual disability (ID) are often unable to tell their doctor these things. They may act differently when they are not feeling well, but may be unable to say exactly what they are feeling. The information gathering sheets are designed to fill in much of the information that the PCP needs. This will greatly increase the likelihood of making the correct diagnosis and obtaining the right treatment for the resident. **You are vital to making that happen!**

What is a symptom?

A symptom is something a staff person might notice about a resident that seems unusual or troubling. It might be something small, such as the resident waking up more frequently during the night or wincing in pain when getting up from the table at breakfast. It might be something more obvious such as aggressive behavior, screaming or weight loss. **It is important for staff to understand the importance of recognizing and reporting these symptoms.**

Aggression

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

Signs that someone may become aggressive include:

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

What are possible causes of aggression?

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

Physical conditions

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

Mental conditions

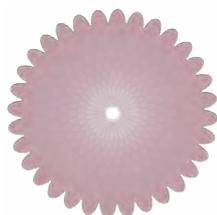
- depression
- dementia

Situational conditions

(may not be health related)

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

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



If this is an emergency, follow proper emergency procedures for your workplace. If this is not an emergency, one important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from

other staff and those close to the resident and discuss with your house manager/supervisor how to proceed.

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

Who can I call for help after the Primary Health Care Provider?

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

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

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

What are my resources?

Dealing with combative behavior. Wellington Parc.

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

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

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

Behaviour Support Plans. Office of the Senior Practitioner. (Australia).

http://www.dhs.vic.gov.au/_data/assets/pdf_file/0008/608579/osp_bsp_practice_guide_2007.pdf

Understanding Intellectual Disability and Health. Behavior Management.

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

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

<http://www.racgp.org.au/download/documents/AFP/2011/April/201104woods.pdf>

Related sections of Manual

- Depression
- Resistance to Care

Information Gathering Worksheet: Aggression

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

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

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Breathing difficulty

Sudden difficulty breathing or a sudden worsening of breathing difficulty is an emergency. If this happens, follow your organization's emergency procedures.

Some people are chronically 'short of breath.' They have noisy breathing, feel like they are having difficulty getting enough air when they exert themselves and are very limited in physical activity. Having trouble breathing or feeling short of breath is not a normal part of aging. It can be extremely frightening as well. Chronic breathing trouble can be caused by many different illnesses. These are all more common in older people, particularly people who have smoked.

What are possible causes for breathing difficulty?

Trouble breathing can be a sign of:

- Emphysema which is also called Chronic Obstructive Pulmonary Disease (COPD).
- Asthma.
- Heart failure.
- Pulmonary fibrosis.
- Lung cancer.

Each of these is a serious medical issue and needs to be treated. However, even with treatment, the resident will continue to have some difficulty breathing or shortness of breath. Breathing difficulty can be progressive, increasing over time, or there can be more sudden increases in breathing difficulty. **Even when people have one of these diagnoses, any sudden increase in breathing difficulty needs quick medical attention.**

Some other possible, more sudden, causes of breathing difficulty are:

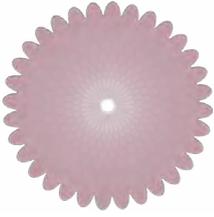
- Infections, such as pneumonia or tuberculosis.
- A blood clot in the lung, known as a pulmonary embolism.
- Heart attack.
- Irregular heart beat or rhythm (also called arrhythmia).
- Anxiety.
- Choking.
- Collapsed lung.

Observable signs of breathing trouble that need immediate medical attention include:

- Difficulty speaking.
- Feeling of heaviness or pain in the chest.
- High pitched sounds heard while breathing, known as wheezing.
- New appearance of unusual movement of the chest or abdomen while breathing.
- Blue lips or fingernails.

Other indications of trouble breathing may be less noticeable. Someone who is experiencing trouble breathing may try to avoid situations that cause shortness of breath by decreasing activities and staying in an upright position, even to sleep. Other signs of trouble breathing are confusion, light-headedness, dizziness or weakness. These are a result of not getting enough oxygen while breathing.

What to do if you notice trouble breathing



If the difficult breathing is sudden, or worsening, this is an emergency. Follow your organization's emergency procedures. If the resident has had difficulty breathing, there is often a treatment or medication that can be taken to provide relief. If this is an ongoing problem, talk to the PCP about how you can support the resident.

Who can I call for help after the Primary Health Care Provider?

American Lung Association.

<http://www.lung.org>

1-800-586-4872

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

What are my resources?

COPD. American Lung Association.

<http://www.lung.org/lung-disease/copd/>

Breathing Problems. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/breathingproblems.html>

COPD. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/copd/whatiscopd/01.html>

Related sections of Manual

- Pain
- Heart disease
- Hypertension
- Lung disease
- Obesity
- Stroke

Information Gathering Worksheet: Breathing Difficulty

If a resident is experiencing breathing problems (see previous page), please complete this worksheet to assist with information gathering in order to present helpful data to the medical professional.

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| When did you first notice the change? | | |
| Is the trouble breathing new? Has it changed recently? Has it been assessed by a medical professional? | | |
| Do you notice any abnormal movement of the chest, abdomen or muscles in the neck while the resident is breathing? | | |
| Are there any hives or a rash? | | |
| Do you hear a high-pitched sound while the resident is breathing? | | |
| Is the resident coughing? Is the resident coughing up any mucus or blood? | | |
| Does the resident have a fever? | | |
| Is the breathing trouble constant or does it come and go? | | |
| Does the breathing trouble occur at certain times of the day? | | |
| Does the breathing trouble occur when the resident is at rest or only during periods of activity? Is it during a specific activity? | | |
| Were any new medications added or dosages of previous medications changed recently? | | |
| Does the resident appear confused, dizzy, or weak? | | |
| Are the resident's lips or fingertips a bluish color? | | |
| Does the resident have a history of anxiety? | | |

Information Gathering Worksheet: Breathing Difficulty

| Information to Collect | Yes/No | Observations/Comments |
|--|--------|-----------------------|
| Is the resident having difficulty sleeping? | | |
| Has the resident been sleeping upright? | | |
| Does the resident have any swelling in their feet or legs? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Choking/Swallowing Difficulty (Dysphagia)

Swallowing difficulties occur for many reasons and increase with age. Normal swallowing requires over 50 pairs of muscles and nerves to work together. Problems in any of these can lead to swallowing difficulty, increasing the likelihood of choking, which can be life threatening.

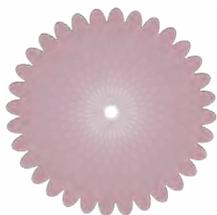
Some of the things which can happen as a consequence of swallowing problems are:

- Choking.
- Regurgitation of food.
- Lack of interest in food.
- Avoiding certain foods.
- Decreased quality of life.
- Drooling.
- Accumulation of food/fluid in lungs, leading to chest infection.

What are some possible causes for swallowing difficulty?

- Stroke.
- Tumors of the esophagus.
- Past treatment for cancer.
- Aging muscles in food tube (esophagus).
- Scars from esophageal reflux (damage to the esophagus from stomach acid).
- Cerebral palsy.
- Medication side effects.
- Parkinson's disease.

What should I do if I am noticing a resident is having difficulty swallowing?



Choking can be an emergency. Follow your organization's emergency procedures. If this is not an emergency, one of the most important things you can do is to collect and document what you are seeing. The information you collect will assist health practitioners to determine the cause and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet with input from other staff and those close to the resident and discuss with your house manager/supervisor how to proceed.

- If the swallowing problem has already been assessed by a professional, and there is no change, bring the worksheet to your house manager/supervisor to discuss options for managing the choking.
- If the problem is new, increased in frequency or has not been assessed by a medical professional, please notify the resident's PCP and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Speech pathologists may be able to assist.

Contact the PCP or ADRC (see 'Resources' section of this Manual) to inquire about these services.

What are my resources?

American Speech-Language-Hearing Association.

<http://www.asha.org/slp/clinical/dysphagia/>

Barriers to healthy eating (scroll down for swallowing difficulties). UMass-Amherst.

http://www.morethanameal.info/manual/chapter3/chap3_sec13.html

Difficulty swallowing. Mayo Clinic.

<http://www.mayoclinic.com/health/difficulty-swallowing/DS00523>

Swallowing disorders. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/swallowingdisorders.html>

Related sections of Manual

- Stroke
- Parkinson's Disease

Information Gathering Worksheet: Choking/Swallowing Difficulty

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| Did you observe any signs of swallowing difficulties, e.g. cough, dribbling, avoidance of certain foods, apparent discomfort with swallowing? | | |
| Is the resident having a difficult time eating or drinking? What kinds of foods are difficult (liquids, cereals, vegetables, meats, etc.)? | | |
| Is the resident having a difficult time swallowing pills? | | |
| Does it help to change the texture of food or cut into smaller bites? | | |
| Has a medication recently been added or dosage changed? | | |
| Does the resident seem to have difficulty getting food down? | | |
| Has the resident had any complaints about pain in his/her mouth or anywhere else? | | |
| If this resident wears dentures, have they been checked recently? Do they fit properly? | | |
| Has the resident's walking style/ability (gait) changed? How? | | |
| Has the resident's speech changed? How? | | |
| Has the resident had recurrent chest infections? | | |

Resident Name:
 Staff Name(s):
 Date Reviewed:
 Next Steps:

Confusion

Confusion is not a normal part of aging. It may be caused by medical problems and is often treatable and reversible. Missing the underlying cause leads to long delays in treatment and sometimes permanent damage. Confusion can present itself in many ways such as:

- Increased fatigue, sleepiness, disinterest in normal activities, low mood.
- Restlessness, agitation, aggression or lack of cooperation.
- General decline in abilities such as eating, dressing, toileting, transferring, personal hygiene.
- Loss of control of bowel or bladder.
- Sleep disturbances such as night awakenings.
- Seeing or hearing things that are not present.
- Memory problems such as not recognizing familiar people, places, things or how to do something.
- Difficulty speaking or communicating.
- Antisocial behavior.

What are possible causes for confusion?

There are several medical problems that can cause confusion. Many of these problems can be treated and the confusion can be reversed. Although confusion is a symptom of dementia, many other causes of confusion should be considered first. Some causes of confusion are:

- Delirium (sudden appearance of confusion related to medical causes such as infection).
- Depression.
- Urinary tract infection.
- Pain.
- Pneumonia.
- Medication side effects.
- Medication errors.
- Dehydration (excessive sweating, failure to drink enough fluids, diarrhea).
- Changes in vision or hearing.
- Dementia (slow, progressive onset of confusion).
- Recent hospitalization.

What should I do If I am noticing confusion in a resident?

If this is an emergency, follow proper emergency procedures for your workplace. After determining that this is not an emergency, one important thing you can do is to collect information and document your observations. This can assist their PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering

Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident and discuss with your house manager/supervisor how to proceed.

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

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

Memory Clinic and WAI-Affiliated Dementia Diagnostic Clinic Network

Diagnostic clinics work to promote the early diagnosis and treatment of dementia and Alzheimer's disease. The clinics address concerns of people experiencing changes in memory, behavior, or thinking skills as well as those who support them. The following list of dementia clinics may be found at <http://www.wai.wisc.edu/clinics/cliniclist.html>. Clinics noted with an * are part of the WAI-Affiliated Dementia Diagnostic Clinic Network. The network clinics follow common guidelines and have staff that receive training/observation time or additional guidance from the WAI and the UW Health Memory Assessment Clinic. More information about the WAI-Affiliated Dementia Diagnostic Clinic Network may be found at <http://www.wai.wisc.edu/clinics/networkoverview.html>.

| | | |
|----------------|---|---------------------------------|
| Adams County | Moundview Hospital and Clinic Memory Assessment Clinic* Friendship | 608-839-8360 |
| Ashland County | Essentia Health – Ashland Memory Clinic* Ashland | 715-685-7500 |
| Barron County | Marshfield Clinic Memory Disorders Clinic-Rice Lake* Rice Lake http://www.marshfieldclinic.org | 866-333-1996 or 715-858-4444 |

| | | |
|-----------------|--|---------------------------------|
| Brown County | Prevea Health Center-East De Pere Site* De Pere | 920-496-4700 |
| | Prevea Health Center-Green Bay Site* Green Bay | 920-496-4700 |
| Chippewa County | Marshfield Clinic Memory Disorders Clinic-Chippewa Falls* Chippewa Falls http://www.marshfieldclinic.org | 866-333-1996 or 715-858-4444 |
| | | |
| Dane County | UW-Health Neurology Memory Disorders Clinic* Madison | 608-263-5442 |
| | Dean Memory Assessment Clinic* Madison http://www.deancare.com/medicalservices/neurology/memory-assessment-center/ | 608-260-3425 |
| | Geriatric Research, Education, and Clinical Center Memory Assessment/Dementia Clinic William S. Middleton Veterans Hospital, Madison | 608-280-7000 or 608-280-7061 |
| | UW-Health Clinics Geriatric Assessment Clinic (East) Madison | 608-265-1210 or 800-323-8942 |
| | UW-Health Hospital and Clinics Memory Assessment Clinic* Madison | 608-263-7740 |
| | | |
| Dodge County | Memory Care Clinic* Beaver Dam Community Hospital, Beaver Dam | 920-887-4321 |
| Door County | Ministry Memory Clinic Door County* Sturgeon Bay www.dcmemoryclinic.org | 800-864-6179 |

| | | |
|-------------------|--|---------------------------------|
| Eau Claire County | Marshfield Clinic Memory Disorders Clinic-Eau Claire* Eau Claire www.marshfieldclinic.org | 866-333-1996 or 715-858-4444 |
| | Mayo Clinic Health System Memory Care Clinic* Eau Claire www.mayoclinic.org | 715-838-1900 |
| | UW Health-Eau Claire Family Medicine Clinic* Eau Claire | 715-839-5175 |
| Grant County | Southwest Health Center Memory Diagnostic Clinic* Platteville | 608-348-3656 |
| Green County | Monroe Clinic Memory Diagnostic Center* Monroe | 608-324-2200 |
| Jefferson County | Fort Healthcare Memory Center* Fort Atkinson | 920-568-5334 |
| Juneau County | Mile Bluff Medical Center Memory Assessment Clinic* Mauston | 608-847-9701 |
| Kenosha County | Aurora Senior Services Kenosha | 262-948-6648 |
| La Crosse County | Gunderson Lutheran Memory Disorders Clinic* La Crosse | 608-782-7300 |
| | Mayo Clinic Health System Dementia Program* La Crosse www.franciscanskemp.org | 608-791-9505 |

| | | |
|------------------|--|---------------------------------|
| Manitowoc County | Manitowoc Area Memory Assessment Center* Manitowoc | 920-320-8600 |
| Marathon County | Aspirus Memory Clinic* Wausau | 715-847-2004 or 866-236-1573 |
| Milwaukee County | Center for Senior Health and Longevity* Aurora Sinai Medical Center, Milwaukee www.aurorahealthcare.org | 414-219-7300 |
| | Latino Geriatric Center Memory Center* Milwaukee | 414-649-2855 |
| | Memory Disorders Clinic at Froedtert & Medical College of Wisconsin* Froedtert Memorial Lutheran Hospital, Milwaukee | 414-805-8710 |
| | Milwaukee Health Services* MLK Heritage Health Center, Milwaukee | 414-372-8080 |
| | Senior Health Memory & Mood Disorders Clinic (Geriatric Memory Disorders Clinic)* Froedtert Hospital, Milwaukee | 414-805-6644 |
| | Wheaton Franciscan Memory Diagnostic Center* Milwaukee http://www.wai.wisc.edu/clinics/wheatonfranciscan-milwaukee.html | 414-357-5233 |
| | Wheaton Franciscan Memory Diagnostic Center* Wauwatosa http://www.wai.wisc.edu/clinics/wheatonfranciscan-wauwatosa.html | 414-874-1201 |

| | | |
|-------------------|--|---------------------------------|
| Oneida County | Northern Wisconsin Memory Diagnostic Center Rhineland Regional Medical Group, Rhineland | 715-361-4880 |
| Outagamie County | The Memory Care Center at Neuroscience Group, a Collaboration with St. Paul Elder Services* Neenah | 920-725-9373 |
| Racine County | Aurora Senior Services Racine | 262-884-4138 |
| | Wheaton Franciscan Comprehensive Memory Care* Racine | 262-687-8322 |
| Richland County | Richland Area Geriatric Assessment Clinic* Richland Center | 608-647-6161 |
| Rock County | Janesville Geriatric Assessment Center* Janesville | 608-755-7960 |
| | SAM-C (Stateline Area Memory Clinic)* Beloit | 608-364-1288 |
| Sauk County | Richland Area Geriatric Assessment Clinic Reedsburg* Reedsburg | 608-647-6161 |
| Washburn County | Spoooner Health System Memory Clinic* Spoooner | 715-635-2170, ext. 442 |
| Washington County | Memory Assessment Center* West Bend Clinic, West Bend | 262-334-9218 or 800-825-0513 |

| | | |
|-----------------|---|---------------------------------|
| Waukesha County | Center for Senior Health and Longevity at Summit* Aurora Summit Medical Center, Oconomowoc www.aurorahealthcare.org | 262-434-5000 or 414-219-7300 |
|-----------------|---|---------------------------------|

| | |
|--|--------------|
| Senior Health Center* Waukesha Memorial Hospital, Waukesha www.prohealthcare.org | 262-928-7898 |
|--|--------------|

| | |
|---|--------------|
| Senior Health Memory and Mood Disorders Clinic* Menomonee Falls | 262-253-2450 |
|---|--------------|

| | | |
|-------------|--|---------------------------------|
| Wood County | Memory Disorders Clinic Marshfield Clinic Marshfield | 715-387-5350 or 800-782-8581 |
|-------------|--|---------------------------------|

| | | |
|----------|--|--------------|
| Illinois | Rush Alzheimer's Disease Center Chicago, IL | 312 942-3333 |
|----------|--|--------------|

| | | |
|----------|--|---------------------------------|
| Michigan | Northstar Health System Memory Clinic* Crystal Falls, MI | 906-875-4486 |
| | Upper Michigan Memory Diagnostic Center * Marquette, MI http://www.memorylosshelp.org/SitePages/Home.aspx | 888-886-4644 or 906-225-3993 |

| | | |
|-----------|---|--------------|
| Minnesota | Duluth Clinic-Downtown Duluth, MN http://www.essentiahealth.org/EssentiaHealthDuluthClinic2ndStreetBuilding/FindaClinic/173.aspx | 218-786-1216 |
| | The Mayo Alzheimer's Disease Research Center Rochester, MN http://mayoresearch.mayo.edu/mayo/research/alzheimers_center/ | 507-284-1324 |

What are my resources?

Medline Plus. Confusion.

<http://www.nlm.nih.gov/medlineplus/ency/article/003205.htm>

Forgetfulness: Knowing When to Ask for Help. National Institute on Aging.

http://www.nia.nih.gov/sites/default/files/forgetfulness_0.pdf

Understanding Memory Loss. National Institute on Aging.

<http://www.nia.nih.gov/sites/default/files/UnderstandingMemoryLoss.pdf>

Planning Guide for Dementia Care at Home: A Reference Tool for Case Managers. Alzheimer's Association - South Central Wisconsin Chapter, the Wisconsin Alzheimer's Institute and the Wisconsin Bureau of Aging and Long Term Care Resources, Division of Disability and Elder Services, Department of Health and Family Services.

<http://www.dhs.wisconsin.gov/aging/dementia/homecare.htm>

Related sections of Manual

- Vision Loss
- Obesity
- Dizziness
- Hearing Changes
- Delirium
- Diabetes
- Dementia
- Dehydration
- Aggression

Information Gathering Worksheet: Confusion

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|---|
| Is the resident showing any signs of confusion (see list on previous page)? | | |
| If yes, did the change happen recently? (within the last 1-5 days?) | | |
| When did you first notice the change? | | |
| Are the symptoms new or different? Has confusion ever been assessed by a medical professional? | | |
| Is the confusion worse at any particular time (such as during the day or night)? | | |
| Has the resident been urinating more or less frequently than normal? | | |
| Diarrhea/ loose stools? Constipation? | | |
| Sleeping more than usual? Restless nights/ night awakenings? | | |
| Decreased appetite? Difficulty swallowing? | | |
| New medications added recently? Recent dosage changes on medications? | | |
| Difficulty breathing? New cough? | | |
| Recent fall? | | |
| Recent hospitalization? | | |
| Pain complaints (grimacing, rubbing, moaning, limping, restlessness)? | | |

Resident Name:
 Staff Name(s):
 Date Reviewed:
 Next Steps:

Constipation

Constipation is a very common problem that occurs more frequently in older people. While constipation is often related to diet and exercise, it is sometimes caused by serious medical problems that need to be treated. Constipation can take many forms:

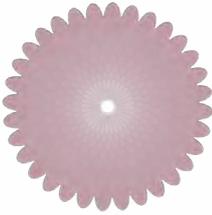
- Stool is too hard and lumpy.
- Stool is too small.
- Difficulty having a bowel movement or need to strain to have a bowel movement.
- Infrequent bowel movement (less than what is usual for the resident).
- Feeling of incomplete bowel movement.
- Feeling of blockage and unable to have bowel movement.
- Sometimes need to use finger to manually take out the stool from rectum.

What are some possible causes for constipation?

- Poor nutrition and food intake.
- Frequent use or misuse of laxatives.
- Inadequate intake of fluid and fiber.
- Medications that may cause constipation include most pain medications and some types of antihistamines (medications to treat allergies), antispasmodics (medications to treat muscle spasms or seizures), antidepressants (medications to treat depression), antipsychotics (medications to treat anxiety or other psychiatric conditions), iron supplements, antacids (medications for treating excessive acid problems in stomach and esophagus) and antihypertensive (medications to treat high blood pressure).
- Difficulty chewing food well because of poor teeth, gum, or mouth condition.
- Lack of physical activity.
- Ignoring the urge to have a bowel movement or delaying until later can result in diminished urge to have a bowel movement.
- Change in lifestyle or routine, such as travel, moving into a new place.
- Pain related to having bowel movement such as haemorrhoids can lead to fear of having a bowel movement.
- Diseases that can cause constipation such as diabetes, multiple sclerosis, spinal cord injury, Parkinson's disease, irritable bowel syndrome or low thyroid (hypothyroidism).

For some people there may be one cause for constipation, but for most people there is more than one cause. Medications are a very common cause of constipation because many medications slow down digestion. When people must take medications that cause constipation, it can become a challenging, chronic problem. Diet and exercise are often effective ways to treat chronic constipation. Sometimes other assistance is required. However, **chronic use of laxatives should be avoided as it often causes constipation.** The body can become dependent on laxatives, making the problem worse.

What should I do if I am noticing a constipation problem?



One of the most important things you can do is to collect and document what you are seeing. The information you collect will assist health practitioners to determine the cause and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the constipation has been assessed by a practitioner in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for helping the resident with constipation be more comfortable and prevent more serious problems
- If the constipation is new, increased in frequency or severity or has not been assessed by a professional, please notify the resident's PCP and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lc/lc/adrc/customer/adrccontactlist.pdf>

What are my resources?

What I Need to Know About Constipation. National Institute of Diabetes and Digestive and Kidney Disease.

http://digestive.niddk.nih.gov/ddiseases/pubs/constipation_ez/constipation.pdf

Constipation. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/constipation.html>

Concerned About Constipation? National Institute on Aging.

http://www.nia.nih.gov/sites/default/files/concerned_about_constipation.pdf

Constipation. Mayo Clinic.

<http://www.mayoclinic.com/health/constipation/DS00063>

Related sections of Manual

- Aggression
- Confusion
- Dehydration
- Pain
- Weight gain
- Weight loss
- Cancer
- Diabetes
- Parkinson's Disease
- Stroke

Information Gathering Worksheet: Constipation

If a resident is showing any signs of constipation, please complete this worksheet to assist with information gathering in order to present helpful data to the medical practitioner.

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| Is the resident having difficulty with bowel movements? | | |
| Does the resident strain when having a bowel movement? | | |
| Is the resident having stomach cramps? | | |
| What does the stool look like? Is it hard, lumpy, small? Black? | | |
| Is there any blood in the stool? How much? | | |
| Is this a new condition? | | |
| When did the resident or you first notice the change? | | |
| How frequent are his/her bowel movements? How many bowel movements does he/she have in a day? A week? | | |
| Is the resident eating differently than in the past? Type or amount of food? | | |
| What are his/her typical meals? | | |
| How much fluid does he/she drink in a day? | | |
| Is he/she able to chew food well? | | |
| If not, what's the reason? Tooth problem, gum problem, sore mouth, poorly-fitting dentures? | | |
| Any recent change in routine, such as moving to a new place, new room, travelling in general or recent hospitalization? | | |
| Is he/she on medications for pain, depression, anxiety, other psychiatric conditions, allergies, high blood pressure or is he/she on chemotherapy? List any new medication | | |

Information Gathering Worksheet: Constipation

| Information to Collect | Yes/No | Observations/Comments |
|---|--------|-----------------------|
| Does he/she have other medical conditions such as diabetes, hypothyroidism, gastrointestinal diseases, Parkinson's disease, spinal cord injuries, any type of cancer or history of stroke? (list) | | |
| Has the resident's physical activity changed recently? | | |
| Has the resident had recent weight change? | | |
| Is the resident having fever, weakness, fatigue? | | |
| Has the resident had recent mood or behavioral changes? Depressed, anxious, aggressive, confused? | | |
| Has the resident had pain complaints (grimacing, rubbing, moaning, restlessness)? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Dizziness

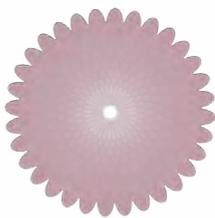
There are many sensations associated with dizziness. Sometimes dizziness is feeling faint, light-headed, 'woozy,' unsteady or simply just 'funny.' Sometimes people feel like the room is spinning or they are spinning. This spinning sensation is sometimes referred to as vertigo. It can be difficult to tell if someone is feeling dizzy unless they can tell you about the sensations they are feeling. However, if a person is dizzy, they will appear unsteady or unbalanced and may grab for nearby objects to hang on to. When someone is dizzy, particularly when they are already unsteady, they are at risk of falling.

What are possible causes for dizziness?

Dizziness is quite common and there are a number of reasons why it may occur. Some of these causes include:

- Standing up too fast.
- Benign positional vertigo is a condition where changes in head position cause lightheadedness and/or dizziness.
- Ear infections.
- Allergies.
- Side effect of medications.
- Abnormal heart rhythm.
- Poor circulation from chronic illnesses such as arteriosclerosis or heart disease.
- Anemia.
- Low blood pressure, especially in the presence of dehydration, diarrhea, vomiting, or bleeding.
- Straining while coughing or trying to have a bowel movement.
- Low blood sugar.
- Heart attack.
- Stroke.

What to do if a resident is experiencing dizziness



It is important to pay attention to any symptoms associated with the dizziness. **If the resident has sudden dizziness with shortness of breath, chest pain or pressure, weakness in an arm or leg, change in vision or speech, drooping of facial features or a change in overall awareness, this is an emergency. Follow your organization's emergency procedures.** If this is not an emergency, one important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the dizziness has already been assessed by a medical professional in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for helping the resident with the dizziness.

- If the dizziness is new, changing, has increased in frequency or has not been assessed by a medical professional, please notify the resident's PCP and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcicare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Balance Problems. American Geriatrics Society.

<http://www.healthinaging.org/aging-and-health-a-to-z/topic:balance-problems/>

Dizziness: What to Ask. American Geriatrics Society.

<http://www.healthinaging.org/resources/resource:balance-problems-what-to-ask/>

Related sections of Manual

- Confusion
- Constipation
- Falls and difficulty walking
- Pain
- Dehydration
- Diabetes
- Delirium
- Heart disease
- Hypertension
- Stroke

Information Gathering Worksheet: Dizziness

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| Is the dizziness new, more intense or more frequent than it was before? | | |
| Has the resident already seen a PCP or other professional for this problem? | | |
| If this is new, when did you or someone else first notice it? | | |
| If it has recently worsened, when did you first notice a worsening of the problem? | | |
| How does the resident describe the dizziness? | | |
| Have you noticed the resident walking unsteadily or using objects to keep balanced? | | |
| Is the dizziness constant or does it come and go? | | |
| Does anything help to relieve the dizziness? | | |
| What is the resident usually doing when dizziness occurs? | | |
| Does the resident have ringing of the ears? | | |
| Has the resident had a cold or flu recently? | | |
| Does the resident have ear pain? | | |
| Does the resident have a headache or history of migraines? | | |
| Does the resident have a fever? | | |
| Did the resident have a recent or prior fall that could have led to injury to the head or face? | | |

Information Gathering Worksheet: Dizziness

| Information to Collect | Yes/No | Observations/Comments |
|---|--------|-----------------------|
| Does the resident ever complain of pain in their chest, arm or neck while feeling dizzy? | | |
| Does the resident have an irregular heartbeat, either fast or slow? | | |
| Were any new medications added or dosages of previous medications changed recently? | | |
| Has the resident been experiencing vomiting, diarrhea, bleeding or low fluid intake recently? | | |
| Does the resident have allergies? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Falls and Difficulty Walking

It is not normal for people to fall, regardless of their age. It may be normal for people to have increased difficulty walking as they age. However, changes in walking ability should be examined carefully as there may be underlying causes that need to be treated. Walking ability can often be improved with exercises. Difficulty walking can take many forms such as:

- Slowed walking.
- Unsteady walking.
- Pain while walking.
- Loss of balance.
- Limping.
- Shuffling.

Difficulty walking can interfere with social activities. Walking problems may be a symptom of an underlying medical problem. Even more significant is the risk of falling that is associated with any kind of walking difficulty.

What are possible causes for walking difficulties?

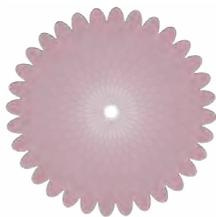
- Poor balance.
- Ear infections.
- Dizziness.
- Poor vision.
- Foot problems.
- Poorly fitting shoes.
- Environmental hazards.

Sometimes falls are caused by walking difficulties but sometimes falls are related to other problems. Falls look different depending on the cause. For example, a fall caused by heart problems is quite different than a fall caused by balance problems.

What are some of the other causes for falls?

- Standing up too quickly (orthostatic hypotension).
- Medication side effects (very common).
- General weakness.
- Heart problems.
- Stroke.
- Seizure.

What should I do if I am noticing that a resident is having difficulty walking?



If a resident falls, is injured, loses consciousness, becomes incontinent, confused or hits their head, follow your organization's emergency protocols. One of the most important things you can do is to collect information about the fall and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at

the end of this section. Please complete the worksheet, with input from other staff and from those close to the resident. Discuss with your house manager/supervisor how to proceed.

- If the falls or difficulty walking have already been assessed by a medical professional in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for preventing future falls.
- If the falls or difficulty walking are new, increased in frequency or have not been assessed by a medical practitioner, please notify the resident's medical practitioner of the issues and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lc/lc/adrc/customer/adrccontactlist.pdf>

Stepping On. 1-608-243-5690

<http://wihealthyaging.org/stepping-on>

Sure Step. 1-608-243-5690

<http://wihealthyaging.org/sure-step>

What are my resources?

Falls Prevention. American Geriatrics Society.

<http://www.healthinaging.org/aging-and-health-a-to-z/topic:falls/>

What are ways to prevent falls and fractures? National Institutes of Health.

http://www.niams.nih.gov/Health_Info/Bone/Osteoporosis/Fracture/prevent_falls_ff.asp

Check for Safety: A Home Fall Prevention Checklist for Older Adults. Centers for Disease Control and Prevention.

http://www.cdc.gov/HomeandRecreationalSafety/pubs/English/booklet_Eng_desktop-a.pdf

Registered Nurses' Association of Ontario.

<http://ltctoolkit.rnao.ca/resources/falls>

POSTER: What to do after a fall Public Health Agency of Canada.

http://www.phac-aspc.gc.ca/seniors-aines/publications/public/injury-blessure/falls_poster-chutes_affiche/assets/pdf/WhatToDoAfterFall_QueFaireCasChute-eng.pdf

Home Safety Tips for Older Adults. American Geriatrics Society.

<http://www.healthinaging.org/resources/resource:home-safety-tips-for-older-adults/>

Falls Prevention. Mayo Clinic.

<http://www.mayoclinic.com/health/fall-prevention/HQ00657>

About Falls. National Institute of Health.

<http://nihseniorhealth.gov/falls/aboutfalls/01.html>

Balance Problems. National Institutes of Health.

<http://nihseniorhealth.gov/balanceproblems/aboutbalanceproblems/01.html>

Related sections of Manual

- Vision Loss
- Stroke
- Parkinson's Disease
- Obesity
- Heart Disease
- Hearing Changes
- Diabetes
- Dementia
- Dehydration
- Pain
- Foot Problems
- Swelling

Information Gathering Worksheet: Falls and Difficulty Walking

If a resident has fallen or is having difficulty walking (see previous page), please complete this worksheet to assist with information gathering in order to present helpful data to the medical practitioner.

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|--|
| Have you noticed any change in the way the resident is walking? | | |
| When did you first notice the change? | | |
| Have others noticed any change? (other staff, family, the resident) | | |
| Has the walking difficulty changed since you first noticed it? If yes, how has it changed? | | |
| Has he/she ever had this problem before? If yes, what was done? | | |
| Does he/she seem to have difficulty lifting his or her feet? | | |
| Have there been any other recent changes in behavior, activities, mood, abilities? | | |
| Is the resident taking any new medications? | | |
| Has the resident fallen? If so, how often? | | |

If Someone Has Fallen:

| | | |
|---|--|--|
| Did someone see the fall? If yes, did he/she seem to drop to the ground quickly? | | |
| When the resident fell, was there time for him/her to break his/her fall or try to stop the fall? | | |
| Did the resident sustain an injury during the fall? | | |
| Did the fall happen right after the resident rose from a sitting position? | | |
| Did he/she seem to trip on something before falling? | | |
| Is there a pattern in the time of day, location, activity related to the fall(s)? | | |
| Has the resident fallen more than once? | | |

Information Gathering Worksheet: Falls and Difficulty Walking

| Information to Collect | Yes/No | Observations/Comments |
|--|--------|-----------------------|
| Did he/she lose control of bowel or bladder during or after the fall? | | |
| Do his/her shoes fit properly? | | |
| Do his/her feet have any sores or redness? | | |
| Is the resident limping or favoring one side? | | |
| Have any new medications been added recently? Have there been recent dosage changes in medications? | | |
| Has the resident complained of pain (grimacing, rubbing, moaning, limping, restlessness)? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Fatigue

Fatigue is a feeling of tiredness, lack of energy or exhaustion. Fatigue is different from weakness, which is a lack of physical strength. While occasional fatigue is common in older adults, continued fatigue may interrupt daily activities and could be a warning sign of a serious health condition. Sometimes fatigue is obvious. Sometimes it's not so easy to identify. For example, fatigue can also appear as:

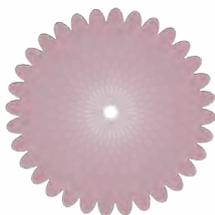
- Inability to concentrate.
- Irritability.
- Resistance/agitation.
- Lack of appetite.
- Depression.
- Withdrawal from social activities.

What are possible causes of fatigue?

Mild fatigue may be caused by lack of sleep, lack of exercise or boredom or can be a side effect of many medications. Persistent fatigue can be a symptom of more serious physical or mental health problems. Many of these problems can be treated and the fatigue can be reversed. Possible causes of fatigue include:

- Depression.
- Diabetes.
- Infections.
- High or low thyroid hormone levels (Hyper- or hypothyroidism).
- Stressful emotional situations.
- Sleep disorders.
- Heart problems such as heart failure or heart disease.
- Low number of red blood cells (anemia).
- Kidney problems (renal failure).
- Bladder or bowel problems.
- Lack of certain vitamins/minerals.

What should I do if I am noticing fatigue in a resident?



One of the most important things you can do is to collect information and document your observations. This can assist the PCP to find the source of the fatigue and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

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

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lc/adc/customer/adccontactlist.pdf>

What are my resources?

Fatigue. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/ency/article/003088.htm>

Sleep Disorders in the Elderly. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/ency/article/000064.htm>

Fatigue. AARP Health Tools.

<http://healthtools.aarp.org/adamcontent/fatigue>

- Outlines causes, symptoms, and what to expect at a PCP visit and home care.

Related sections of Manual

- Obesity
- Heart Disease
- Depression
- Arthritis
- Sleep Problems

Information Gathering Worksheet: Fatigue

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|---|
| Is fatigue unusual for this resident? If not unusual, is it happening more often or becoming more severe? | | |
| When did you first notice the fatigue? | | |
| Was there something that occurred outside of the resident's regular routine such as a visitor, new resident, an examination procedure or unusual weather that may have affected comfort or sleep patterns? | | |
| What types of activities does the resident usually participate in during the week? Has this changed lately? | | |
| Has the resident complained of pain recently or reacted negatively to being touched? Can the resident tell you where the pain is located? | | |
| Has the resident recently complained of headaches? | | |
| Has the resident recently complained about being dizzy or feeling faint? | | |
| What does this resident usually eat during the day? Has the resident's appetite, thirst or diet changed recently? | | |
| Is the resident sleeping as well as usual? Or sleeping more than usual? Or only able to sleep in certain positions? | | |
| Does the resident become breathless or have any difficulty catching their breath? If yes, what are they usually doing when this happens? | | |
| Recent weight loss or gain? | | |
| Bowel or bladder problems such as loose stools, pain or less/more frequent elimination? | | |

Information Gathering Worksheet: Fatigue

| Information to Collect | Yes/No | Observations/Comments |
|---|--------|-----------------------|
| Mood changes? Is the resident acting sad or depressed? | | |
| Fever or night sweating (sheets and bed clothes may be damp in the morning)? | | |
| Vomiting or complaints of nausea (stomach ache), heartburn or gas (burping)? | | |
| Persistent cough? Does the cough occur more when the resident is laying down or sitting up? | | |
| Confusion or difficulty remembering things? | | |
| Consider tracking this resident's sleep patterns over one week, including: <ul style="list-style-type: none">• Wake time• Nap time(s)• Bed time• Times awake during the night Report any changes here. | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Foot Problems

As people age they are increasingly likely to experience problems with their feet. Common foot problems include swelling, pain and redness. It is important to pay attention to foot problems as they are often the cause of chronic pain, can lead to falls and serious injury and may even represent the first sign of serious illness. Some of the more common foot problems are:

- Bunions.
- Corns.
- Plantar fasciitis.
- Fractures.
- Fungal infections.

What are possible causes for foot problems?

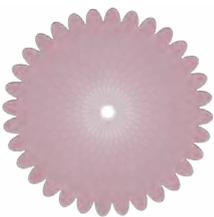
Foot problems can be quite distressing but can often be treated effectively. Some are more serious than others and each would be treated differently. For problems included in the list above, the treatments would be directed to the feet. In some cases (bunions) surgery might be necessary. In other cases (plantar fasciitis, fractures), it would be important to allow the condition to heal, being careful to protect the area. Corns and fungal infections are often left untreated or can be treated with over-the-counter medications.

Foot problems can also be symptoms of a more significant illness such as:

- Heart conditions.
- Diabetes and diseases of the blood vessels.
- Pain or swelling in the big toe (or other joints) from Gout.
- Arthritis.

The second list includes conditions that can have more serious consequences; these are diseases that need to be treated. Foot swelling from heart disease is not painful but is sometimes a sign that the heart disease is worsening. Increased swelling should be immediately reported to the resident's PCP.

What should I do if I am noticing foot swelling, pain or redness?



One of the most important things you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the foot problem has already been assessed by a medical professional in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for helping the resident with their foot problems.

- If the foot problem is new, changing, has increased in frequency or has not been assessed by a medical professional, please notify the resident's PCP and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

American Diabetes Association. 1-800-DIABETES (800-342-2383)

<http://www.diabetes.org>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

Podiatrist — Ask the PCP about seeing this Foot Specialist.

What are my resources?

Foot Health. American Podiatric Medical Association.

<http://www.apma.org/learn/FootHealthList.cfm?navItemNumber=498>

Foot Complications. American Diabetes Association.

<http://www.diabetes.org/living-with-diabetes/complications/foot-complications/>

Fitting Footwear — Disability Services Commission.

See the Appendix of this Manual.

Related sections of Manual

- Diabetes
- Falls
- Difficulty Walking
- Pain
- Swelling

Information Gathering Worksheet: Foot Problems

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|--|
| Describe the foot problem. | | |
| Is there swelling? If yes, does it seem to change during the day or night? | | |
| When is it most pronounced? Do any activities seem to change the amount of swelling? | | |
| Has the resident been unusually tired or had other new problems lately? Please describe. | | |
| Is the resident having difficulty lying down flat at night or using more pillows than usual? | | |
| Has the resident developed a cough or rattling sound when they breathe? | | |
| Does the resident have any history of heart disease? | | |
| Has the resident had any chest or shoulder discomfort or pain lately? | | |
| Is the resident having difficulty with activities, keeping up with the others? | | |
| Does the resident have foot pain? Is the pain always there or does it come and go? | | |
| How severe is the pain? | | |
| What seems to make the pain worse or better, if anything? | | |
| Has the resident had a recent injury or fall? | | |
| Had the resident been doing anything unusual before this condition started? Please describe. | | |
| Does the resident have pain or swelling anywhere else? | | |

Information Gathering Worksheet: Foot Problems

| Information to Collect | Yes/No | Observations/Comments |
|---|--------|-----------------------|
| Do you see any redness on the feet, toes, between toes, bottom of foot, heel? Do any of those places cause pain when touched? | | |
| Does the redness come and go during the day or night? If so, what does it seem related to? | | |
| Has the resident been consuming more salt? Describe any other changes in diet. | | |
| Have any of the resident's medications changed lately? | | |

Resident Name:
Staff Name(s):
Date Reviewed:
Next Steps:

Loss of Daily Living Skills (or ability to take care of routine daily tasks)

As people age, they sometimes lose the ability or find it difficult to engage in daily living skills. For example, people might have difficulty with activities such as:

Self Care

- Bathing
- Using the toilet
- Dressing
- Grooming
- Getting up in the morning
- Feeding oneself

Managing household affairs:

- Using the telephone
- Doing laundry
- Preparing meals
- Doing housework
- Shopping
- Taking medications

Getting around

- Walking
- Climbing stairs
- Going out

What are possible causes for a loss of daily living skills?

There are many medical problems that can result in a loss of daily living skills. Many of these problems can be treated, preventing, reversing or at least minimising the loss.

Possible causes include:

- Many illnesses (arthritis, Parkinson's disease, strokes, etc.).
- Changes in vision or hearing.

Cognitive changes can also make some activities difficult. Some of these are:

- Depression.
- Alzheimer's Disease.
- Dementia.

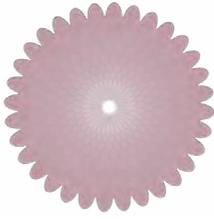
However, it is important to remember that cognitive changes can also be caused by:

- Medication side effects.
- Infections.
- Dehydration.
- Hearing and vision problems (can appear to be change in cognition).

NOTE: Medication side effects are a common cause and should always be considered first.

For people with ID, it is important to compare any difficulties a resident is having with what is usual for him/her (baseline). A baseline of daily living skills can be used to determine whether a resident is experiencing new problems related to illnesses or medications. Without baseline information, it is very difficult for health professionals to determine whether the resident might be experiencing a health problem.

What should I do if I am noticing a resident losing daily living skills?



One of the most important thing you can do is to collect information and document your observations. This can assist their PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the loss of daily living skills has already been assessed by a medical professional in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for managing the loss of daily living skills.
- If the loss is new, increased or has not yet been assessed by a medical professional, please notify the resident's PCP and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcicare/adrc/customer/adrccontactlist.pdf>

Community Options Program.

http://www.dhs.wisconsin.gov/LTC_COP/COP.HTM

What are my resources?

Wisconsin Assistive Technology Program.

<http://www.dhs.wisconsin.gov/disabilities/wistech/index.htm>

Independent Living Centers.

<http://www.dhs.wisconsin.gov/disabilities/physical/ILCs.htm>

Related sections of Manual

- Confusion
- Falls and difficulty walking
- Fatigue
- Slowing Down
- Urinary Frequency

Information Gathering Worksheet: Loss of Daily Living Skills

If a resident is showing a loss of daily living skills (see previous page), please complete this worksheet to assist with information gathering in order to present helpful data to the medical practitioner.

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| Which daily living skills has the resident lost? | | |
| Is this new or different? Has this ever been assessed by a medical professional? | | |
| Did the change happen recently? Did the change come on quickly? | | |
| When did you first notice the change? | | |
| Is the problem worse at any particular time such as during the day or night? | | |
| Any recent weight gain/loss? | | |
| Has the resident changed in their ability to dress? | | |
| Has the resident had any changes in their ability to use a toilet? | | |
| Has the resident had a decrease in appetite? | | |
| Has the resident had any new medications recently added or recent dosage changes? | | |
| Has the resident had any difficulty swallowing? | | |
| Which of the following areas have you seen changes in: combing hair, brushing teeth, washing, and drying face and hands, using the toilet, dressing, other? | | |
| Has the resident had any recent falls and/or hospitalization? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Pain

Pain is *not* a normal part of aging. Pain is generally a sign that something is wrong. So knowing when someone is in pain and finding out what is causing the pain is important. In many cases the cause will be treatable. Determining whether a resident with ID is in pain can be difficult, especially if the resident has a limited ability to communicate verbally. Pain can present in many different ways, such as:

Vocal Reactions

- Moaning, whining, whimpering, crying
- Screaming/yelling

Emotional Reactions

- Not-cooperating, cranky, irritable, unhappy
- Being difficult to distract, and/or satisfy
- Withdrawing from others, activities, staying in his/her room

Body Language

- Moving more or moving less
- Stiff, spastic, tense, rigid

Physiological Reactions

- Change in facial color (increased redness or pallor)
- Breathing irregularities (holding breath or gasping)

Facial Expressions

- Furrowed eyebrows, raising eyebrows
- A change in eyes, including: squinting of eyes, eyes opened wide, eye frowning
- Turning down of mouth
- Movements of the lips and tongue (lips puckering up, tight, pouting, or quivering lips, teeth grinding, tongue pushing)

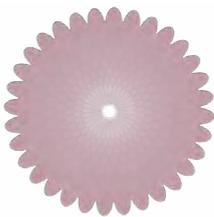
Protective Reactions

- Gesturing to or touching part of the body that hurts
- Protecting, favoring, or guarding part of the body that hurts
- Flinching or moving the body part away, being sensitive to touch
- Moving the body in a specific way to show pain (head back, arms down, curls up)

What are possible causes for pain?

There are many medical problems that cause pain. Pain can range from mild to severe and include almost every part of the body. Most problems can be treated and the pain symptoms can be relieved. The causes of pain are too numerous to list. Determining when the pain occurs, how severe it is, what activities it seems to be associated with and what other symptoms the resident is experiencing will be very important in identifying the cause.

What should I do if I am noticing pain in a resident?



Sudden severe pain can be an emergency. After determining that you are not in an emergency situation, one important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

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

Who can I call for help after the Primary Health Care Provider?

American Chronic Pain Association. 1-800-533-3231

<http://www.theacpa.org/>

Living Well with Chronic Conditions. 1-608-243-5690

<http://www.dhs.wisconsin.gov/aging/CDSMP/LivingWellwithChronicConditions/index.htm>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

What are my resources?

Pain Management. American Geriatrics Society.

<http://www.healthinaging.org/aging-and-health-a-to-z/topic:pain-management/>

Pain and Dementia. Alberta Caregiver College.

<http://caregivercollege.org/scoa/?PainandDementia.html>

Wong-Baker FACES Pain Rating Scale

Wong-Baker FACES™ Pain Rating Scale



National Cancer Institute. (U.S.). Pain Control.

- Covers causes of pain, ways to describe pain, and how to work with health care providers. Includes 'Questions to ask your health care team.'

<http://www.cancer.gov/cancertopics/coping/paincontrol.pdf>

Pain. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/pain.html>

Related sections of Manual

- Arthritis
- Breathing difficulty
- Constipation
- Dizziness
- Falls and difficulty walking
- Foot problems
- Obesity
- Swelling

Information Gathering Worksheet: Pain

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| Is the resident showing any signs of pain (see list on previous page)? Which ones? | | |
| Has the resident ever been assessed by a medical professional? Are the symptoms new or different? | | |
| When did you first notice the symptoms? | | |
| Are the symptoms worse at any particular time such as during the day or night? Are they worse during or following any particular activity such as eating, walking, sitting? | | |
| Does the pain seem to come and go? Or does it remain constant? | | |
| Can the resident communicate where the pain is located? If not, where does it appear to be located? | | |
| Have you noticed any functional decline? (difficulty completing daily tasks like eating, dressing, toileting?) | | |
| Have you noticed more frequent urination from the resident? Less frequent urination? | | |
| Have you noticed diarrhea/ loose stools? Constipation? | | |
| Is the resident sleeping more than usual, or having restless nights/night awakenings? | | |
| Is the resident's appetite decreasing? Has the resident had difficulty with swallowing? | | |
| Has the resident had any new medications added or dosage changes on medications recently? | | |
| Has the resident had a fall/injury recently? | | |
| Has anything worked to relieve the pain or distract the resident from the pain? | | |

Information Gathering Worksheet: Pain

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Resistance to Care

Resistance to care is when a person does not want help that they usually accept willingly. It is usually related to bathing, eating, toileting, dressing, and/or grooming. People may become upset with caregivers and hit, slap, bite, scream, flee, argue or just refuse to cooperate.

What are possible causes for resistance to care?

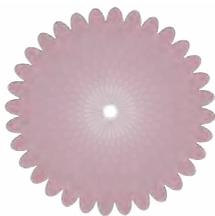
There are many things that could result in resistance to care. Examples of medical problems include:

- Illness or pain
- Medication side effects
- Physical factors: mouth sores, ill fitting dentures, gum disease, dry mouth, anorexia, poor vision, trouble hearing
- Dementia
- Depression
- Fatigue
- Dehydration
- Pain

Other things that can lead to people resisting care are:

- Fear (e.g., of feeling pain, of water, of falling)
- Feeling powerless or embarrassed
- Misunderstood environmental stimuli (e.g., someone laughs at television, thinks person is laughing at them)
- Change in routine
- Change in caregiver
- Previous abuse

What should I do if I am noticing resistance to care?



One important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

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

Who can I call for help after the Primary Health Care Provider?

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

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

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

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Caring For a Person with Alzheimer's Disease. National Institute on Aging.

http://www.nia.nih.gov/sites/default/files/caring_for_a_person_with_alzheimers_disease_0.pdf

Dealing with combative behavior. Wellington Parc.

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

Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease National Institute on Aging.

http://www.nia.nih.gov/sites/default/files/alzheimers_caregiver_guide.pdf

Related sections of Manual

- Confusion
- Aggression
- Screaming
- Pain
- Constipation

Information Gathering Worksheet: Resistance to Care

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|--|
| How is the resident resisting? | | |
| What were you, or someone else, trying to do when the resident resisted? | | |
| Is the resistance new or different? | | |
| When did you first notice the resident resisting? | | |
| Is the resident new to the home? Are there other residents who are new? | | |
| Does the resident seem to have pain or discomfort? | | |
| Are there environmental changes ? (e.g. odor, noises, staff, etc.) | | |
| Is the resident showing any nonverbal signs of pain? | | |
| Has there been a change in mealtimes? | | |
| Has there been a recent change in staff? | | |
| Does the resident have diarrhea/loose stools or constipation? | | |
| Have any new medications been added recently? Or are there any recent dosage changes on medications? | | |
| Has the resident had a recent fall or injury? | | |

Resident Name:
 Staff Name(s):
 Date Reviewed:
 Next Steps:

Screaming/Vocalizing

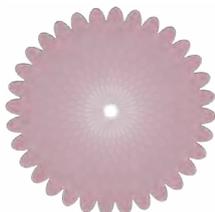
Screaming can convey a variety of physical and emotional needs or problems. The noise is sometimes disruptive to other people and may raise the stress level of other residents and staff in the household. People who scream may have a higher incidence of depression, be more prone to falling, sleeplessness or feel more pain. Taking time to understand the reasons for a resident's screams is worthwhile for the resident and others in the house.

What are possible causes for screaming?

When underlying problems are treated or managed, screaming will often lessen or stop completely. Some reasons for screaming include:

- Depression
- Delirium
- Psychiatric conditions
- Pain
- Fear
- Boredom or frustration
- Loss of bowel or bladder control (incontinence)
- Discomfort with temperature or other conditions in the environment
- Pain with urination or defecation
- Feeling tired, thirsty or hungry
- Confusion, including dementia
- Feeling rushed/pushed
- Constipation

What should I do if a resident has been screaming?



If you determine that this is an emergency situation, follow your agency's emergency procedures. One important thing you can do after determining this is not an emergency situation is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

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

Who can I call for help after the Primary Health Care Provider?

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

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

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

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lrcare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Dealing with combative behavior. Wellington Parc. <http://www.wellingtonparc.com/>

[Dealing With Combative Behavior.pdf](#)

Related sections of Manual

- Confusion
- Aggression
- Pain
- Depression
- Constipation
- Dizziness

Information Gathering Worksheet: Screaming/Vocalizing

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| Describe the vocalizing (e.g., screaming vs. moaning, duration, frequency, etc.) | | |
| Is screaming unusual for this resident? If not unusual, has it become more frequent or intense? | | |
| Was anyone near the resident, or interacting with the resident, when the screaming occurred? | | |
| What time of day does the screaming occur? Is it always at the same time? | | |
| Was the resident doing anything unusual prior to the screaming, even if it seems unrelated? | | |
| Has the resident changed their usual activities? | | |
| Is the resident taking any new medications? | | |
| Have there been any changes in the household lately (e.g., new resident, new staff, remodelling, or noises/work going on outside the home) that might cause distress? | | |
| Has the resident had any speech changes? Such as slurring words, stopping mid-sentence and forgetting about the conversation, or becoming confused? | | |
| Has the resident shown signs of pain or reacted badly to being touched? If yes, can the resident tell you where the pain is located? | | |

Information Gathering Worksheet: Screaming/Vocalizing

| Information to Collect | Yes/No | Observations/Comments |
|---|--------|-----------------------|
| Does taking the resident to the bathroom for urination/defecation stop the screaming or make it worse? | | |
| Does eating or drinking stop the screaming or make it worse? | | |
| Does sitting with the resident and speaking calmly seem to help? | | |
| Does the screaming lessen or stop if a family member or familiar person is there? Is there anything that seems to help? | | |
| Does changing the resident's room temperature (e.g., offering a blanket, turning on a fan) help? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Sleep Problems

Sleep patterns change throughout life. It is common for older adults to sleep less deeply and wake more frequently during the night. However, sleeping problems could also be a sign of an underlying illness. Sometimes people are not tired or have difficulty falling asleep. Sometimes people have difficulty staying asleep. Sleeping problems may present themselves in many ways, including:

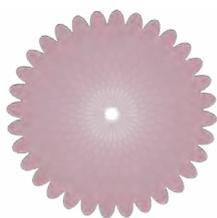
- Taking more time than usual to fall asleep.
- Waking during the night.
- Waking up tired in the morning.
- Irritability.
- Changes in ability to concentrate.
- Fatigue.
- Frequent daytime naps.
- Attention/memory problems.
- Night-time falls.

What are possible causes for sleeping difficulty?

There are many things that can cause a resident to wake during the night. Possible causes of night waking include:

- Frequent urination caused by urinary tract infections or prostate enlargement.
- Irritable bladder.
- Pain or discomfort.
- Heart conditions that make it difficult to breath lying down.
- Confusion or disorientation (dementia).
- Depression.
- Sleep apnea.
- Too much stimulant (coffee, tea, sodas, chocolate).
- Indigestion.
- Leg cramps.
- Medication side effects.

What should I do if I am noticing sleep problems in a resident?



The most important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the sleep problem has already been assessed by a medical professional in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for managing the night waking.
- If the sleep problem is new, increased in frequency, or has not been assessed by a medical professional, please notify the resident's PCP of the issues and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lc/arc/customer/adrccontactlist.pdf>

What are my resources?

Sleep disorders in the elderly. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/ency/article/000064.htm>

National Sleep Foundation. Search by topic and specific problems.

<http://www.sleepfoundation.org/>

Sleep Problems. American Geriatric Society.

<http://www.healthinaging.org/aging-and-health-a-to-z/topic:sleep-problems/>

Related sections of Manual

- Depression
- Falls and difficulty walking
- Fatigue
- Parkinson's Disease
- Urinary Frequency
- Urinary Incontinence

Information Gathering Worksheet: Sleep Problems

If a patient is having sleep problems (see previous page), please complete this worksheet to assist with information gathering in order to present helpful data to the medical practitioner.

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|---|
| Is the resident having difficulty lying flat? | | |
| Is the resident having difficulty falling asleep? If yes, when did you first notice this? | | |
| Is the resident having trouble staying asleep? If yes, when did you first notice this? | | |
| Is the resident getting up and moving when they wake? Are they 'wandering'? | | |
| Has the problem been assessed by a medical professional? | | |
| Has it increased in frequency? | | |
| Has the resident's bed time changed? | | |
| Does the resident take naps during the day? How many naps? How long is each nap? Has this changed recently? | | |
| Does the resident eat or drink anything before going to bed? Does the resident consume drinks containing caffeine in the afternoon or evening? | | |
| Does the resident snore at night? Can you describe the snoring pattern (e.g., continuous rhythm or irregular?) Is this new or changed? | | |
| Has the resident experienced belching, burning in their throat or indigestion during the night? | | |
| Does the resident seem to have a bad taste in their mouth when they wake up? | | |
| Does the resident complain of pain (verbal complaints or non-verbal signs such as grimacing or wincing)? | | |

Information Gathering Worksheet: Sleep Problems

| Information to Collect | Yes/No | Observations/Comments |
|--|--------|-----------------------|
| Has the resident had any recent hospitalizations or illnesses? | | |
| Has the resident had any recent changes in medications (dosage or types)? | | |
| Has the resident had any recent changes in mood (such as sadness or disinterest in activities previously enjoyed)? | | |
| Has the resident been confused or had difficulty remembering things? Is this new or unusual? | | |
| Has the resident had any recent bowel or bladder problems, such as loose stools, pain or less/more frequent elimination? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Slowing Down

People slow down naturally when they age, but there are also many medical conditions that can slow someone down. Therefore, it should not be assumed that aging is the cause of slowing down, particularly if this occurs suddenly. Slowing down manifests as:

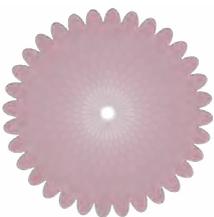
- Taking a long time to eat.
- Not being able to get ready on time for usual activities.
- Walking slowly.
- Not being able to keep up with the group on outings.
- Getting up later and/or going to bed earlier.
- Taking naps.

What are possible causes for slowing down?

There are many medical problems that slow people down. Some of these include:

- Low thyroid hormone (Hypothyroidism).
- Pain.
- Depression.
- Medication changes.
- Arthritis.
- Dementia.
- Dehydration.
- Recent hospitalization, illness or injury.
- Changes in vision or hearing.
- Dizziness or balance problems.
- Many more.

What should I do if I am noticing a resident slowing down?



One important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the slowing down has already been assessed by a medical professional in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for managing the slowing down.
- If the slowing down is new, increased in frequency, or has not been assessed by a medical professional please notify the resident's PCP of the issues and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcaredrc/customer/adrccontactlist.pdf>

Related sections of Manual

- Confusion
- Hearing changes
- Vision changes
- Loss of Daily Living Skills

Information Gathering Worksheet: Slowing Down

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|---|
| Is the slowing down general or only with certain activities? | | |
| Are there certain activities at which the resident is particularly slow? | | |
| Have you noticed any change in the way the resident walks, such as short or shuffling steps, balance problems, or discomfort with walking? | | |
| Are there any signs of confusion present? | | |
| Has the resident shown signs of pain in a specific part of the body when moving or engaging in specific activities? (grimacing, rubbing, moaning, limping, or restlessness, touching or protecting parts of the body) | | |
| Is the slowness at any particular time of day? Does it improve/increase as the day goes on? | | |
| Are there changes in the resident's behavior? | | |
| Are there any changes in the resident's speech? | | |
| Has the resident been sleeping more than usual or had any trouble sleeping? | | |
| Has the resident had any recent falls or injuries? | | |
| Has the resident had any new medications added or dosage changes made recently? | | |

Resident Name:
 Staff Name(s):
 Date Reviewed:
 Next Steps:

Swelling (Edema)

Swelling is an enlargement of an area on the body, causing the body part to look 'puffy'. Sometimes there are also changes to the skin color over the puffy area. Swelling can be accompanied by changes in the temperature of the skin. The area might feel hot when touched. Sometimes swollen areas are painful, particularly when touched or moved. But sometimes swelling is not associated with pain. Swelling can occur almost anywhere on the body.

Color, temperature, pain and the location of the swelling all provide important clues to the cause of the swelling. For example, when swelling is caused by an infection, the area is often red, warm and painful. When it is caused by heart problems, it generally occurs in feet and lower legs, is not painful and is not associated with any changes in temperature or color of the skin in that area. Swelling related to arthritis often occurs in joints (knees, ankles, hands and feet), is often painful but not usually hot or red. When the body has trouble getting rid of fluid, which can result from many different health conditions, you will often see swelling. The excess body fluid tends to settle in legs and feet (extremities) but can also collect in the abdomen. When this happens, there will be swelling. Swelling can even be hidden. For example, swelling related to heart, liver or kidney disease could be mostly internal or hidden under clothing. A sudden weight gain is often an indicator of internal swelling or 'fluid retention'.

Swelling is common, but should always be taken seriously. It is often uncomfortable or even painful and can be a warning sign of illness. Medical professionals refer to swelling as 'Edema'. Another term often used by medical people is 'pitting Edema'. If someone pushes gently on the swelling and then takes their finger away, pitting Edema occurs if a clear impression is left. Pitting refers to the slight indentation that is left in the area, which then fills slowly. It is important to remember that Edema is a reaction to something that is going on in the body. It always has an underlying cause. Sometimes the cause is serious and sometimes it is only minor and temporary. Professional medical assessment is often needed to distinguish the minor from the serious causes. The information you collect for the PCP can be vital in making the right diagnosis.

What are possible causes of swelling?

Swelling can be caused by many illnesses, injuries or conditions. Common causes of swelling in joints:

- Gout (a build-up of uric acid, often in the foot).
- Arthritis.
- Infections.
- Injury.

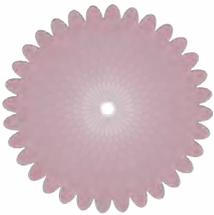
Ankle, wrist and knee injuries can be common in older adults who may have trouble walking. If someone has unexplained swelling, they might have fallen or hurt themselves.

Other common causes for swelling

- Heart disease.
- Cellulitis (common in diabetics), can affect feet, legs, the face, and cause reddened, warm skin. Affected areas expand with time. Common after cuts, blisters, insect bites. **Requires immediate medical attention.**
- Swelling in the mouth or gums can be a common sign of dental problems.
- Congestive Heart Failure, or CHF, can cause unexplained swelling in the feet, ankles or leg.
- Blood clots.
- Liver and kidney diseases.
- Surgery and cancer treatment.
- Medication side effects.
- Varicose veins (a condition of knotted or damaged veins, often in legs).
- Vitamin and mineral deficiencies, as well as high salt intake.
- Thyroid problems.

What should I do if I see swelling in a resident?

One important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.



Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

What are my resources?

Edema. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/edema.html>

Depending on the cause of the swelling, there may be other resources to help you support the resident. For example, there are organizations that provide useful, practical tips for people living with each of the illnesses that can cause swelling. Once the diagnosis has been made and appropriate treatment begun, it might be helpful for you and the resident to explore some of these resources. There are organizations designed to help consumers with:

- Arthritis.
- Kidney disease.
- Liver disease.
- Diabetes.
- Thyroid disease.
- Cancer.

See the 'Conditions' chapter of this manual for links to condition specific resources.

Related sections of Manual

- Falls and difficulty walking
- Foot problems
- Pain
- Thirst
- Weight Gain
- Arthritis
- Cancer
- Heart Disease
- Hypertension
- Obesity
- Diabetes

Information Gathering Worksheet: Swelling (Edema)

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|---|
| Where can you see the swelling (what body part(s)? | | |
| What does the swelling look like (how big is the area, is it discolored)? | | |
| Do you know how long the area has been swollen? When did the swelling begin? | | |
| Does the resident have pain? (see 'Pain' symptom in this Manual). Where? | | |
| Is the area warm to touch? | | |
| Has the resident experienced this swelling before? If yes, explain when and what happened. | | |
| Is the swelling worse at a specific time of day? | | |
| Any other recent injuries? | | |
| Has the resident had any recent falls or injuries? | | |
| Has the resident had surgery or been hospitalized recently? | | |
| Has the resident gained weight recently? | | |
| Has the resident been sitting or standing for long periods of time? | | |
| Has the resident had any medication changes? | | |
| Does the resident eat salty foods frequently? | | |
| Has the resident complained of excess thirst? | | |
| Has the resident had any difficulty breathing or sleeping? | | |

Information Gathering Worksheet: Swelling (Edema)

| Information to Collect | Yes/No | Observations/Comments |
|--|--------|-----------------------|
| Has the resident's appetite changed? If so, when and in what way? | | |
| Is the resident less socially engaged than previously or not wanting to participate in activities? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Thirst

Thirst is a normal response to the body needing more fluids. It can also be a symptom of many medical problems. When people cannot tell you they are thirsty there are other things that suggest the resident is not getting enough fluids. Some of these are:

- Dry mouth, throat, tongue, lips, and gums.
- Dry skin (not by itself).
- Excess hunger or loss of appetite.
- Dizziness, light-headedness, imbalance (especially on standing up).
- Fatigue and weakness.
- Constipation.
- Dark amber-color urine.

What are possible causes for thirst?

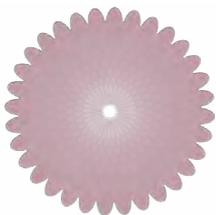
Many medical conditions can increase thirst. Some can be serious. Most of these conditions can be treated and the symptoms can be reversed. Examples include:

- Diabetes.
- Thyroid disease.
- Medication side effects.
- Diarrhea.
- Excessive sweating.

Sometimes older people experience a decrease in thirst, making them more vulnerable to dehydration. Older people can become quite dehydrated and still not be thirsty. The signs of dehydration include:

- Dizziness on standing.
- Cracked lips.
- Difficulty swallowing.
- Appetite loss.
- Not drinking fluids.
- Falls or loss of balance.
- Fatigue or slowing down.

What should I do if I am noticing an increase in thirst in a resident?



One important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the thirst has already been assessed by a medical professional in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for managing thirst.
- If the thirst is new, increased in frequency, or have not been assessed by a medical professional, please notify the resident's PCP of the issues and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

What are my resources?

Medline Plus. Excessive thirst.

<http://www.nlm.nih.gov/medlineplus/ency/article/003085.htm>

- Causes of thirst and what to expect at a health care provider visit.

Related sections of Manual

- Diabetes
- Obesity
- Dehydration
- Swelling
- Dizziness

Information Gathering Worksheet: Thirst

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|---|
| Is the resident showing signs of frequent thirst (see list on previous page)? What specific signs? | | |
| Are these signs new or different? | | |
| When did you first notice the change? | | |
| Have you noticed any other changes in eating or drinking? Has the resident's appetite changed? | | |
| Does the resident have any nausea or has he/she vomited? | | |
| Is the resident urinating more/less frequently? Is there a change in the color of the urine (darker/lighter)? | | |
| Does the resident have diarrhea/loose stools? | | |
| Has the resident been constipated? | | |
| Is the resident sleeping more than usual or had trouble sleeping? | | |
| Has the resident had new medications added recently or have there been any dosage changes? | | |
| Has the resident had a decreased appetite, difficulty swallowing, or decreased fluid intake? | | |
| Has the resident had a recent fall or injury? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Urinary Frequency

Frequent urination can be very frustrating. It is often, mistakenly, thought to be a normal change as people grow older. There are many consequences of frequent urination.

Frequent urination can lead to:

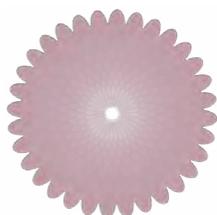
- Chronic tiredness/fatigue from sleep interruption.
- Falls from hurrying to the bathroom.
- Withdrawal from important activities.
- Avoidance of friends.
- Reluctance to leave the home.
- Anxiety over finding a bathroom quickly enough.
- Impatience from others who don't understand.
- Soiled clothing and the embarrassment that goes along with that.

What are possible causes of frequent urination?

There are many things that can cause someone to urinate more frequently than usual. Some of these things are minor and reversible, some are quite serious but reversible, and sometimes frequent urination is a chronic condition. Most of these problems can be treated and the symptoms can often be reversed. Some of the most common reasons for frequent urination are:

- Diabetes.
- Prostate enlargement.
- Urinary tract infection.
- Medication side effects.
- Changes in bladder function.

What should I do if a resident is urinating more frequently?



One important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

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

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

What are my resources?

Frequent and Urgent Urination. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/ency/article/003140.htm>

A Basic Guide to Bladder Health. American Urological Association.

<http://www.urologyhealth.org/content/moreinfo/bladderbasics.pdf>

Related sections of Manual

- Diabetes
- Obesity
- Urinary Incontinence

Information Gathering Worksheet: Urinary Frequency

If a resident has increased frequency in urination (see previous page), please complete this worksheet to assist with information gathering in order to present helpful data to the medical practitioner.

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|--|
| How many times is the resident urinating each day? | | |
| When did you first notice the change? | | |
| Is there an unusual or unpleasant odor to their urine? | | |
| Is it always a problem or does it only occur at certain times? (during the night, during certain times of the day) | | |
| Is the resident getting up at night to use the toilet? If yes, how often? How long after going to bed? | | |
| Is the resident urinating a lot each time, or only a very small amount? | | |
| Has his/her appetite changed? In what way? | | |
| Has he/she had any other changes (fatigue, pain, irritability)? | | |
| Has he/she had a fever? | | |
| Has he/she had any recent medication changes? New medications or changes in dosage? | | |

Resident Name:
 Staff Name(s):
 Date Reviewed:
 Next Steps:

Urinary Incontinence

Urinary incontinence refers to leaking urine or losing bladder control. Incontinence is a very common problem and although it can affect both younger and older populations, both men and women, it occurs most often in older people, especially in older women. Despite the fact that it is a common problem in older people, it is not a normal part of aging. Urinary incontinence can interfere with a person's life and can affect the quality of life. People do not always have to 'live with it.' For most people, it can be improved. Urinary incontinence can also be a symptom of a serious underlying condition. It is important that urinary incontinence be evaluated.

There are different types of urinary incontinence. The common ones are:

- Urge incontinence is a sudden, overwhelming need to urinate and the resident is unable to control or stop the urine. Some common triggers are running water, hand washing and going out in the cold. When this happens, the resident might lose urine very quickly or may leak slowly on the way to the toilet. Some people with urge incontinence also need to go to the toilet frequently during the day and sometimes during the night.
- Stress incontinence occurs when there is sudden increased pressure in the abdomen, like when you cough, laugh, sneeze or exercise, which leads to urine leakage.
- Mixed incontinence occurs when a resident has a combination of stress and urge incontinence.
- Overactive bladder occurs when there is a sudden, overwhelming urge to urinate. Leakage of urine may occur before arriving at the toilet. People with overactive bladder often have to go to toilet frequently during day and night.
- Overflow incontinence is when the bladder becomes full and starts to overflow.
- Functional incontinence occurs when a resident is unable to get to the toilet, sometimes because of a physical disability such as arthritis. There is nothing wrong with their bladder. It is simply a matter of circumstances preventing the resident from getting to the toilet.

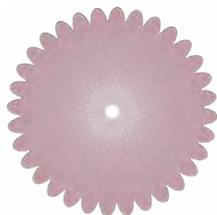
What are other causes of urinary incontinence?

Incontinence has many causes. Sometimes people have more than one underlying cause. For some people, there may be only one cause, but for most elderly there are multiple factors that cause urinary incontinence. Some possible causes are:

- Urinary tract infection, bladder infection or kidney infection.
- Obesity or being overweight.
- Caffeine.
- Alcohol.
- Enlarged prostate, or past prostate surgery.
- Radiation therapy to prostate.
- Constipation or stool impaction.
- Weakened urinary tract muscles.

- Other medical conditions such as: diabetes, stroke, heart problems, dementia, Parkinson's disease, spinal stenosis, etc.
- Medications: medications to treat high blood pressure, medications to treat psychiatric disorders, diuretics (water pills), and pain medicines.

What should I do if I am noticing urinary incontinence in a resident?



Collecting information to take to the PCP can be very helpful in determining the cause of the incontinence and treating it appropriately. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the urinary incontinence has been assessed by a practitioner in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for helping the resident live with/manage the urinary incontinence.
- If the urinary incontinence is new, increased in frequency or severity, or has not been assessed by a medical professional, please notify the resident's PCP and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

National Association for Continence. 1-800-BLADDER or 1-843-377-0900

<http://www.nafc.org>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Urinary Incontinence. National Institute on Aging.

<http://www.nia.nih.gov/health/publication/urinary-incontinence>

Urinary Incontinence. American Geriatrics Society.

<http://www.healthinaging.org/aging-and-health-a-to-z/topic:urinary-incontinence/>

What I Need to Know About Bladder Control for Women. National Institute of Diabetes and Digestive and Kidney Disease.

http://kidney.niddk.nih.gov/KUDiseases/pubs/bcw_ez/bcw_508.pdf

Your Daily Bladder Diary. National Institute of Diabetes and Digestive and Kidney Disease.

http://kidney.niddk.nih.gov/KUDiseases/pubs/diary/diary_508.pdf

Related sections of Manual

- Constipation
- Dementia
- Depression
- Obesity
- Parkinson's Disease
- Stroke

Information Gathering Worksheet: Urinary Incontinence

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|--|--------|---|
| Does the resident have problems with urine leakage? | | |
| How much does leaking urine bother the resident? | | |
| Are others upset by the leaking urine? If so, does this cause problems for the resident? | | |
| Does the resident leak urine (many times a day, a few times a week, or a month?) | | |
| How much urine leaks each time (be specific; teaspoon, cup, variable)? | | |
| Does the resident have to get up at night to urinate? If yes, how often? | | |
| When does urine leak? On the way to toilet, when the resident is asleep, when the resident is laughing, coughing? List all that apply. | | |
| Does the urine have an unusual odor or color? | | |
| Is the resident able to use the toilet without assistance? | | |
| Does the resident have problems with walking? Do they have arthritis or muscle weakness which might make it difficult to get to the toilet quickly enough? | | |
| Is the resident consuming beverages such as coffee or other drinks with caffeine? List the kinds, amounts and usual times of day. | | |
| Is the resident using medications for pain, depression or high blood pressure? | | |
| Does the resident have diabetes, stroke, dementia, Parkinson's disease or heart disease? Which one(s)? | | |

Information Gathering Worksheet: Urinary Incontinence

| Information to Collect | Yes/No | Observations/Comments |
|---|--------|-----------------------|
| If this is a man, does he have any prostate problems? Does he take a long time to pass urine? | | |
| Has he had any prostate surgery or treatment? | | |
| Does the resident have problems with constipation? | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Weight Gain

Unintentional weight gain is an increase in body weight that occurs when a person takes in more calories than the body needs or uses. As we age, our metabolism slows down, which can cause weight gain unless we reduce the amount of food we eat and/or increase how much we exercise. However, weight gain could also indicate a serious medical problem, such as fluid retention or a thyroid condition.

If weight gain is slow or there is a change in caregivers, the weight gain may go unnoticed. Some things that might suggest recent weight gain include:

- Tight fitting clothes.
- Belt notches loosened.
- Feeling tired often.
- Moving less.
- Sore joints.
- Appetite changes.

What are some possible causes for weight gain?

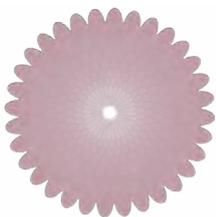
There are many medical problems that could result in weight gain. These problems can be mild or serious. Many of these problems can be treated. Examples include:

- Thyroid disease (hypothyroidism).
- Heart disease.
- Depression.
- Medication side-effects or changes.
- Congestive heart failure.

Weight gain is most often caused by:

- Eating too much and exercising too little.
- A slower metabolism, which is normal with aging.

What should I do if I am noticing weight gain in a resident?



One important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the weight gain has already been assessed by a medical professional in the past and there is no change, bring the worksheet to your house manager/supervisor to discuss options for managing weight gain.
- If the weight gain was sudden or has not been assessed by a medical professional, please notify the resident's PCP of the issues and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcaredrc/customer/adrccontactlist.pdf>

What are my resources?

Weight Control. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/weightcontrol.html>

Related sections of Manual

- Diabetes
- Obesity
- Heart Disease
- Depression

Information Gathering Worksheet: Weight Gain

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

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| How much weight has the resident gained? | | |
| Has the resident been less active? (If you are unsure, how tight is the resident's clothing?) | | |
| How quickly has the weight gain occurred? | | |
| Does the weight fluctuate (go up and down)? Has it been a steady increase? | | |
| Has the resident been eating more? | | |
| Has the resident had any trouble breathing? | | |
| Is the resident urinating more frequently? | | |
| Is the resident urinating less frequently? | | |
| Does the resident have swelling or puffiness in their feet or lower legs? | | |
| Has the resident been tired or slowing down lately? | | |
| Is the resident sleeping more often or having trouble sleeping? | | |
| Does the resident sleep sitting up or with several pillows (this can indicate a serious medical problem)? | | |
| Has the resident had a change in appetite or experienced difficulty swallowing? | | |
| Has the resident had any new medications added recently, or had any changes in dosage? | | |

Information Gathering Worksheet: Weight Gain

| Information to Collect | Yes/No | Observations/Comments |
|--|--------|-----------------------|
| Has the resident had a recent fall or injury? | | |
| Has the resident had any recent changes in their life? (eg: new move, hospitalization, death of a loved one, etc?) | | |

Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

Weight Loss

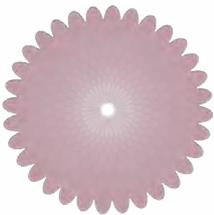
Unintentional weight loss is a decrease in body weight that is not voluntary. In other words, the person did not try to lose the weight by diet or exercise.

What are possible causes for unintentional weight loss?

Sometimes people lose weight because they want to. Sometimes environmental changes can cause a loss in body weight, and sometimes weight loss may be caused by illness. In fact, weight loss is often the first indicator of illness. Some illnesses that can result in weight loss include:

- Thyroid disease (hyperthyroid).
- Intestinal conditions.
- Infections.
- Cancer.
- Depression.
- Swallowing problems.

What should I do if I am noticing weight loss in a resident?



One important thing you can do is to collect information and document your observations. This can assist the PCP to find the source of the problem and treat the problem as quickly as possible. An Information Gathering Worksheet is found at the end of this section. Please complete the worksheet, with input from other staff and those close to the resident, and discuss with your house manager/supervisor how to proceed.

- If the weight loss has already been assessed by a medical professional and there is no change, bring the worksheet to your house manager/supervisor to discuss options for managing the weight loss.
- If the weight loss is sudden or significant, or has not been assessed by a medical professional, please notify the resident's PCP of the issues and bring the worksheet to the resident's next appointment.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

Dietitian.

What are my resources?

Weight Loss in the Elderly: What's Normal and What's Not? Lewko M, Chamseddin A, Zaky M, Birrer Rb. Pharmacy and Therapeutics Journal.

<http://www.formkit.com/ptjournal/fulltext/28/11/PTJ2811734.pdf>

Unexplained Weight Loss. Mayo Clinic.

<http://www.mayoclinic.com/health/unexplained-weight-loss/MY00713/DSECTION=causes>

Related sections of Manual

- Depression

Information Gathering Worksheet: Weight Loss

If a resident has experienced weight loss (see previous page), please complete this worksheet to assist with information gathering in order to present helpful data to the medical practitioner.

| Information to Collect | Yes/No | Observations: Also ask anyone else who may have information (such as staff on other shifts or family members) |
|---|--------|--|
| How much weight has the resident lost? If you don't know, is clothing loosely fitting or are belts using a new notch? | | |
| Has the resident ever been assessed by a medical professional for weight loss? | | |
| Did the weight loss happen suddenly or was it a slow, steady decline? | | |
| Does their weight fluctuate? | | |
| Have you noticed any restlessness or irritability? Increased sweating? | | |
| Is the resident having any trouble, chewing, swallowing, choking? | | |
| Has the resident recently experienced diarrhea/ loose stools/bloody stools? How often? | | |
| Has the resident been constipated? | | |
| Has the resident's appetite increased or decreased? | | |
| Has the resident been unusually thirsty? | | |
| Has the resident been sleeping more than usual or had difficulty sleeping? | | |
| Has the resident had any new medications or dosage changes recently? | | |
| Has the resident had any recent changes in their life? (eg: new move, hospitalization, death of a loved one, etc?) | | |
| Has the resident had a recent fall or injury? | | |

Information Gathering Worksheet: Weight Loss

| Information to Collect | Yes/No | Observations/Comments |
|--|--------|-----------------------|
| Does the resident have any dental problems, mouth sores, or poorly fitting dentures? | | |
| Has the resident been urinating more frequently? Been incontinent or urine? | | |

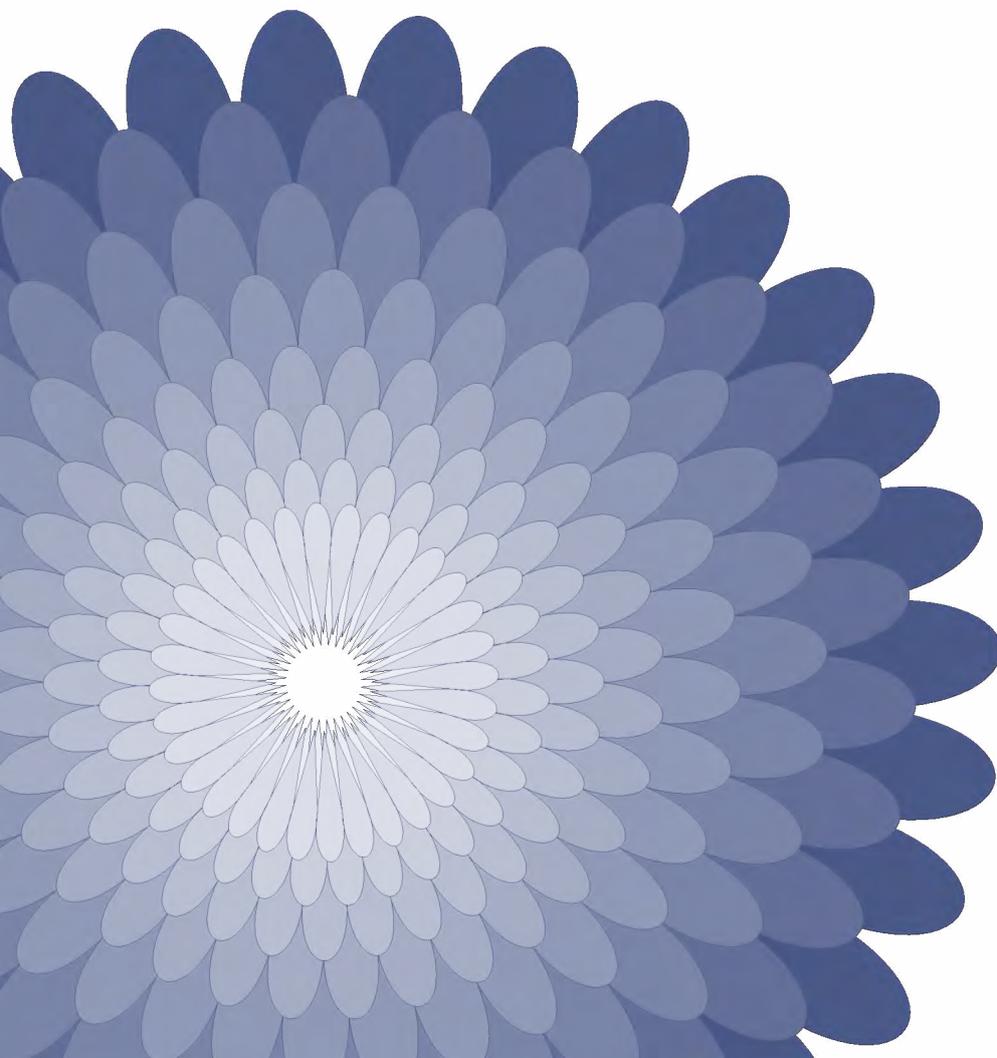
Resident Name:

Staff Name(s):

Date Reviewed:

Next Steps:

*Understanding and
Supporting Residents with
Common Age
Related Health
Conditions*



Arthritis

If left untreated, a person with arthritis is at higher risk for depression, chronic pain and loss of function. People with arthritis who are non-verbal should be watched carefully for loss of function, social withdrawal and pain since this may suggest worsening of the disease. In particular, social and behavioral changes are common with increasing pain. Sometimes several different treatments need to be tried before finding one that works well and has tolerable side effects.

Types of arthritis

There are several different types of arthritis.

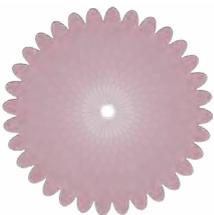
- **Rheumatoid arthritis (RA):** may occur in younger people, but can also occur in older adults. It is often very painful and can cause joint deformities (particularly in the hands and feet). It often leads to significant physical disability.
- **Osteoarthritis (OA):** occurs in older adults. It is the result of wear on the joints and loss of cartilage so that bones begin to rub together. It occurs mostly in weight bearing joints such as knees and hips, and occurs more often in people who are overweight. It can cause serious pain.
- **Gout:** is an extremely painful condition caused by inflammation and swelling in the joint. Gout is often related to diet, so making dietary changes is extremely important in controlling gout.

What should I be alert for?

Some residents with intellectual disability (ID) have difficulty telling you when something is wrong. Therefore it is important to be alert for common distress signs suggesting that the disease is worsening or that the treatment is no longer working well. If a resident has been diagnosed with arthritis you will want to watch for:

- **Pain:** If the resident is on a pain reducing medication, monitor how well the medication is working. The Faces of Pain scale (see page 83) was developed for use in children but is also useful in people who are nonverbal or cannot tell someone about the pain they are experiencing (<http://www.iasp-pain.org/Content/NavigationMenu/GeneralResourceLinks/FacesPainScaleRevised/default.htm>). It can help you determine how much pain a resident is feeling. Medications taken for arthritis pain should only be adjusted after consulting with a doctor as all medications have side effects that need to be monitored. Arthritis medications are particularly likely to cause side effects. It is important to speak with the resident's PCP about over-the-counter medications used for arthritis pain since over-the-counter medications can have very serious side effects, especially when taken over long periods of time or at higher doses.
- **Difficulty with daily living:** including dressing, undressing, grooming and eating are common consequences of arthritis. Arthritis can also cause difficulty rising from a chair, walking or climbing stairs. Consultation with an occupational therapist may be needed to recommend assistive devices.

- **Decreased movement:** If the resident is experiencing pain, he/she may not want to move or may resist activities such as getting out of bed and going on outings. As the pain increases, the resistance will increase. To maintain function, however, it is important for the resident to incorporate movement into their daily routine. Lack of daily activity can also lead to a loss of function. Getting the right balance is very important. One way to help the resident continue to be active is to be sure that medications are timed so that pain is minimized during activity. PCPs, nurses and pharmacists will be able to help you with this. The goal should be to maintain the right type and amount of activities.
- **Mood changes:** Depression is common in those with arthritis pain. Helping the resident engage in activities and continue to do things that are important or meaningful will help to decrease depression.
- **Medication side effects:** If a resident is taking medication for arthritis, it is extremely important to know what side effects to look for. You might want to ask the pharmacist or PCP about possible side effects of a medication and what you should look for and report. There are several types of medication options available and people react differently to medications. Therefore it is important to communicate problems with any medication to the resident's PCP. In particular, be alert for stomach aches, abdominal pain, loss of appetite, gas or bloating and bowel problems such as constipation, diarrhea or rectal bleeding.



If you notice...

any changes in the resident following treatment, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of a problem can prevent more severe problems from developing, and will help maintain a high quality of life.

What are some tips to manage arthritis?

- For both rheumatoid and osteoarthritis, maintaining a balance of activity and rest periods is important. Staying in one place too long can make joints stiffen. Safe, gentle activity with periods of rest is encouraged. Daily range-of-motion exercise can be very helpful.
- Simple tasks such as opening a jar, walking down the hall, putting on clothes and opening a door can be difficult for people with arthritis. There are several assistive devices that can help these people maintain function. Visit <http://www.aidsforarthritis.com> to get ideas of what might be challenging and useful for the resident with arthritis. Consult with the resident's PCP or physio before obtaining any assistive devices.
- For gout, resting the affected area is important.
- Consult with a dietitian or PCP to help the resident maintain a balanced diet and ideal weight. Gout requires very specific diet changes.
- Because pain medication has so many side effects, controlling pain with a combination of medications and non-medication strategies is a good idea. For example, music has

been found to reduce feelings of pain by up to 25%.

Who can I call for help after the Primary Health Care Provider?

Wisconsin Arthritis Program. 1-608-266-2593

<http://www.dhs.wisconsin.gov/health/arthritis/index.htm>

Arthritis Foundation. 1-800-333-1380

<http://www.arthritis.org>

Living Well with Chronic Conditions. 1-608-243-5690

<http://www.dhs.wisconsin.gov/aging/CDSMP/LivingWellwithChronicConditions/index.htm>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Gout. Mayo Clinic.

<http://www.mayoclinic.com/health/gout/DS00090>

Gout. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/gout/whatisgout/01.html>

Osteoarthritis. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/osteoarthritis/toc.html>

Rheumatoidarthritis. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/rheumatoidarthritis/whatisrheumatoidarthritis/01.html>

Cancer

Cancer is the general name for a group of more than 100 diseases in which cells in a part of the body begin to grow out of control. Some cancers are very treatable and can be cured. Some cancers become chronic diseases requiring treatment over many years. Some cancers are quickly terminal. Cancers left untreated can cause serious illness, disability and even death. While the incidence of cancer increases with age, it is not a normal part of aging.

Cancer can cause almost any physical or behavioral symptom. A few of the many possible symptoms are: fever, extreme tiredness (fatigue), pain, skin changes or unexplained weight loss. The symptoms will depend on where the cancer is, how advanced it is and how much it affects organs or tissues. If a cancer has spread (metastasized), symptoms may appear in different parts of the body. As a cancer grows, it can begin to push on nearby organs, blood vessels and nerves, causing new symptoms. If the cancer is in a critical area, such as certain parts of the brain, even the smallest tumor can cause symptoms such as behavioral changes.

The incidence of cancer in people with ID is lower than for the general population, although it is rising as their life expectancy increases. Therefore, it is important that aging people with ID are routinely screened for cancers that occur more often in older people. Support staff can play an important role in making sure that the national Guidelines for cancer screening are followed for all aging residents.

How is cancer treated?

Treatment depends on the type and stage of cancer. Surgery, chemotherapy (medications) and radiation are the three main types of cancer treatment. A person with cancer may have none, some, or all of these treatments.

Surgery

When the cancer is a tumor, surgery is often the first treatment. Sometimes only part of the cancer can be removed. In this case, a person will often have radiation or chemotherapy as well.

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. Chemotherapy drugs can be given intravenously (IV or into a vein) or orally. Chemotherapy drugs travel through the bloodstream to reach cancer cells that may have metastasized (spread) from the tumor to other places.

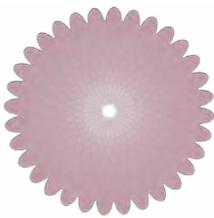
Radiation

Treatment with high-energy rays (such as x-rays) are often used to kill or shrink cancer cells. The procedure is much like that of having an x-ray and is painless, although some people have side effects from radiation. The side effects depend largely on the location of the radiation treatment.

What should I be alert for?

Some people with ID have difficulty telling you that something is wrong. Therefore, it is important to be alert for signs of distress that might tell you that something is wrong. New symptoms might suggest a worsening of the cancer or a reaction to the treatment. As each cancer and treatment causes different symptoms, ask the resident's PCP what symptoms you should look for. It is important to contact a PCP as soon as possible about any new symptoms.

- **Medication side effects:** If a resident is taking a medication for cancer, ask the pharmacist or PCP about possible side effects and what you should look for and report. Each person reacts a bit differently to medications. What works for one person, may not work for someone else. Fortunately, there are usually several medicines that can be used for the same purpose. This means this is important to communicate problems with a medication to the resident's PCP so the medication can be switched to one that works for them.



If you notice...

any changes in the resident following their treatment, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of a problem can prevent more severe problems.

What are some tips to manage cancer?

- Remember that cancer is not contagious.
- Cancer is often a treatable disease. Offer words of encouragement and hope. With assistance from the PCP or other health professionals, support staff can help the resident understand their treatment options.
- Pain can often be controlled. Talk to a health care provider about your role in pain control.
- Good nutrition is important, especially during chemotherapy and radiation therapy. A dietitian and the resident's PCP or oncologist (cancer specialist) can help you plan a diet that will assure proper nutrition, even when the resident may not have an appetite.
- There may be good days and bad days with symptoms coming and going. Try to be patient and understand the resident's needs each day.
- Coordinate visits to the radiology or chemotherapy units prior to treatment. Meet with oncology (cancer care) staff prior to the treatments to help them understand the individual's communication preferences, fears and any other tips that might help everyone have a better appointment.
- Ask doctors for visual materials to help the resident understand the diagnosis and treatment.

Who can I call for help after the Primary Health Care Provider?

American Cancer Society. 1-800-227-2345

<http://www.cancer.org>

National Cancer Institute. 1-800-422-6237

<http://www.cancer.gov>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcicare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Understanding Intellectual Disability and Cancer.

<http://www.intellectualdisability.info/physical-health/cancer-palliative-care-and-intellectual-disabilities>

Mammogram Preparation Kit for Women with Intellectual Disabilities (Australia). <http://www.som.uq.edu.au/media/274878/Mammogram%20info%20for%20woman.pdf>

'It's Easier Said Than Done': Perspectives on Mammography From Women With Intellectual Disabilities. Wilkinson, J. E., Deis, C. E., Bowen, D. J., & Bokhour, B. G. (2011). *The Annals of Family Medicine*, 9(2), 142-147.

<http://www.annfammed.org/content/9/2/142.full.pdf#page=1&view=FitH>

Cancer. National Institutes of Health.

<http://nihseniorhealth.gov/category/cancer.html>

Dehydration

Dehydration occurs when your body does not have as much water as it needs. Your body needs the right balance of water and nutrients to function properly, so dehydration can cause serious problems. As people age, they often lose their sense of thirst. When this happens, people sometimes just forget to drink fluids. This can cause serious problems.

Dehydration can be mild, moderate or severe depending on how much of the body's fluid is lost. It is often hard to tell when people are becoming dehydrated. Some of the early signs are: not urinating, urinating only very small amounts, dark, concentrated urine and not perspiring. When dehydration is recognized and treated promptly, the outcome is good. Untreated severe dehydration may result in seizures, permanent brain damage or death.

Common causes of dehydration include losing too much fluid from:

- Vomiting or diarrhea.
- Excessive urine output such as with uncontrolled diabetes or diuretic (medication) use.
- Excessive sweating (for example, from exercise).
- Fever.
- Not drinking enough fluids.
- Combinations of the above.

Sometimes people don't drink enough fluid because of:

- Nausea.
- Loss of appetite due to illness.
- Sore throat or mouth sores.
- Just forgetting.

How is dehydration treated?

- Drinking fluids is usually sufficient for mild dehydration. It is better to have frequent, small amounts of fluid than to force large amounts of fluid all at once. Drinking too much fluid at once can bring on more vomiting.
- Sports drinks that can replenish electrolytes, such as sodium and potassium, are especially effective. However, sports drinks are high in sugar and can make diarrhea worse.
- Intravenous fluids and hospitalization may be necessary for moderate to severe dehydration. The doctor will also try to identify and then treat the cause of the dehydration.
- Most cases of stomach viruses (gastro) resolve on their own after a few days. People should be encouraged to drink frequent small amounts of fluids during their illness.

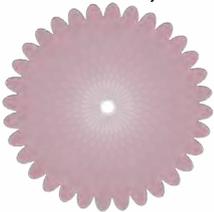
If dehydration is not managed well, several problems may occur:

- | | |
|------------------------------------|------------------------------|
| • Seizures | • Confusion |
| • Loss of consciousness (pass out) | • Fatigue, sometimes extreme |
| • Brain damage | • Dizziness and falls |

What should I be alert for?

When people are able to tell you about their symptoms and how they feel, you can ask about the symptoms listed below. When they are not able to tell you, it is important to watch for these symptoms:

- Loss of balance
- Falls
- Confusion (frequently an older adult will appear confused when they are dehydrated)
- Dry or sticky mouth
- Low or no urine output; concentrated urine appears dark yellow
- Not producing tears
- Sunken eyes
- Lethargic or comatose (with severe dehydration)
- **Medication side effects:** (Normally someone is not placed on a medication for dehydration. Frequently people will be given supplements to replace the missing fluids.)



If you notice...

Any of the changes listed above, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of dehydration can prevent serious issues problems from developing.

What are some tips to manage dehydration?

- Even when healthy, encourage older people to drink plenty of fluids every day. People should always drink more when the weather is hot or they are exercising.
- If someone has been dehydrated in the past, they are much more likely to become dehydrated again.
- Carefully monitor people who are ill, especially if they are having diarrhea or vomiting. If you believe that dehydration is developing, consult a doctor before the resident becomes dehydrated. Begin encouraging fluids as soon as vomiting and diarrhea start -- DO NOT wait for signs of dehydration.
- Always encourage people to drink during an illness and remember that fluid needs are greater when people have a fever, are vomiting or have diarrhea. The easiest signs to monitor are urine output, saliva in the mouth and tears when crying.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcicare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Dehydration. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/ency/article/000982.htm>

Delirium

Delirium can look very much like dementia in that it can cause confusion, agitation, distress and inability to focus or cooperate. It differs from dementia in that it is:

- Caused by a medical problem that is often reversible.
- Comes on suddenly, in hours or days.
- Often fluctuates throughout the day.
- Is reversible if identified and treated promptly.

Dementia, by contrast, is not caused by underlying medical illnesses, is not reversible, develops slowly over time and generally is the same throughout the day. With any new confusion, delirium should be considered first. The most common cause of delirium is medication side effects but it can also be caused by a wide range of treatable medical problems. Some of these are:

- Over or underactive thyroid (hyper/hypothyroidism).
- Infection.
- Dehydration.
- Blood sugar too low or too high.
- Hearing problems (can mimic delirium).
- Falls and head injuries.
- Pain.
- Many other medical problems.

Many older adults experience delirium when hospitalized. This is usually caused by a combination of factors such as: drugs, treatments, the illness they were hospitalized for and being unfamiliar with the environment. Hospital staff often mistake delirium for dementia and fail to treat the problem. The most effective treatment is eliminating the underlying cause. Hospital staff do not know the resident, do not know what their baseline is and can easily miss delirium. So when a resident with ID is hospitalized, support staff can provide very important baseline information about the resident. Otherwise, it would be easy for hospital staff to mistake delirium for ID or dementia.

Medications most commonly causing delirium include:

- Pain medications.
- Sedatives or anti-anxiety medications.
- Anti-depressants.
- Steroids for inflammation.
- Anesthetics.
- Antibiotics.
- Anti itch medications.

How is delirium treated?

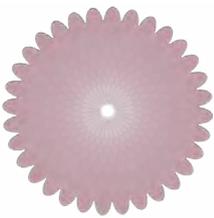
Delirium can represent a medical emergency and consequently immediate intervention is important. The most important thing to do is to identify and treat the underlying cause of delirium. This may include, for example, administration of fluids to correct dehydration, medications to treat an infection or discontinuation of the medication causing the problem.

Delirium is usually completely reversible if the underlying cause is determined and treated promptly. Any delay in treatment greatly decreases the chances of a full recovery. However, even with treatment some symptoms may persist for weeks or months and improvement may take some time.

What should I be alert for?

The hallmark symptom of delirium is the inability to pay attention. Other common symptoms to be alert for include:

- Disorganized thinking.
- Difficulty following directions.
- Perceptual disturbances (auditory and/or visual hallucinations).
- Agitation.
- Changes in sleeping patterns.
- Personality and/or mood change.



If you notice...

any of the above changes in the resident, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of delirium can prevent permanent losses and will help maintain a high quality of life for the resident.

What are some tips to manage delirium?

Once delirium is identified and treatment has been started, recovery may be improved by:

- Providing a calm, comfortable, familiar environment.
- Allowing uninterrupted sleep at night.
- Avoiding any stress.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

What are my resources?

Delirium. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/ency/article/000740.htm>

Delirium. Mayo Clinic.

<http://www.mayoclinic.com/health/delirium/DS01064>

Dementia

Dementia is not a normal part of aging. It is a chronic condition affecting brain function that causes a person to act in ways that he/she normally would not. This often leads to an inability to carry out everyday activities. Dementia generally develops slowly over time. It is characterized by forgetfulness, difficulty communicating, personality changes and difficulty performing tasks that involve thinking or decision making, such as taking a bus, playing games or managing money.

The most common types of dementia in older adults are:

- Degenerative (slow loss of function), including Alzheimer's Disease.
- Vascular (generally caused by tissue damage from a stroke, can worsen with untreated diabetes and is often linked with high blood pressure).
- A person could have both types of dementia at the same time.

Symptoms most commonly occur after age 65. People with Down Syndrome have a 2 to 3 times higher risk of developing dementia than the general population and often develop dementia earlier than other older adults (generally between ages 40 to 50). It is common for a person to live approximately 10 years beyond diagnosis, but this may be slightly less in people with ID.

How is dementia treated?

Once diagnosed, the goals of treating dementia are:

- Achieving the best possible physical and mental function.
- Identifying and managing behavioral symptoms.
- Identifying and treating any other health conditions that might make the dementia worse (e.g., diabetes, high blood pressure).

Medications and other treatments will not cure or reverse signs of dementia, but they can help maintain quality of life and increase safety for people with dementia and those around them. Treatments may include:

- Medications to increase function and cognition.
- Medications to treat any associated depression.
- Medications to treat any associated agitation.
- Alterations to the physical home and other spaces to increase safety and decrease confusion.
- Use of memory aids.
- Avoidance of stressful situations.

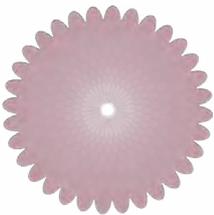
If the dementia is not managed well, the following may occur:

- Falls.
- Wandering or getting lost.
- Depression.
- Harm to self or others when stressed or confused.
- Forced movement to a more restrictive environment (e.g., nursing home).
- Loss of social and family connections.

What should I be alert for?

Some people with ID have difficulty telling you when something is wrong, therefore it is important to be alert for common distress signs or new developments. If a resident has been diagnosed with dementia, you will particularly want to watch for:

- Trouble with daily living skills (See Symptoms: Loss of Daily Living Skills)
- Tripping/falling hazards in the home and at other locations where he/she spends time
- New things that can cause anxiety such as different care workers, new residents, etc.
- Difficulty eating or not finishing meals
- Bowel or bladder issues (trouble finding the bathroom, medication side effects)
- **Medication side effects:** Medications used to manage dementia have a long list of potential side effects. Vomiting, diarrhea and weight loss have been reported. If a resident is placed on a medication for dementia, ask the pharmacist or doctor about any potential side effects of this medication and what you should look for and report. There are sometimes other medication options available and each resident may react differently to a medication, therefore it is important to communicate problems with a medication to the resident's doctor.



If you notice...

any of the above changes in the resident, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of a problem can prevent more severe issues from developing, and will help maintain a high quality of life for residents.

What are some tips to manage dementia?

Dementia can be a challenging health condition for the resident with dementia, their loved ones and caregivers. It is important that everyone surrounding the individual is educated about the condition and is committed to adjusting the environment to achieve a good quality of life and safety for all.

- Noisy environments and/or large spaces can cause confusion and stress. If the resident goes to a day center for activities, inform staff to find a smaller room with quiet space if the individual starts to become confused or agitated. Recognizing a potentially uncomfortable situation before it escalates is important.
- Create memory aids for the individual (see resources below).
- When transitions in staff or living arrangements occur, try to create a slow transition and make an effort to keep some items/routines familiar.
- Practice 'reminiscence' (see resources below) with the individual. Encourage family and friends to do the same. Others in the home may enjoy this activity as well.
- Remove any tripping or falling hazards such as rugs, cords or lightweight furniture.
- Put signs up to cue the resident, such as a photo of themselves on their room door, signs for 'hot' and 'cold' with colors on the tap and a photo of a toilet on the bathroom door.
- Use effective communication strategies such as saying the resident's name often while you are talking to them, looking directly at them when talking, slowing down, and explaining things before you do them (e.g., explain you'll take a fork and help them cut their food, you'll help them walk to the bathroom, etc.).
- Break tasks into easy to manage segments (e.g., 'One step at a time').

Who can I call for help after the Primary Health Care Provider?

Alzheimer's Association. 1-800-272-3900

<http://www.alz.org>

Alzheimer's Disease Education and Referral Center. 1-800-438-4380

<http://www.nia.nih.gov/alzheimers>

Memory Clinic and WAI-Affiliated Dementia Diagnostic Clinic Network: diagnostic clinics that work to promote the early diagnosis and treatment of dementia and Alzheimer's disease. The clinics address concerns of people experiencing changes in memory, behavior, or thinking skills as well as those who support them.

<http://www.wai.wisc.edu/clinics/cliniclist.html>

Alzheimer's & Dementia Alliance of Wisconsin. 1-888-308-6251

<http://www.alzwisc.org/>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcrae/adrc/customer/adrccontactlist.pdf>

What are my resources?

Down Syndrome and Alzheimer's Disease. Alzheimer's Association.

http://www.alz.org/dementia/downloads/topicsheet_downsyndrome.pdf

Dementia. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/dementia.html>

Dementia Care Academy. Teepa Snow.

<https://dementiacareacademy.com/static/resources.htm>

Alzheimer's. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/alzheimersdisease/whatisalzheimersdisease/01.html>

Caring for Someone with Alzheimer's. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/alzheimerscare/dailyactivities/01.html>

Behaviors: What causes dementia-related behavior like aggression, and how to respond. Alzheimer's Association.

http://www.alz.org/national/documents/brochure_behaviors.pdf

Planning Guide for Dementia Care at Home: A Reference Tool for Case Managers.

Alzheimer's Association - South Central Wisconsin Chapter, the Wisconsin Alzheimer's Institute and the Wisconsin Bureau of Aging and Long Term Care Resources, Division of Disability and Elder Services, Department of Health and Family Services.

<http://www.dhs.wisconsin.gov/aging/dementia/homecare.htm>

Person-Directed Dementia Care Assessment Tool. A Guide for Creating Quality of Life and Successfully Refocusing Behavior For People with Alzheimer's Disease and Related Dementia In Long Term Care Settings. State of Wisconsin Department of Health and Family Services. Division of Disability and Elder Services.

<http://www.dhs.wisconsin.gov/aging/genage/Pubs/pde0084.pdf>

Depression

Depression is a mood disorder that is often described as feeling sad, blue, and unhappy. Most people feel this way at one time or another, however these feelings are typically short-lived. Depression involves feeling this way for a longer period of time and having these feelings interfere with everyday life. Depression can occur at any time in the life course, including during later life.

Adults with ID are more likely to have depression than are adults without disabilities. Unfortunately, depression is often missed in adults with ID and goes untreated. In part, this is because it can be difficult to assess the feelings and thoughts of adults with low cognitive and verbal abilities. Depression in elderly adults with ID can also be confused with age-related declines in physical and mental health or side effects of medications.

There are different types of depression. Symptoms of depression can be short-term (lasting a few weeks) or chronic (lasting several years) and can be mild or severe. Depression also presents in different ways for different people; some people become sad and feel 'down in the dumps,' whereas other adults may become irritable and grouchy and exhibit aggression or behavior problems. Some adults who have depression also experience times of heightened mood and energy (mania).

Ruling out medical problems

Adults with ID can appear depressed if they are experiencing pain because of an undiagnosed medical problems. Therefore, it is important to rule out the possibility that a medical condition has caused the change in the resident's mood. Some medications can also cause depression as a side effect and it is important to talk to the PCP if you notice signs of depression.

What should I be alert for?

The following table lists several symptoms of depression and the types of behaviors that may be observed.

| Symptoms of Depression | What to Look For: |
|---|--|
| Depressed or irritable mood | Sad expressions or lack of emotional expressions, rarely smiles, cries or appears tearful. May appear grouchy or angry and display agitated or aggressive behaviors. |
| Loss of interest in things they used to enjoy | Not wanting to do activities that they used to enjoy doing; spending a lot of time alone; displaying few signs of enjoyment. |
| Change in appetite | Eating too much or not hungry. |

| Symptoms of Depression | What to Look For: |
|--------------------------------------|---|
| Sleep Problems | Cannot fall asleep, wakes up early in the morning or sleeps too much; always seems tired. |
| Restlessness or slowed movements | Fidgets (e.g., rarely sits down or constantly stands up and down) or has slowed movements (talks less or talks more slowly and/or is less physically active). |
| Fatigue | Appears tired or refuses to do activities that require physical effort; spends a lot of time just sitting. |
| Feelings of worthlessness or guilt | People with mild or moderate ID may talk about themselves as a 'bad' person, may blame themselves for problems, have unrealistic fears that others will be angry with them, or ask for reassurance that they are a good person. |
| Difficulty concentrating or thinking | Easily distracted or cannot complete tasks that he/she used to be able to finish (e.g., activities of daily living). Memory may appear to 'come and go' or they may become agitated when asked to do activities that require concentration. |
| Talking about death | People with mild or moderate ID may often talk about death or people who have died, or even make threats to kill or harm themselves. |

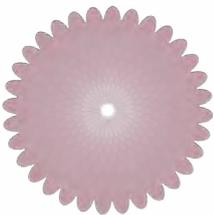
How is depression treated?

Medications are frequently used to treat depression. It often takes some trial and error to find the right medication and dosage. Also, some medications can take several weeks to take their full effect and can have side effects. Psychological counseling (psychotherapy) can also be effective for treating depression. Psychotherapy involves learning how to identify and make changes to your behaviors, thoughts and feelings and to find ways to better cope with and solve problems. The most effective treatment for depression is often a combination of medication and psychotherapy. Less commonly used treatments for depression include phototherapy, dietary changes and herbal supplements.

What are some tips to manage depression?

- **Medication:** Make sure medications are taken as prescribed; it can often take several weeks before medications take their full effect. Talk to the PCP about the types of side effects that may occur and ways to manage these side effects. Do not stop taking a medication without talking to the PCP; some medications can cause withdrawal symptoms unless you slowly taper the dose. Know the side effects of medications and talk to the PCP about any you are observing.

- **Recognize patterns in mood:** Many adults with depression feel worse at certain times of the day (often in the morning). Try to arrange the resident's schedule so that demands are the least during times of the day when he/she tends to feel the worst.
- **Break down tasks:** Depression often makes people feel as if tasks are too hard to accomplish. Break large tasks into smaller steps. Help the resident focus on accomplishing these smaller steps.
- **Reduce stress:** Stress can make symptoms of depression worse and can put people at risk for future depression. Identify situations that cause stress. Wherever possible, try to find ways to problem solve these situations. It is also important to help the resident learn how to cope with feelings of frustration and anger (e.g., listen to music, counting to ten, focusing on breathing or talking to a staff person or friend). Stability is also important for people with depression. If a change must occur, such as new staff or a new resident, prepare him/her slowly for the change.
- **Exercise:** Make sure the resident gets regular exercise.
- **Nutrition:** Eating well is important for feeling healthy and happy. Encourage healthy food choices and consult with a nutrition expert or PCP to identify helpful dietary changes or supplements.
- **Natural light:** Try to get the resident outside each day or sit in natural light (e.g., near window).
- **Remain active:** Encourage the resident to participate in activities despite feeling tired and sad. Establish a daily routine to encourage the resident to get out of bed, get dressed, and stay active despite their feelings of fatigue and lack of desire to do so.



If you notice...

any of the above changes in the resident, talk to your house manager/supervisor about contacting the resident's PCP. Quick identification and treatment of a problem can prevent more severe issues from developing and will help maintain a high quality of life for residents.

Additional tips for managing depression

When someone has depression, there are several things you can do to help the resident:

- Make sure medications are taken as prescribed.
- Know medication side effects and talk to the doctor about them.
- Try to get the resident outside each day, or at least have them sit in natural light (e.g., near a living room window).
- Make sure the resident gets regular exercise.
- Help arrange things that are enjoyable but don't push the resident to do things they don't want to do.
- Help the resident interact positively with others in the house.
- Help the resident find an activity that he/she finds enjoyable.
- Find something such as music or an activity that helps calm the resident if he/she gets anxious.
- Stability is helpful for people with depression. If a change must occur, prepare him/her slowly for the change (a death in the house, a move, changes in staff).
- Encourage a healthy sleep routine and diet.

- Ask the resident's PCP or a nutrition expert about any diet changes or nutritional supplements that might help the resident manage their depression.

Who can I call for help after the Primary Health Care Provider?

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

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

National Institute of Mental Health. 1-866-615-6464 <http://www.nimh.nih.gov/health/topics/depression/index.shtml>

National Alliance on Mental Illness. 1-800-950-6264 <http://www.nami.org>

Mental Health America. 1-800-969-6642

Mental Health America. 24 Hour Crisis Center Line 1-800-273-8255

<http://www.nmha.org>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lrcare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Torr, J. & Iacono, T. (2006). Depression in adults with intellectual disability: Depression checklist. Accessed from <http://www.cddh.monash.org/research/depression/>

Sleep Tips. Mayo Clinic.

<http://www.mayoclinic.com/health/sleep/HQ01387>

Depression in People with Intellectual Disabilities (UK). Sheila C Hollins.

<http://www.intellectualdisability.info/mental-health/depression-in-people-with-intellectual-disabilities/>

Depression in older adults. National Institutes of Health.

<http://nihseniorhealth.gov/depression/aboutdepression/01.html>

Depression in older adults. Mental Health America.

<http://www.nmha.org/index.cfm?objectid=C7DF94FF-1372-4D20-C8E34FC0813A5FF9>

Contribution by Sigan Hartley

Diabetes

Diabetes is a common disease characterized by high blood sugar levels. This is caused by changes in the body's ability to produce and/or use insulin. The prevalence of diabetes increases with age but it is not a normal part of aging. There are two main types of diabetes:

- **Type 1:** Usually diagnosed in children and young adults. The body does not produce insulin. Insulin is a hormone that is needed to convert sugar (glucose), starches and other food into energy needed for daily activity.
- **Type 2:** The most common form of diabetes. Either the body does not produce enough insulin or the cells ignore the insulin. Insulin is necessary for the body to be able to use sugar/glucose for energy.

When people have too much sugar in their blood (a high blood sugar or blood glucose level), fluids are drawn out into the urine, causing frequent urination. This in turn can make people very thirsty.

How is diabetes managed?

Diabetes is a common disease, but it varies quite a bit from one person to another. Diabetes is sometimes pretty easy to manage and is sometimes very complicated. Some people need to stick very strictly to a diet and keep their activities consistent from day to day or they can become seriously ill. Other people can stray from their diet regularly without any trouble. All diabetics should check their blood sugar on a prescheduled/regular basis. The doctor or nurse can set up a monitoring plan for you to follow.

- **Blood glucose monitoring:** The main tool for checking how well diabetes is being controlled is to check blood sugar levels. Using a meter is the most accurate way to check. It is important to keep a log of the blood glucose results in order to review them with doctors. This should include time of day, time of last meal and any unusual physical activities or health problems at the time. Doctors have additional tests they use to check blood sugar. This usually requires a blood test.
- **Medications:** There are two main types of medications for diabetes. Pills are used to lower the blood sugar levels in many people with Type 2 diabetes. Insulin is an injection that is used to lower blood sugar levels in people with Type 1 diabetes and sometimes Type 2 diabetes.
- **Diet and Exercise:** Well-balanced meals in appropriate portions and consistent in calories from day to day, as well as consistent daily exercise are important for diabetes management.

If diabetes is not well managed, the disease can lead to many problems such as:

- Increased risk of heart attack and stroke.
- Poor circulation and sensation in arms and legs.
- Blindness.
- Kidney disease.

- Slow and difficult wound healing.
- Severe illness requiring hospitalization.
- Foot ulcers, (diabetics should always wear socks and well fitting shoes) and any sores on their feet should be examined by a doctor or nurse.
- Infections.

What should I be alert for?

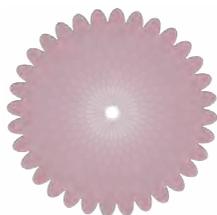
Hypoglycaemic symptoms (low blood sugar):

- Dizziness.
- Hunger.
- Shakiness or trembling.
- Confusion.
- Sweating.
- Weakness.
- Headache.
- Loss of consciousness.

Fast treatment: **Low blood sugar can be an emergency.** Blood sugar can be raised quickly by drinking 120mls (4 oz) juice, eating a glucose tablet or other small sugary snack. Notify the doctor if blood sugar levels are frequently low. Nurses from local agencies or the community health center can show you how to test blood sugar, how to record the results and when to contact the doctor or nurse. Changes in diet, activity or health status can cause changes in blood sugar levels. Forgetting to eat after taking medications can cause a sudden drop in blood sugar levels, which can be dangerous.

Hyperglycemic symptoms (high blood sugar level):

- Excessive thirst.
- Frequent urination.
- Blurred vision.
- Headaches.
- **Treatment:** Unlike very low blood sugar, high blood sugar is not an emergency. However, the resident's PCP or nurse can give you instructions on the range of blood sugars that are acceptable and when they would need to be notified.
- **Medication side effects:** If a resident is placed on a medicine (pill or insulin) for diabetes, ask the pharmacist or doctor about possible side effects of the medication and what you should look for and/or report. Each resident will react differently to the medication, so two residents on the same medication could react quite differently.



If you notice...

any of the above changes, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of a problem can prevent more severe problems from developing, and will help maintain a better quality of life for residents.

What are some tips to manage diabetes?

- Be sure that the resident is eating a healthy, well-balanced and consistent diet and exercising or staying active daily.
- Know how to use diabetic equipment and how to monitor blood sugars levels.
- Know what range of blood sugar is acceptable for that resident and when they tend to develop symptoms.
- Be alert for signs and symptoms of hypoglycaemia (low blood sugar) and hyperglycaemia (high blood sugar) and respond quickly, **especially with low blood sugar.**
- Schedule regular appointments with a PCP to monitor the resident's eyes, feet, kidneys, heart and overall diabetes care plan.
- Be particularly alert for symptoms of low blood sugar if the resident has changed their usual eating or exercise patterns or is ill.

Who can I call for help after the Primary Health Care Provider?

The Wisconsin Diabetes Prevention and Control Program. 1-608-267-3835

<http://www.dhs.wisconsin.gov/diabetes/index.htm>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

American Diabetes Association. 1-800-342-2383

<http://www.diabetes.org>

What are my resources?

"Diabetes Self-Care Information and Record Booklet." Developed by the Wisconsin Diabetes Prevention and Control Program Wisconsin Diabetes Advisory Group and other partners Division of Public Health Wisconsin Department of Health Services.

<http://www.dhs.wisconsin.gov/publications/P4/P43081.pdf>

Food Advisor. Recipes for Healthy Living. American Diabetes Association.

<http://www.diabetes.org/mfa-recipes/grocery-list-2012-06.html>

Diabetes. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/diabetes/diabetesdefined/01.html>

Diabetes in Older People - A Disease You Can Manage. National Institute on Aging.

http://www.nia.nih.gov/sites/default/files/diabetes_in_older_people_0.pdf

Epilepsy/Seizure Disorders

Epilepsy and seizure disorders result from surges in electrical signals inside the brain. Approximately 50% of people with a seizure disorder also have an intellectual disability. The incidence of epilepsy is 15-30 times more frequent among people with intellectual disabilities than in the general population. Note that people with Down syndrome may develop symptoms of dementia at an earlier age than the typical population. Due to changes in the brain as dementia progresses, people with Down syndrome may experience late-onset seizures.

Many different types of seizure disorders are common in people with intellectual disabilities. In most cases, people with seizures will have the same types of seizures from episode to episode.

Seizures are classified into two main categories:

- Partial or focal seizures
- Generalized seizures

Partial or Focal Seizures

Simple Partial Seizures

These can be motor seizures with twitching, abnormal sensations, abnormal visions, sounds or smells, and distortion of perception. Seizure activity can also include flushing, tingling, or nausea. During a seizure, people will have full consciousness and recall of the seizure.

Complex Partial Seizures

Other names for this seizure type include: "psychomotor seizures", "temporal lobe seizures", or "limbic seizures". Complex partial seizures may have an aura, which is a warning that a seizure is about to occur. Typically, an aura may be a familiar feeling (*déjà vu*), nausea, feeling hot or tingling, or distortion of sensory perceptions. About half of people with this type of seizure do not remember the aura. During the seizure, people may fumble or perform purposeless movements or "automatisms" like lip smacking, picking at their clothes, walking around aimlessly, or saying nonsense phrases over and over again. Automatisms occur in about 75% of people with complex partial seizures. Those who do not have automatisms simply stop, stare, and blank out for a few seconds to minutes.

Generalized Seizures

Tonic-Clonic

This seizure type was previously referred to as grand mal. They may begin as a localized seizure and evolve to a more generalized seizure or may start with a sudden loss of consciousness and stiffening (tonic) followed by rhythmic jerking (clonic) of the arms and legs. The person's eyes will roll up at the beginning of the seizure and, typically, the person will cry out, not due to pain, but due to contraction of the respiratory muscles against a closed throat. A tonic-clonic seizure can last 1-3 minutes. The seizure, itself, is called the ictus. After the seizure, the person is in a "post-ictal" state; sluggish, sleepy and confused. The post-ictal state may last for a variable length of time.

NOTE: A tonic-clonic seizure lasting 5-10 minutes can be a medical emergency. It is

very important to be fully aware of action(s) to be taken when this occurs.

Atonic

This type of seizure is also referred to as drop attacks or drop seizures. An atonic seizure causes the loss of normal muscle tone, often resulting in a sudden collapse or fall. People with this type of seizure may wear a helmet to protect from serious injury.

Tonic

This type of seizure is characterized by a stiffening of the muscles, generally those in the back, legs, and arms. The arms and legs may extend forward or up in the air. There is no jerking phase. In a tonic seizure, the person may fall to the ground; however, tonic seizures often occur while the person is asleep and may or may not cause loss of consciousness.

Myoclonic

This type of seizure is a brief jerk or series of jerks of the arms, neck, face, shoulders, and occasionally the legs. These jerks may or may not have a rhythmic pattern.

Absence Seizures

This seizure type was formerly called petit mal seizures. Absence seizures consist of staring spells, lasting several seconds, sometimes in conjunction with eyelid fluttering or head nodding. Absence seizures are usually shorter and have a quicker recovery period than complex partial seizures.

The main risks associated with each type of seizure vary; however, the risks from the types of epilepsy and seizure disorders common in people with intellectual disability include fractures due to falls or epileptic jerking; trauma from accidents due to loss of consciousness; medication interactions and side-effects; and even Sudden Unexpected Death caused by Epilepsy (SUDEP). Additionally, people with an intellectual disability and a seizure disorder may have increased mortality due to aspiration episodes and pneumonia.

How are epilepsy/seizure disorders treated?

The most common treatments for epilepsy and seizure disorders in older adults include anti-epileptic drugs, diet, and environmental manipulation. Epilepsy in people with intellectual disabilities may be difficult to diagnose or treat. Inadequately treated seizure disorders can impair cognitive function, so efforts should be made to limit the duration and frequency of seizures.

Treatment of epilepsy and seizure disorders in people with intellectual disabilities requires a well-coordinated and comprehensive plan of care that considers the co-existence of other medical conditions, as well as the risks associated with medication interactions and/or side effects. The treatment plan, including medication management, should be regularly monitored to ensure that it is appropriate.

With the exception of people who have Down syndrome or develop dementia, some

people with intellectual disabilities may exhibit a remission of the epilepsy with age. However, abrupt withdrawal from anti-epileptic medication may induce extended seizures lasting more than 30 minutes, so any medication changes should be done only under the strict supervision of the primary care physician.

How are epilepsy/seizure disorders treated?

The most common treatments for epilepsy and seizure disorders in older adults include anti-epileptic drugs, diet, behavior therapy, and environmental manipulation. Epilepsy in people with intellectual disability may be difficult to diagnose or treat. Inadequately treated seizure disorders can impair cognitive function, so the longer a person does not have a diagnosis or treatment plan, the more progressive the cognitive impairment.

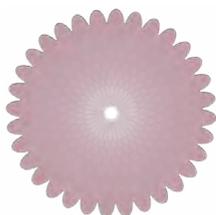
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With the exception of people who have Down syndrome and dementia, some people with intellectual disability may exhibit a remission of the epilepsy with age. However, abrupt withdrawal from anti-epileptic medication may induce extended seizures lasting more than 30 minutes, so any medication changes should be done only under the strict supervision of the primary care provider (PCP).

What should I be alert for?

If you provide care for a resident who has a seizure disorder, you need to be familiar with the resident's history so that you may be able to identify any changes. As previously indicated in the seizure descriptions, seizures may include any of the following:

- A staring spell
- Temporary confusion
- Uncontrollable jerking movements
- Loss of consciousness or awareness
- Medication side effects:
- If the resident is taking anti-epileptic medication, ask the pharmacist or doctor about side effects of the medication and what you should look for and report.
- Since there are different medication options available depending on the seizure type and other medications that resident may be taking, it is important to communicate problems with any medication to the resident's PCP.
- Anti-epileptic medications often have side effects that reduce bone density, which predisposes people to fractures. Therefore, weight bearing exercises and taking vitamin D and calcium may help to prevent the loss of bone density, reducing the potential injury that may result from seizures.



If you notice...

any changes in the resident that could be related to their condition, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of a problem can prevent more severe problems from developing and will help maintain a better quality of life for residents.

What are some tips to manage epilepsy/seizure disorder?

The approach to seizure management will differ depending on the type of seizure disorder. The primary goal is to keep the resident safe until the seizure ends naturally.

- Remain calm and reassure other residents.
- Do not attempt to restrain the resident. If the seizure involves jerking movements, make sure to clear the area of any hard or sharp objects that may cause a fall or result in head trauma or other physical injury if the person does fall.

As possible, roll the person on his/her side to prevent potential aspiration of saliva or other fluids as vomiting may occur.

- Do not put anything into the person's mouth; the tongue cannot be swallowed.
- Loosen clothing that may restrict breathing.
- Understand the resident's history of seizures. This will help you know what to expect during a seizure and to identify changes in duration or behavior that you should document and report to the resident's PCP if necessary.
- Stay with the resident until the end of the seizure and be present when he or she regains consciousness.
- Promptly document information about each seizure:
 - time the seizure started
 - specific seizure activity/movements seen
 - how long the seizure lasted or the time the seizure ended
 - if medication was given for the seizure, document the time it was given and whether or not the medication helped.
- Contact emergency services or the PCP if you suspect the resident may be injured and need medical attention.
- **Who can I call for help after the Primary Health Care Provider?**

Epilepsy Resource Center of the Epilepsy Foundation

Call our Toll-Free Hotline: 1-800-332-1000

Aging and Disability Resource Center (see Resources section of this Manual) <http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Epilepsy Foundation

<http://www.epilepsyfoundation.org/>

National Institute of Neurological Disorders and Stroke

<http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm>

Seizures. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/seizures.html>

Seizures and Epilepsy Interactive Tutorial. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/tutorials/seizuresandepilepsy/htm/index.htm>

Understanding Intellectual Disability and Health. Epilepsy.

<http://www.intellectualdisability.info/physical-health/epilepsy>

Gastro-Esophageal Reflux Disease (GERD)/Indigestion

Gastro-esophageal reflux (a type of indigestion) occurs when food or beverages flow backwards, from the stomach back up into the esophagus (the tube that runs from the throat down to the stomach). Reflux, a sour acid, then reaches the throat and causes discomfort. The most common side effect of GERD is heartburn (a burning feeling in the esophagus, right behind the breastbone). Other common effects are upset stomach, hiccups, a hoarse voice and coughing or wheezing.

It is estimated approximately 50% of people with ID have GERD, making it a very common condition. It is easy for caregivers to dismiss signs of GERD as a normal part of aging, but it is a serious problem that gets worse the longer it goes untreated.

How is GERD managed?

The goal of treatment is to limit the number of times a resident experiences gastro-esophageal reflux. The most common treatments are medications that block the production of acid in the stomach and elevating the head of the resident's bed. People with GERD often take medication for a long time. It does not usually go away quickly.

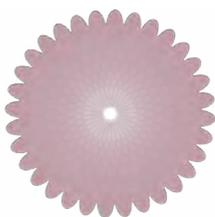
If not managed well, a resident might have severe pain, trouble sleeping, permanent damage to the esophagus, trouble swallowing and choking.

What should I be alert for?

If a resident has been diagnosed with GERD, you will particularly want to watch for:

- Complaints of chest pain. This may be a symptom of their GERD, but it can also be a sign of heart disease (see Conditions: Heart Disease). Chest pain should always be evaluated by a doctor.
- Trouble sleeping can also indicate that GERD is causing pain and discomfort. If this is occurring, talk to the resident's PCP.
- **Medication side effects:** If a resident is taking a medication for GERD, ask the pharmacist or doctor about potential side effects of the medication and what you should look for and report. It is important to communicate symptoms to the resident's PCP. Some medications used to treat GERD can restrict absorption of vitamin B12 and Iron. This might require some diet modifications and a consultation with a dietitian.

If you notice...



any of the above changes in the resident which could be related to their condition, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of a problem can prevent more severe problems from developing, and will help maintain a better quality of life for residents.

What are some tips to manage GERD?

- Keep the resident in an upright position after eating.
- Avoid giving food or beverages 2 to 3 hours before bedtime.
- Encourage slow eating.
- Avoid food with caffeine, peppermint, citrus, tomatoes, high fat content or spicy ingredients.
- Avoid alcohol and cigarettes.
- Elevate the head of the bed a few inches.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lc/adc/customer/adrccontactlist.pdf>

What are my resources?

Gerd. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/gerd.html>

Is it just a little heartburn or something more serious? Understanding Gerd.

<http://s3.gi.org/patients/pdfs/UnderstandGERD.pdf>

Gerd. National Institute of Diabetes and Digestive and Kidney Diseases.

<http://digestive.niddk.nih.gov/ddiseases/pubs/gerd/>

Hearing Changes

Your ears have two jobs: One is hearing and balance. As people age, their ear structures change and become less effective, which leads to changes in both hearing and balance. Sound is produced from airwaves hitting the ear drum which, in turn, causes the small bones of the inner ear to vibrate (see page 4). This vibration is picked up by a nerve in the ear and transmitted to the brain. Problems that affect any of these processes can cause hearing loss. Some of the more common causes of hearing problems are:

- Blockage of the ear canal (wax).
- Swelling in the ear canal or middle ear (ear infections or allergies).
- Thickening or perforation of the eardrum preventing vibrations from being carried to the inner ear.
- Damage to the nerve carrying sound messages to the brain. History of excessive noise exposure makes this more likely.
- Diabetes and other diseases that affect the nerve carrying sound.
- Head injuries.
- Strokes.
- Medication side effects.
- Aging.

Some loss of hearing with age is normal. In fact, most people experience some hearing loss as they age. This normal, age-related hearing loss is called presbycusis. Older people can, of course, have more than one problem affecting their ability to hear. Hearing loss, especially when it happens suddenly, should always be checked by a doctor or audiologist. Blockage of the ear canal by ear wax is one of the most common causes of reversible hearing loss and is easy to correct.

The hearing loss related to aging mostly involves the nerve carrying messages to the brain. Age-related hearing loss causes sounds to be unclear. So even increasing the loudness of sound doesn't always help make it more clear. Hearing aids may be of limited use in this type of hearing loss. High frequency sounds are particularly affected, which makes women's voices more difficult to hear than men's voices. People with ID have a very high rate of hearing problems.

Some signs of ear problems are:

- Tinnitus (ringing in the ears).
- Dizziness or loss of balance.
- Ear pain.
- Ear fullness (a feeling of heaviness or congestion within the ear canal).

Whatever the cause, hearing changes should never be ignored. Hearing loss has a significant negative effect on quality of life. People who have hearing loss often become depressed and socially isolated. Sometimes they are even assumed to have dementia because they appear to be confused.

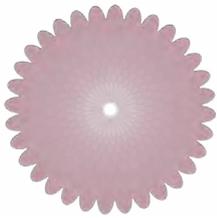
How is hearing loss treated and managed?

The goal of treatment for hearing changes is to maintain a resident's quality of life and safety. Treatment will depend on the type of hearing problem.

What should I be alert for?

Some signs of hearing loss are:

- Social isolation, not participating in activities.
- Depression or confusion.
- Inability to follow directions.
- Balance problems, increased falls.



If you notice...

any changes in the resident which could be related to hearing loss, talk to your house manager/supervisor about contacting the resident's PCP. Quick identification and treatment of a problem can prevent more severe problems from developing and will help maintain a better quality of life for residents.

What are some tips to help the resident with hearing loss?

- Decrease background noise when communicating with someone with hearing loss.
- Speak slowly and in a lower tone.
- Avoid shouting.
- If the resident has hearing aids, make sure the battery is working and they are used daily.
- In an emergency situation (fire, etc), be sure to personally notify the resident as they may not hear alarms.
- Hearing aids can be very helpful but difficult to get used to. It often helps to start using the hearing aid for only short periods of time, building up to longer times. Hearing aids magnify all noise in the environment. So noisy rooms could be very upsetting. People often remove their hearing aids when there is a lot of noise.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

What are my resources?

National Institute on Deafness and Other Communication Disorders.

<http://www.nidcd.nih.gov/>

Communication Tips with People who are Deaf or Hard of Hearing. E-Michigan Deaf and Hard of Hearing People.

http://www.michdhh.org/hearing/comm_tips.html

Hearing Loss. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/hearingloss/hearinglossdefined/01.html>

Communication Access for people who have communication disabilities: Guidelines and Resources on Communicating with People who have Communication Disabilities. Ministry of Community and Social Services. (Canada).

http://www.mcscs.gov.on.ca/documents/en/mcss/publications/accessibility/commAccessCommunicationDisabilities/Communication_Access_ENG.pdf

Heart Disease

There are many different forms of heart disease. Two of the most common are:

- **Coronary Heart Disease:** This is the most common form of heart disease. It is caused by narrowing or blockage of the coronary arteries (the blood vessels that supply blood to the heart). These blockages build up slowly over time. This is the major reason people have heart attacks.
- **Heart Valve Disease:** Heart valves control the flow of blood from one part of the heart to another. Heart valve disease occurs when one of the valves in the heart does not work correctly. When this happens, the heart pumps blood much less efficiently which can cause heart problems. Some people are born with this type of heart disease.

Heart disease symptoms vary depending on the type of heart disease. Some of the most common symptoms for all types of heart disease are:

- Chest pain.
- Shortness of breath.
- Swelling (Edema) in the legs and feet.
- Easily tiring with exercise or activities.
- Fainting or falls.
- General tiredness/weakness/fatigue.

How is heart disease treated?

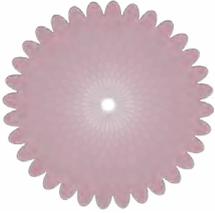
Heart disease treatments vary based on the type of heart disease. People may need changes in their diet and exercise or they may need treatments such as medications or surgery.

If heart disease is not managed well, there is a much greater risk of developing serious, even life threatening problems. However, if well managed, people can live many years with heart problems and are often able to continue the activities they enjoy.

What should I be alert for?

Some of the most significant symptoms and signs of worsening heart disease are:

- Rapid weight gain (usually from extra fluid and swelling in the body).
- Increased fatigue, sluggish behaviors, difficulty participating in activities.
- Discoloration of extremities (arms, hands, legs, feet), especially a bluish, purple color.
- Sweating, nausea and vomiting, or dizziness.
- Sudden swelling in feet and lower legs.
- Chest pain.
- **Medication side effects:** If a resident is taking a medication for heart disease, ask the pharmacist or doctor about any potential side effects that you should look for or report. Each resident reacts differently to medications. There are often several different medication options available, making it possible to change to one that does not cause problems for the individual.



If you notice...

any of the above symptoms, talk to your house manager/supervisor about contacting the resident's PCP. Quick identification and treatment of a problem can prevent more severe problems from developing, and will help maintain a better quality of life for the resident.

What are some tips to manage heart disease?

- Heart disease can improve with exercise. Encourage daily activities and exercise. **Be sure to consult the resident's doctor before beginning an exercise program.**
- Encourage a healthy diet with mostly fruits and vegetables, whole grain carbohydrates and lean protein. People with heart disease should try to follow a low sodium diet if possible.
- People with heart disease do much better if they can maintain a normal weight.
- Encourage no smoking/smoking cessation.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lc/lc/adrc/customer/adrccontactlist.pdf>

American Heart Association. 1-800-242-8721

<http://www.heart.org>

What are my resources?

Heart Disease. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/heartdiseases.html>

Centers for Disease Control and Prevention. Division of Heart Disease and Stroke Prevention.

<http://www.cdc.gov/DHDSP/index.htm>

Heart Health. National Institute on Aging.

http://www.nia.nih.gov/sites/default/files/heart_health.pdf

Hypertension (High Blood Pressure)

Hypertension is the technical term for high blood pressure. It is sometimes mistakenly believed to mean that a person is overly nervous or tense. When a person has high blood pressure, the pressure produced within their arteries is higher than it should be. Hypertension is relatively common. High blood pressure or hypertension is usually chronic. Once someone's blood pressure is found to be high, it must be treated or at least closely followed. This is important because hypertension generally has no symptoms. That is, people cannot tell when their blood pressure is high or when it is not. You cannot tell by looking at someone whether their blood pressure is high or low. Because it has no symptoms, it can only be picked up by taking a blood pressure reading.

All adults should be routinely screened for hypertension. The incidence of hypertension increases with age but it is not normal for older people to have hypertension.

How is hypertension treated?

Sometimes, if it is mild, hypertension can be treated with diet and exercise alone. It is important to work out a diet and exercise plan with someone who has expertise in this area. Only some types of exercise will be helpful and it will only be helpful as long as it continues. A thorough medical assessment is important prior to starting a new exercise program. There are many myths about diets. Dietitians are the best source of information on diets to help bring blood pressure down. It is possible that weight loss alone will bring a mild elevation in blood pressure back to normal.

More serious hypertension, or hypertension that does not respond to exercise and diet, is treated with medications. There are many medications for treating hypertension. Often more than one medication or combination of medications is necessary to bring blood pressure back to a normal range.

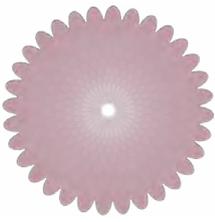
If left untreated, hypertension can lead to:

- Heart attacks.
- Strokes.
- Kidney damage.

What should I be alert for?

The most important thing to be alert for is medication side effects.

- Ask the pharmacist or doctor about any possible side effects of the medications used and what you should look for and/or report.
- One of the most important side effects to look for is dizziness on standing (orthostatic hypotension). This is particularly important as it can lead to falls and serious injury.
- Another side effect of medications for hypertension is frequent urination. This can be particularly problematic at night. Talking to the pharmacist or doctor about when to take the medications can be helpful.



If you notice...

any changes in the resident which could be related to their condition, talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of a problem can prevent more severe problems from developing and will help maintain a better quality of life for residents.

What are some tips to manage hypertension?

- Watch for side effects of medications.
- Be sure medications are taken as directed.
- Make sure the resident has follow-up care even after the blood pressure returns to normal.
- Focus on making the resident comfortable, maintaining activity, improving diet etc.
- Do not stop medications unless directed by the PCP.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

American Heart Association. 1-800-242-8721

<http://www.heart.org>

What are my resources?

Hypertension Information. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/ency/article/000468.htm>

High Blood Pressure. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/highbloodpressure/whatishighbp/01.html>

High Blood Pressure. National Institute on Aging.

http://www.nia.nih.gov/sites/default/files/high_blood_pressure_0.pdf

Lung Disease (Pulmonary, Respiratory Disease)

There are many different types of lung diseases. Some of the more common ones are: asthma, chronic obstructive pulmonary disease (COPD), emphysema, infections such as influenza, pneumonia, tuberculosis, lung cancer, obstructive sleep apnea and many others. People with ID have an increased risk of obstructive sleep apnea. Sleep apnea is when people have periods where they are not breathing during their sleep cycle. People with sleep apnea often snore but not everyone who snores has sleep apnea.

While each disease will have its own characteristics, there are signs and symptoms commonly found in people with lung diseases. These include:

- Persistent cough.
- Difficulty breathing.
- Wheezing or gasping.
- Coughing up blood or sputum (mucous).
- Chest pain that is worse when inhaling or taking in a breath.
- Choking or coughing after eating or drinking.

How is lung disease treated and managed?

The goals of lung disease treatments are:

- Prevent the disease wherever possible (quit smoking and avoid irritants/asthma triggers, aspiration or choking).
- Treat chest infections.
- Treat lung disease to stop or slow the progression of lung damage.
- Relieve symptoms and ease breathing, sometimes requiring inhalers or oxygen.

If lung disease is not well managed, it can lead to permanent lung damage.

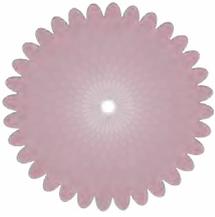
What should I be alert for?

Some people with ID have difficulty telling you when something is wrong. Therefore, it is important to be alert for signs of breathing distress. You should be alert for:

- Sudden, severe shortness of breath or difficulty breathing (**which is an emergency**).
- Bluish-coloring around a resident's lips or fingers.
- More rapid breathing than usual (more breaths per minute).
- Noisy breathing.
- Inability to participate in exercise or activities due to breathing problems.

Breathing difficulty can be very frightening. Anytime a resident has a sudden change in their breathing, they should be seen by a doctor immediately.

Medication side effects: If a resident is taking a medication for lung disease, ask the pharmacist or doctor about potential side effects of the medication and what you should look for or report. Medications to assist people with breathing problems are more effective when taken exactly as prescribed.



If you notice...

any of the symptoms described above, talk to your house manager/ supervisor about contacting their PCP. **If the symptoms are severe, follow your agency's emergency procedures.** Quick identification and treatment of lung diseases problem can prevent more severe problems from developing and will help maintain a better quality of life for residents.

What are some tips to manage lung disease?

- Make sure people with lung disease receive influenza and pneumonia vaccines.
- Understand the correct use of inhalers, nebulizers and oxygen equipment.
- Help the resident to conserve energy. An OT could be very helpful with this.
- Help the resident alternate periods of activity with rest periods.
- Encourage eating slowly, taking small bites of food and small sips of drink to avoid aspiration and choking.

Who can I call for help after the Primary Health Care Provider?

American Lung Association. 1-800-586-4872

<http://www.lung.org>

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Lung Diseases. Medline Plus.

<http://www.nlm.nih.gov/medlineplus/lungdiseases.html>

Obesity (Overweight)

The longer a person is obese, the higher risk for developing diabetes, heart problems, arthritis, some cancers and many other health problems. Obesity can lead to loss of independence and can limit a person's ability to participate in work and social activities.

Obesity is a serious problem. It is more common among people with ID than in the rest of the population. The risk is even higher for those with Down Syndrome. Genetic causes, reduced activity levels and difficulty controlling calorie intake may be reasons for this difference. The risk of obesity also rises with age, as people become less active and need fewer calories to maintain their weight.

How is obesity treated?

The goal of treating obesity is to lower a person's weight while maintaining adequate nutrition. In older adults, weight loss can be very difficult because older people do not need as many calories as they did when they were younger. Older people also tend to exercise less than younger people. In addition, the impact of illness and chronic conditions may make exercising difficult.

Generally, if obesity is due to lifestyle issues (diet and physical activity levels) rather than medication side effects or other health conditions, the most effective diet will be:

- low in calories, including lowering intake of fats and sugars.
- high in fiber from wholegrain breads and cereals, fruit and vegetables.

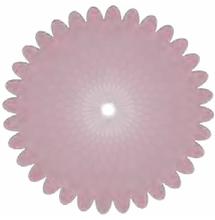
Regular physical activity in accordance with the resident's abilities is very helpful when trying to lose weight.

Obesity puts people at risk for heart disease, skin infections, incontinence, diabetes and even cancer. Quality of life can decline as social activities often become more difficult.

What should I be alert for?

You can help people who are overweight by watching for:

- Difficulty performing personal hygiene and other tasks. As weight increases, people may need extra assistance with routine activities and personal hygiene.
- Difficulty walking. Pay attention to the way the resident moves around the house, in/out of vehicles, and gets up from chairs.
- Urinary or bowel problems. Dieting may cause some minor changes in bowel and bladder functioning (excessive gas or bloating, changes in stool consistency, changes in frequency of elimination). Incontinence is more likely in people who are obese.



If you notice...

any of the problems described above talk to your house manager/supervisor about contacting their PCP. Quick identification and treatment of a problem can prevent more severe problems from developing and will help maintain a better quality of life for residents.

What are some tips to manage obesity?

If a resident is obese, you will need to support him/her in making decisions about diet and exercise and in following decisions through. Obesity in people with ID, just as with the rest of the population, is difficult to manage and having a supportive environment can be helpful.

- While providing support, it is important to remember the resident's choice to take informed risks. If the resident strongly wishes to enjoy cookies each night, despite understanding the health risks, helping to find healthier cookies may be something you can do to support the resident.
- Discuss with your house manager/supervisor ways you can support a healthier diet and activity level for the household, with attention to individual dietary needs.
- Speak with a health care provider about how you can help with movement, comfort and hygiene to decrease injury and the likelihood of infections.
- Avoid using food/sweets as reward.
- Consult with a dietitian to develop a weight loss plan.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

The Dietitian in your workplace or in the resident's provider network.

What are my resources?

Aim for a Healthy Weight. National Heart Lung and Blood Institute.

http://www.nhlbi.nih.gov/health/public/heart/obesity/lose_wt/index.htm

Overweight and Obesity Among People with Disabilities. Obesity Fact Sheet. Centers for Disease Control and Prevention.

<http://www.cdc.gov/ncbddd/disabilityandhealth/documents/obesityfactsheet2010.pdf>

Eating Well as You Get Older. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/eatingwellasyougetolder/benefitsofeatingwell/01.html>

Academy of Nutrition and Dietetics.

<http://www.eatright.org>

Parkinson's Disease

Parkinson's is a brain disease that causes tremors and difficulty with body movement. A person with Parkinson's disease often experiences trembling or shaking movements in the face and/or extremities that are difficult to control. This can lead to difficulty walking or with coordinating movements and can also disrupt speech.

Though tremors are common, not every person with Parkinson's has them. Other symptoms are:

- A stiffening of extremities (rigid muscles).
- Difficulty making facial expressions.
- A quieter voice.
- Imbalanced walking.
- Occasional bursts of fast walking.

Parkinson's is not curable and continues to worsen over time. The average life expectancy for a person with Parkinson's is 15 years after diagnosis.

How is Parkinson's Disease treated and managed?

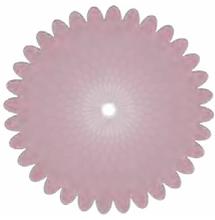
Parkinson's disease is treated with medications aimed at restoring chemical imbalances in the brain. Medications often need to be adjusted, so it is important to communicate with the resident's PCP if any medications seems not to be working. Occupational, physical, and speech therapy may be necessary for a resident with Parkinson's disease. If not managed well, the following results are more likely to occur:

- Falls.
- Infections.
- Breathing problems.
- Choking.
- Depression.
- Loss of daily living skills.
- High blood pressure.

What should I be alert for?

If a resident has been diagnosed with Parkinson's disease, you will particularly want to watch for:

- Eating difficulties (see Symptom: Choking).
- Pain in muscles (see Symptom: Pain).
- Difficulty walking (see Symptom: Walking Problems).
- Difficulty performing activities of daily living (see Symptom: Loss of Daily Living Skills).
- Increased tremors.
- Memory difficulties, as dementia is common in people with Parkinson's.
- Sleep problems (see Symptom: Night Walking).
- **Medication side effects:** If a resident is taking a medication for Parkinson's disease, ask the PCP about any side effects of the medications and what you should look for and report.



If you notice...

any changes in the resident which could be related to his/her condition, talk to your house manager/supervisor about contacting the PCP. Quick identification and treatment of a problem can prevent more severe problems from developing, and will help maintain a better quality of life for residents.

What are some tips to manage Parkinson's Disease?

- Simple tasks such as opening a jar, walking down the hall, putting on clothes and opening a door can be difficult for those with Parkinson's disease. There are several assistive devices that can help people maintain independence. Visit <http://www.aidsforarthritis.com> to explore what might be useful for a resident with Parkinson's Disease. Consult with the resident's PCP or an occupational therapist before using any devices.
- If speech or abilities to perform tasks are becoming difficult, and speech, occupational or physical therapy has not been ordered, request a referral.
- High blood pressure is a risk for people with Parkinson's Disease. Consult with a dietitian about how to provide a diet to lower this risk.
- Constipation and incontinence (see Symptom: Urinary frequency) are common in people with Parkinson's. If the resident is using the toilet frequently, suffering from uncontrolled urination or complaining of pain in the abdomen, speak to your house manager/supervisor and the resident's PCP about how to manage these issues.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/ltcare/adrc/customer/adrccontactlist.pdf>

American Parkinson Disease Association Information and Referral Center of Wisconsin.
1-608-229-7628

<http://www.wichapterapda.org/informationreferral.html>

National Parkinson Foundation. 1-800-473-4636

<http://www.parkinson.org/>

What are my resources?

American Parkinson Disease Association Wisconsin Chapter Support Group List.

<http://www.wichapterapda.org/supportgroups.html>

Parkinson's Disease Overview. National Parkinson Foundation.

<http://www.parkinson.org/parkinson-s-disease.aspx>

Parkinson's Disease. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/parkinsonsdisease/whatisparkinsonsdisease/01.html>

Stroke

A stroke results from damage to a section of the brain. Strokes are also known as CVAs or cerebral vascular accidents. There are two types of strokes, one caused by a bleed into brain tissue and one resulting from a blockage of blood flow to a section of the brain. Both a bleed and a blockage of blood flow cause damage to brain tissue. Depending on the area of the brain where the damage occurs and the severity of the damage, strokes can cause many different problems. Some of the problems resulting from strokes include:

- Weakness or paralysis in a part of the body (usually on one side or the other)
- Loss of speech.
- Difficulty swallowing.
- Loss of ability to walk.
- Failure to recognize parts of their own body.

There are many things that increase the chance of having a stroke. Some of these are:

- High blood pressure that is not treated adequately.
- Certain kinds of heart disease.
- Narrowing of the arteries to the brain or in the brain.
- Altered heart rhythm (arrhythmia or atrial fibrillation).

How is a stroke managed?

People who have had strokes sometimes take medications to help prevent another stroke. It is important to remember that strokes are often preventable, and the damage from a stroke can often be minimized by immediate treatment.

What should I be alert for?

Sometimes strokes are preceded by warning signs. Some of these warning signs are transient or temporary:

- Changes in vision/double vision.
- Slurred speech.
- Numbness or weakness in the face, arms, legs or one side of the body.
- Difficulty with balance, trouble walking or dizziness.

Being alert for the warning signs of a stroke, and seeking immediate treatment, can sometimes prevent serious or permanent damage from occurring, or at least can minimize the damage. Making sure that people have follow up care and stay on their medications for high blood pressure and heart problems is also important.

Medication side effects: If the resident is taking medication to prevent a stroke, ask the pharmacist or doctor about side effects of the medication and what you should look for and report. There are often several types of medication options available and each resident may react differently to a medication, therefore it is important to communicate problems with any medication to the resident's PCP.

What are some tips to manage after a stroke?

People can often recover at least some lost abilities following a stroke if they participate in a rehabilitation program. Rehabilitation should be considered for lost speech, weakness, or balance problems. It is important to start rehabilitation as soon as possible.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcicare/adrc/customer/adrccontactlist.pdf>

What are my resources?

Stroke. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/stroke/aboutstroke/01.html>

Post-Stroke Rehabilitation Fact Sheet. National Institutes of Health.

<http://www.ninds.nih.gov/disorders/stroke/poststrokerehab.htm>

Stroke. National Institute on Aging.

<http://www.nia.nih.gov/sites/default/files/stroke.pdf>

Centers for Disease Control and Prevention. Division of Heart Disease and Stroke Prevention.

<http://www.cdc.gov/DHDSP/index.htm>

Vision Loss

There are many things that can cause vision loss. Some loss of vision is normal with aging. This type of vision loss, called Presbyopia, involves difficulty focusing on objects that are close (see page 2). This often becomes noticeable in people in their early 40's. Glasses can make it much easier to see things that are close up or small. These are often referred to as reading glasses. Although not considered normal aging, there are many eye diseases that are more frequent in older people. These are serious problems and need to be treated. They include:

- **Cataracts:** Cloudiness over the eye lens, progressively worsening, can be in one eye or both eyes.
- **Macular Degeneration:** Loss of central vision, blurred vision, distorted vision (like seeing wavy lines), and colors appearing faded. The most common cause of blindness.
- **Glaucoma:** Increased pressure in the eye. Vision changes include loss of peripheral vision, intolerance to glare, decreased perception of contrast and decreased ability to adapt to the dark. Major cause of blindness. Glaucoma can happen gradually or suddenly -- **if sudden, it's a medical emergency.**
- **Diabetic Retinopathy:** Damage from diabetes causing spotty vision.

Other possible causes of vision problems include fatigue, overexposure to the outdoors (temporary and reversible blurring of vision), and many medications. Whatever the cause, vision changes should never be ignored. They can become more serious, lead to permanent vision loss and have a significant impact on quality of life. Poor vision also contributes to falls, a major risk for nursing home placement.

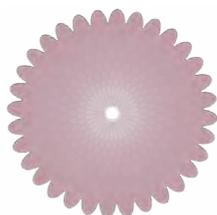
How is vision loss managed?

The goal of treatment for vision changes is to maintain both high quality of life and safety. Treatment can depend on the type of vision change. People may only need glasses if their vision change is related to aging. Sometimes surgery is required to fix vision problems.

What should I be alert for?

If a resident has been diagnosed with vision loss or a problem that can lead to vision loss, you will want to watch for:

- Increased falls (see Symptom: Falls).
- Difficulty with navigation around the house.
- Difficulty recognizing familiar people or objects (see Symptom: Confusion).
- Clumsy behavior.
- Frequent rubbing of eye.
- Head tilting.



If you notice...

anything that might suggest vision changes, talk to your house manager/supervisor about contacting the PCP. Quick identification and treatment of a problem can prevent more severe problems from developing, and will help maintain a better quality of life for residents. Quick action can sometimes prevent permanent vision loss.

What are some tips to support people after vision loss?

- Do not make unnecessary changes to the environment/home.
- Provide adequate lighting.
- Reduce glare produced by lights or sun. This can be done by moving the light source or closing window shades.
- If the resident has glasses or visual aids, make sure he/she is wearing them for activities such as eating, walking, or reading.
- Explain what food is being served and where it is located on the plate if necessary.
- Encourage use of radios, CDs, and talking books.
- Remove environmental barriers to ensure safety (garbage cans, clutter).
- A loss of depth perception can cause significant challenges when using steps/stairs.
- Assure stairs have handrails.
- It can be useful to make the front ledge of steps a different color, such as white or yellow. This will help the resident find each step and can help avoid tripping or falling.
- Remove loose rugs or carpets on the stairs. All rugs should be securely attached to the floor to prevent slipping.

Who can I call for help after the Primary Health Care Provider?

Aging and Disability Resource Center (see Resources section of this Manual)

<http://www.dhs.wisconsin.gov/lcure/adrc/customer/adrccontactlist.pdf>

What are my resources?

Tips for Living with Low Vision. State of Wisconsin Department of Health Services. Division of Long Term Care. Office for the Blind and Visually Impaired.

<http://www.dhs.wisconsin.gov/publications/P2/p23201.pdf>

Creating Safe Environments for People with Vision Loss: The Basics! Massachusetts Commission for the Blind and Department of Developmental Services Partnership.

<http://www.mass.gov/eohhs/docs/dmr/safe-environment.pdf>

Do you know someone with vision loss? Sight Connection.

<http://www.sightconnection.org/wp-content/uploads/know-someone-with-vision-loss.pdf>

How to Best Assist a Person with Vision Impairment. Massachusetts Commission for the Blind and Department of Developmental Services Partnership.

<http://www.mass.gov/eohhs/docs/dmr/best-assist.pdf>

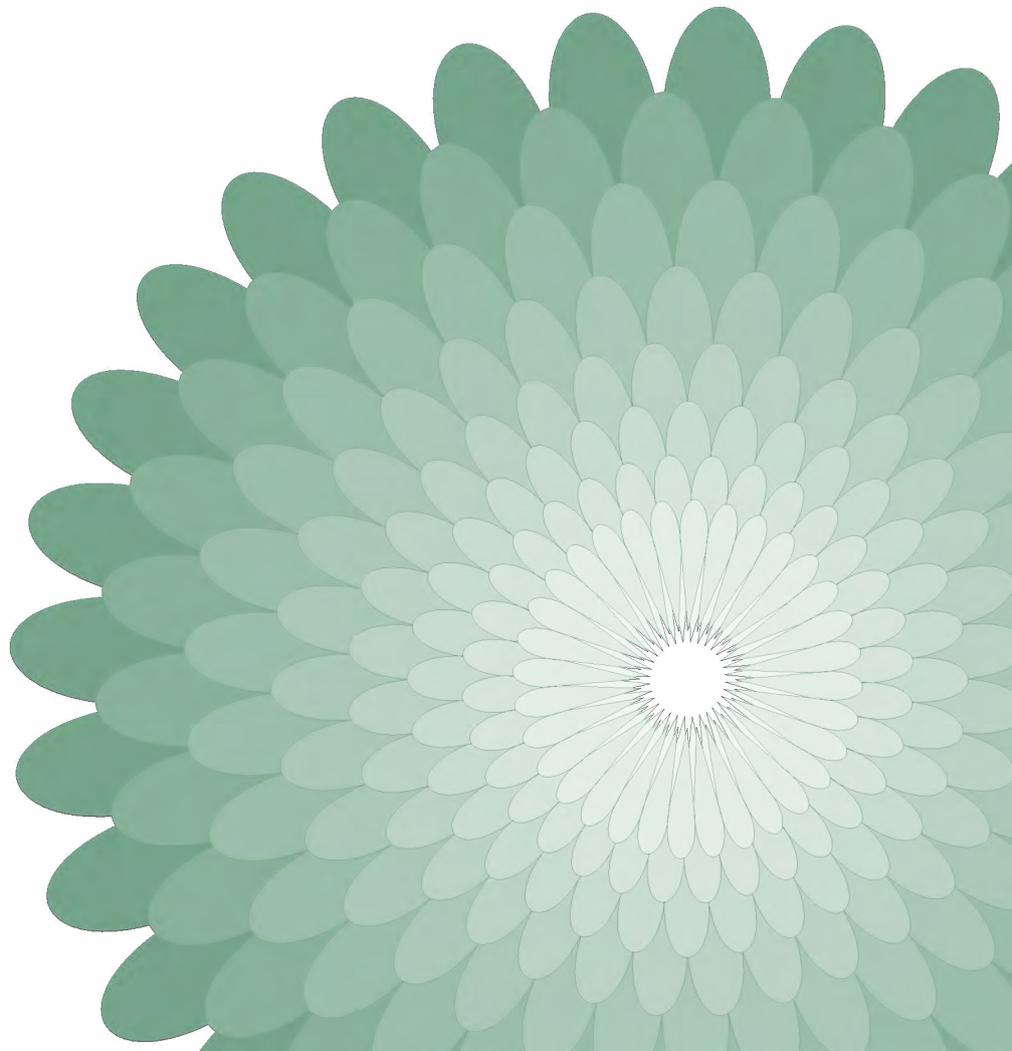
Cataract. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/cataract/whatisacataract/01.html>

Low Vision. Senior Health. National Institutes of Health.

<http://nihseniorhealth.gov/lowvision/lowvisiondefined/01.html>

Accessing Resources



Aging with Intellectual disability resources

Aging and Disability Resource Centers

The Wisconsin Department of Health Services Aging and Disability Resource Centers (ADRCs) are located across the state, providing comprehensive assistance for all those seeking services related to aging or living with a disability. The ADRCs serve families in the community and professionals seeking to identify available resources for their family members and residents.

Services include:

- Health and wellness assessment and care
- Program eligibility determination
- Program application assistance and advocacy
- Discussion of long-term care opportunities.

ADRCs will administer services via the telephone or through home visits if necessary.

For a complete list of services provided by ADRCs, please go to <http://www.dhs.wisconsin.gov/ltcare/adrc/>. A list of ADRC offices may be found at <http://www.dhs.wisconsin.gov/LTCare/adrc/customer/adrccontactlist.pdf>. The DHS provides a list of long-term resources at <http://www.dhs.wisconsin.gov/programs/ltc.htm> to assist those who are in counties that are not currently served by an ADRC office.

Long-term Care Options

Long-term care options for adults with intellectual disabilities in Wisconsin include Family Care, Family Care Partnership and IRIS.

Family Care

Family Care is a home-based program designed to help eligible individuals access resources available in the community or institutions. Family Care eligibility is limited to those who have a disability or are aged 65; have long-term care needs (person must have condition expected to last at least 90 days); meet financial eligibility requirements; and live in a Family Care county. A map of Family Care counties is available at <http://www.dhs.wisconsin.gov/LTCare/Generalinfo/map.pdf>. Please contact your local ADRC office if you have questions about Family Care eligibility requirements.

Managed Care Organizations (MCOs) are responsible for Family Care implementation, so membership in an MCO is part of enrollment. Individuals who are currently receiving Medicaid meet the financial eligibility requirements; however, others may be required to pay a portion of the costs to the MCO. For additional information about Family Care, please contact your local ADRC office or go to <http://www.dhs.wisconsin.gov/ltcare/>.

Family Care Partnership

The Family Care Partnership program is a comprehensive home-based service designed for elderly individuals and those with disabilities. The Partnership employs a collaborative approach, as participants, community-based service providers, physicians, and other medical care givers work together to ensure high-quality, participant-guided care. Partnership program eligibility is restricted to those who are eligible for Medicaid and certified at the Medicaid nursing home level of care.

The program is only available in some Wisconsin counties. A map of Family Care Partnership counties is available at <http://www.dhs.wisconsin.gov/LTCare/Generalinfo/map.pdf>. Additional information regarding the Family Care Partnership program may be obtained by contacting your local ADRC office or go to <http://www.dhs.wisconsin.gov/wipartnership/>. The DHS, Division of Long Term Care has also made a resource booklet entitled, "Being a Full Partner: Important information for Family Care and Family Care Partnership members or for anyone who is trying to decide whether to enroll in managed long-term care." This booklet may be accessed at <http://www.dhs.wisconsin.gov/ltcare/pdf/beinga-fullpartnerlargeprint.pdf>.

IRIS

IRIS (Include, Respect, I Self-Direct) is a long-term care option that allows elderly individuals with intellectual disabilities to access community resources, helping them to retain self-sufficiency and stay in their homes. The participants and their caregivers may be active in long-term care planning. Individuals may design care plans that include community services that they determine to best meet their needs. Participants are given a monthly IRIS budget that they may use to self-select the services and goods. An IRIS Consultant is provided at no charge to the participant. The Consultant is responsible for administering bill payment for participant authorized services.

IRIS is a DHS program implemented by the Bureau of Long Term Support under authorization of the Centers for Medicaid and Medicare Services. Eligible individuals include those who are both eligible for Medicaid and long term care services and who are residing in a Family Care county (see the map found at <http://www.dhs.wisconsin.gov/bdds/iris/irismap.pdf> for IRIS availability). For more information about IRIS, please contact your local ADRC office. You may also visit the DHS website at <http://www.dhs.wisconsin.gov/bdds/iris/general.htm> and review the DHS brochure found at <http://www.dhs.wisconsin.gov/bdds/iris/broch2Pgs.pdf>.

Key Services and Resources by Topic:

Advocacy/Legal Services

- ABC for Health
<http://www.safetyweb.org/>
- Attorney Robert (Rock) Pledl
rtp@pledcohn.com
- Board for People with Developmental Disabilities
<http://www.wi-bpdd.org/>
- Coalition of WI Aging Groups (CWAG)
<http://cwagwisconsin.org/>
- Disability Rights Wisconsin
<http://www.disabilityrightswi.org/>
- Greater WI Agency on Aging Resources, Inc. (GWAAR)
<http://www.gwaar.org/>
- Wisconsin Board on Aging & Long Term Care (BOALTC)
<http://longtermcare.wi.gov>
- Wisconsin Judicare, Inc.
<http://www.judicare.org>

Dementia and Memory

- Alzheimer's Association
<http://www.alz.org>
- Alzheimer's Association of Greater Wisconsin
<http://www.alz.org/gwwi>
- Alzheimer's Association of Southeastern Wisconsin
<http://www.alz.org/sewi>
- Alzheimer's and Dementia Alliance of Wisconsin
<http://alzwisc.org>
- Alzheimer's Disease and Dementia Resources
<http://www.dhs.wisconsin.gov/aging/Genage/ALZFCGSP.HTM>
- Wisconsin's Alzheimer's Disease Research Center
<http://adrc.wisc.edu>
- Wisconsin's Alzheimer's Institute
<http://www.wai.wisc.edu>

Government Publications and Resources

- Wisconsin Long Term Care and Support Resources
<http://www.dhs.wisconsin.gov/programs/ltc.htm>
- Wisconsin Services for the Elderly
<http://www.dhs.wisconsin.gov/aging>

Dental Care and Oral Health

- Apple Tree Dental (Minnesota)
<http://www.appletreedental.org/>
- American Academy of Developmental Medicine and Dentistry (AADMD)
<http://aadmd.org/>
- Special Care Dentistry Association
<http://www.scdonline.org/?page=LinksResources>
- Special Care Dentistry Association (Access to special care training for dental professionals)
<http://www.scdonline.org/?page=EducationModules>
- Wisconsin Community Health Centers
<http://www.wphca.org/For-Patients/warp5-framework.html>
- Wisconsin Dental Association (Reduced rate dental clinics)
<http://www.wda.org/your-oral-health/community-activities/community-dental-clinics>
- Wisconsin Dental Association Mission of Mercy
<http://www.wda.org/wda-foundation/mission-of-mercy/patients>

Mental Health

- National Center for Trauma-Informed Care
<http://www.samhsa.gov/nctic/>
- SAMHSA - Promoting Emotional Health and Preventing Suicide:
<http://store.samhsa.gov/product/Promoting-Emotional-Health-and-Preventing-Suicide/SMA10-4515>
- Wisconsin Community Mental Health Services
http://www.dhs.wisconsin.gov/mh_bcmh/

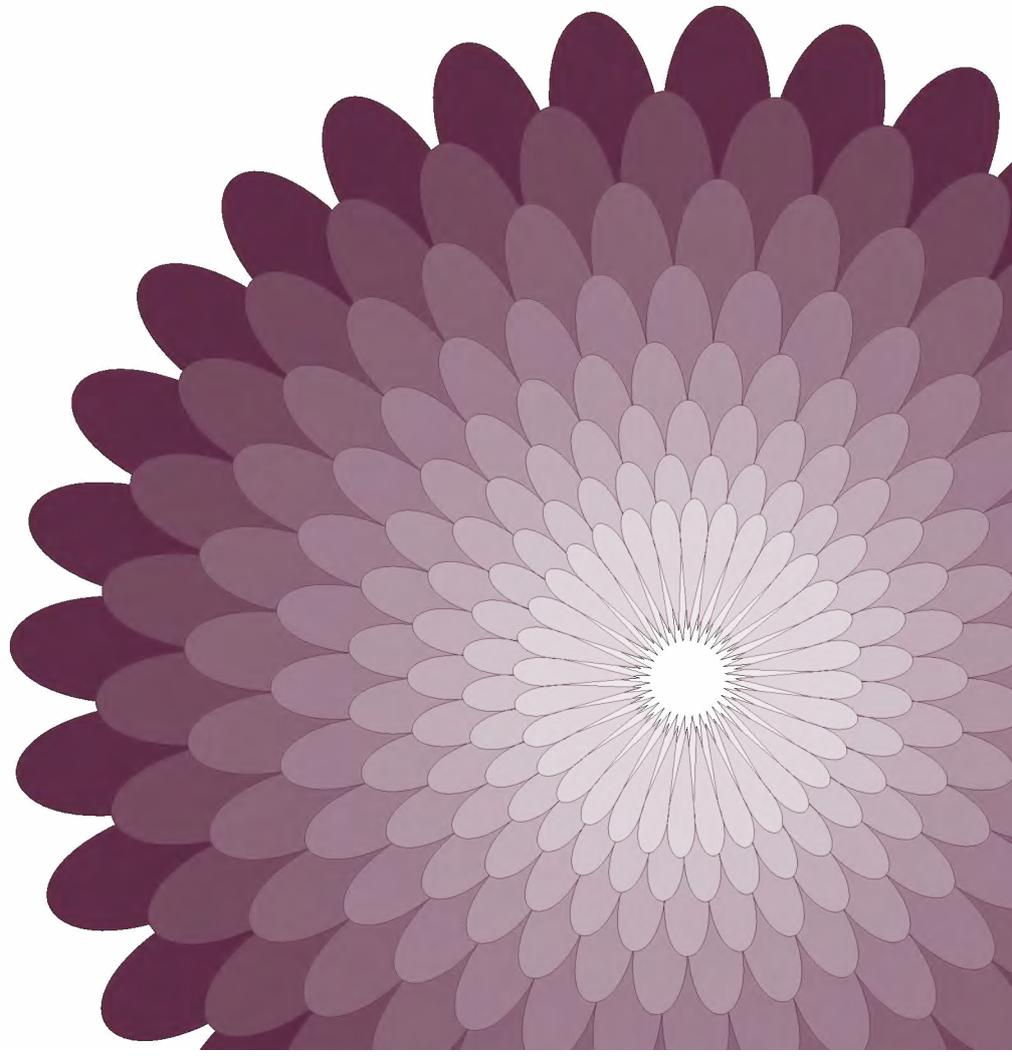
Nursing Care

- Developmental Disabilities Nurses Association (DDNA)
www.ddna.org
- Family Care/Family Care Partnership
<http://www.dhs.wisconsin.gov/lcicare/>
- IRIS
<http://www.wisconsin-iris.com/>
- LeadingAge Wisconsin
<http://www.leadingagewi.org>
- Wellness Inclusion Nursing (WIN)
<http://cow.waisman.wisc.edu/win.html#maincontent>
- Wisconsin Health Care Association
<http://whca.com>
- Wisconsin Home Health Agencies
<http://www.dhs.wisconsin.gov/bqaconsumer/healthcare/homehealth.htm>

Hospice Care

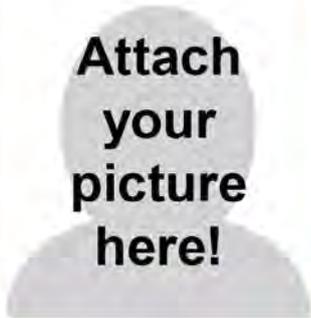
- Care Coordination for Hospice Patients in Community Based Residential Facilities (CBRFs)
<http://www.dhs.wisconsin.gov/publications/p0/p00314.pdf>
- Department of Health Services (Provider Search - Hospice)
<https://www.forwardhealth.wi.gov/WIPortal/DQA%20Provider%20Search/tabid/318/Default.aspx>
Leave Provider Name blank. Select name of County. In 2nd section under Provider/Facility type, click on Hospice.
- The HOPE (Hospice and Palliative Care Experts) of Wisconsin
<http://www.hopeofwisconsin.org/>

Appendix



H My Health Passport H

! If you are a health care professional who will be helping me, **PLEASE READ THIS** **!**
before you try to help me with my care or treatment.

| | |
|--|--|
| <p>My full name is: _____</p> <p>I like to be called: _____</p> <p>Date of birth: ____ / ____ / ____</p> <p>My primary care physician: _____</p> <p>Physician's phone number: _____</p> | <p>Attach your picture here!</p>  |
|--|--|

This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

Please keep this with my other notes, and where it may be easily referenced.

My signature: _____ Date completed: ____ / ____ / ____

You can talk to this person about my health: _____

Phone number: _____ Relationship: _____

| | |
|---|--|
|  | <p>I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)</p> <p>_____</p> <p>_____</p> <p>_____</p> |
|---|--|



My brief medical history: (include other conditions (e.g. visual impairment, hearing impairment, diabetes, epilepsy) past operations, illnesses, and other medical issues)



My current medications are:

- _____
- _____
- _____
- _____
- _____
- _____



When I take my medication, I prefer to take it: (e.g. with water, with food)



I am allergic to: (list medications or foods, e.g. penicillin, peanuts)



If I am in pain, I show it by: (also note if I have a low/high pain tolerance)



If I get upset or distressed, the best way you can help is by: (e.g. play my favorite music)



How I cope with medical procedures: (e.g. how I usually react to injections, IV's, physical examinations, x-rays, oxygen therapy—also note procedures never experienced before or in recent years)



My mobility needs are:
(e.g. whether I can transfer independently, devices I use, pressure relief needed)



When getting washed and dressed, you may assist me by:



When drinking, you may assist me by:



When eating, you may assist me by:



My favorite foods and drinks are:



I do not like to eat or drink the following:



I am very sensitive to: (specific sights, sounds, odors, textures/fabric, etc. that I really dislike, e.g. fluorescent lights, thunderstorms, bleach, air freshener)



Things I like to do that will help pass the time:



How to make future/follow-up appointments easier for me:

(e.g. give me the first/last appointment of the day, allow extra time for the appointment, let me visit before my appointment, give information to my caregiver, etc.)

What is a Blood Test?

Queensland Center for Intellectual and Developmental Disability, University of Queensland

A blood test is when blood is taken out of your arm. You go to the desk to tell them you have come.



You might have to sit and wait.



You will walk into the collection room and be asked to sit in a collection chair.



The nurse will ask your name and when your birthday is and will tell you what will happen.



You will put your arm on the side of the chair with your hand facing up.



A cord is put around the top of your arm.



What is a Blood Test?

Included with permission. Excerpt from: Rey-Conde, T., Lennox, N., & Tucker, M. Diabetes and People with Intellectual Disability. Queensland Center for Intellectual and Developmental Disability, University of Queensland.

Your arm will be cleaned with a cotton ball.
This is cold and wet.



A needle is put into your arm. It might hurt.



Blood will go into the tube.



The cord will be taken off your arm.



The needle is taken out. It might hurt.



A cotton ball is put on your arm with sticky tape.
A bruise can develop where the needle was, but
this goes away. It might also be sore.



*A Manual on how to properly fit shoes in order to avoid foot problems
Included with author permission from Disability Services Commission*

Heel Counter (the back of the shoe)

- The heel counter of the shoe should be firm. This provides stability and support for the heel.
- A good heel counter should be firm enough to resist flattening when pushed from behind (figure 5a). Firm resistance should also be felt when squeezing the heel counter at the sides (figure 5b).

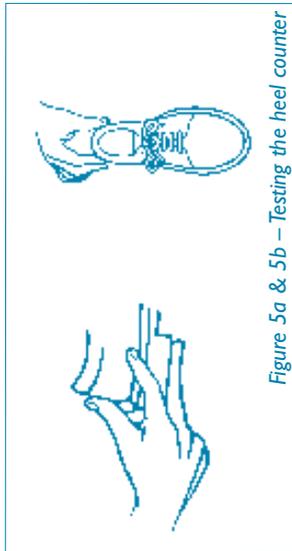


Figure 5a & 5b – Testing the heel counter

Heel Height

- For stability and safety a heel height less than 2.5cm and a broad base is essential. Heel styles with a slight out-flare provide added stability.

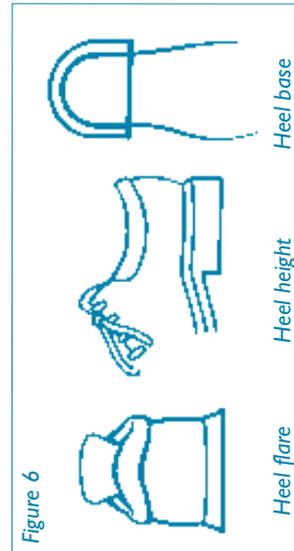


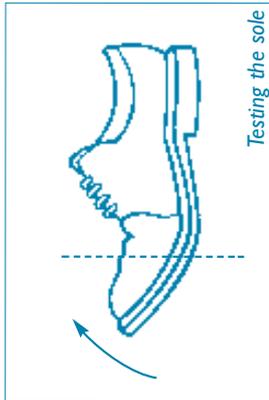
Figure 6

Around the Heel

- The shoe should fit snugly around the heel. To check the heel grip, have the person seated with the shoe firmly secured, pull the heel of the shoe firmly downward to ensure there is no heel slippage.

The Sole

- The sole of the shoe should provide firm support, but also be able to flex where the foot bends as we walk or run. This flex should be directly under the ball of the foot. The shoe should not bend or flex in the mid-sole or heel area.



Testing the sole

Tying Laces

- If an individual has difficulty tying laces then there are devices to assist. 'Lace Lox' is an example of a product that is a useful alternative to tying bows.
- Information is available on alternative methods of lace securing techniques and products, including a technique for lace tying for individuals who have the use of only one hand.

Disability Services Commission

Level 1, Joondalup House,
8 Davidson Terrace, Joondalup WA 6027
Telephone: 9301 3800
71-73 Norma Road, Myaree WA 6154
Telephone: 9329 2300
Web: www.dsc.wa.gov.au (go to 'publications')



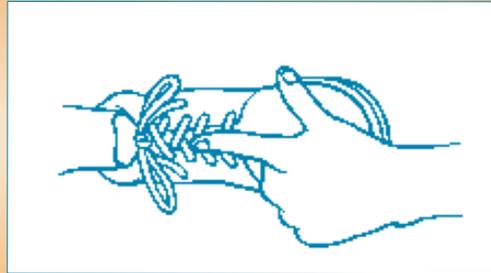
For Further Help

If you require further information not covered in this brochure or details on suppliers of footwear or other associated products, contact the service where you were given this brochure or contact:



Information on

FITTING FOOTWEAR



making a difference

When Buying Footwear:

Do

- Have both feet measured so that both feet are fitted correctly.
- Buy shoes for the larger foot to give both feet enough room.
- Buy shoes with laces, buckles or velcro strap fastenings so the feet do not move in the shoe and are well supported.
- Buy shoes with leather or fabric uppers which allow good airflow to the feet.
- Buy shoes with a firm heel counter to support the heel.
- Buy shoes with a broad low heel for better stability.
- Buy shoes with a firm sole to provide support and stability.
- Buy shoes with rubber or composite soles for better shock absorption and grip.

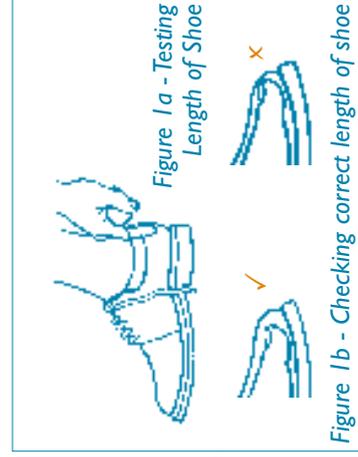
Don't

- Don't buy shoes too big as this can cause tripping and rubbing of the toes.
- Don't buy too many pairs of shoes, instead get good wear from two pairs.
- Don't buy slip-on shoes or boots as they give poor foot support and restrict free toe movement.
- Don't buy shoes with flimsy soles as they give poor support for the feet.

Tips on Fitting Footwear

Length Test

- While sitting, loosen fastenings and push the foot forward in the shoe until the longest toe is up against the end of the shoe. Stand up. While standing, you should be able to fit one index finger comfortably behind the



heel (figure 1a). If not, the shoe is too short, or if there is a lot of room, the shoe is too long.

- Alternatively, secure the fastening of the shoe. While standing, feel for the end of the longest toe (remember the big toe is not always the longest). The shoe should be approximately an index finger's width longer than the longest toe (figure 1b).

Width Test

- While standing, feel the inner and outer borders of the shoe's upper. If the upper overlaps the edges of

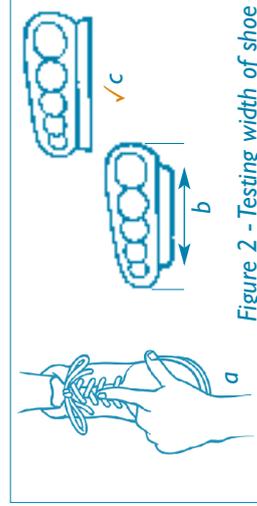


Figure 2 - Testing width of shoe

- Shoe width can also be tested by securely fastening the laces, taking note of the gap between the laces. This should be approximately 1cm apart or one finger width (figure 2a). A gap greater than 1.5-2cm between the lace edges indicates that the shoe is too narrow. If the lace edges meet then the shoe is too broad.

- In other footwear, the fastenings should join securely, if not, the shoe is too narrow. If there is excess bulging on the upper part of the shoe then the shoe is too broad.

Shoe Shape

- The sole shape of a shoe should reflect the shape of the feet. Children's shoes should have minimal or no

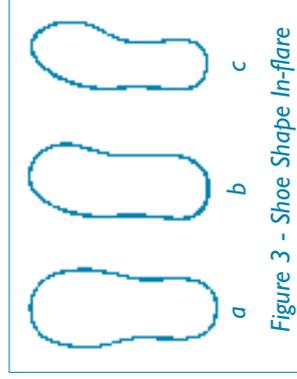


Figure 3 - Shoe Shape In-flare

'in-flare' (figure 3a and 3b). In-flare is the shape of the sole of the shoe and the degree to which it curves inwardly. If a shoe has too much

in-flare (figure 3c), it will not fit the foot correctly and may cause rubbing and blisters. It may also contribute to tripping.

The Toe Box

- The shape, depth and width of the toe box of the shoe should allow the toes to spread naturally. In some footwear, especially slip-on footwear, the toe box of the shoe can cause constriction of the toes, damage to toenails and blisters.



Check the shape of the toe box