

# **Management of Pain for People with Intellectual Disabilities And Other Developmental Disabilities**



**Philadelphia Coordinated Health Care  
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*Management of Pain  
For People with Intellectual Disabilities  
and  
Other Developmental Disabilities*

*Dedication:*

*This book is dedicated to Marge, Anna, and all people with Intellectual Disabilities and other developmental disabilities who also experience pain which has not been properly assessed and diagnosed and who, therefore, have not received adequate pain management.*

# THEIR STORIES

## Marge

Marge is a 42 year-old woman who cannot speak and has a diagnosis of profound intellectual disability (ID). She has always lived at home with her parents. Last year, her father retired and began to pressure Marge's mother to find a place for Marge to live away from the family home. Marge's mother would not even discuss the issue.

During this time of upheaval, Marge started to refuse to go to work. She was often seen crying and her sleep patterns became so erratic that the entire family routine was disrupted. Marge would wake between 1 am and 3 am and indicate that she wanted a bath. Everyone attributed this "behavior" to the talk of change in the family setting.

Eventually, Marge had a thorough physical examination, which revealed a vaginal infection causing severe itching. She was also diagnosed with a painful degenerative joint disease. The suggested treatment of a warm bath before bedtime allowed Marge to sleep through the night.

## Anna

Anna lived in a state institution most of her life. She had been admitted as a 6 year old child and finally moved back to her family home in the community at the age of 56. Anna could not walk, and therefore, used a wheelchair. She screamed whenever she was required to stand for transfers from her bed to the wheelchair. Anna hated to be touched and screamed especially when an unfamiliar person approached her. The cause of her pain was eventually determined to be severe arthritis of both knees.

Anna had a total replacement of her right knee. While in the hospital recuperating after this surgery, Anna continued to scream, often throughout the night. The orthopedic surgeon told Anna's support team that she could not possibly be experiencing any pain because he had removed a very painful joint and replaced it, therefore, the pain was gone. Nobody thought to mention Anna's other knee.

Anna was transferred to the psychiatric unit of the hospital and given strong doses of anti-psychotic medications. She continued to scream since the anti-psychotic medications did not relieve the pain.

A nurse consultant was asked to develop a discharge plan and to provide training to Anna's support team. She conducted a "parallel interview" with a person who had recently recovered from a knee replacement and with information from this person, the staff was convinced that Anna was in pain and developed pain management strategies. Once the pain was relieved, Anna stopped screaming and began enjoying her life.

## Purpose

This book was written as a tool for all those supporters who may have watched a person they care about experience pain while they felt helpless and unable to assist. We hope that this tool will replace the helplessness with support and offer relief from pain.

## Introduction to Pain Management

According to Webster's, the definition of health is "the condition of being sound in *body, mind, and soul; especially freedom from physical disease and pain.*" Merck's (1986) definition of pain is "any unpleasant sensory and emotional experience associated with actual or potential tissue damage." A person's perception of painful experiences differs for each individual. Pain is meant to be a signal of danger to the body. Therefore, if a person indicates they feel pain, they do!

Certain challenges face those who support individuals who cannot clearly state their wants and needs. This booklet focuses on methods to identify, assess, and manage pain to promote health and wellness of people who depend on others to interpret their unique communications. It is the responsibility of supporters to learn to recognize symptoms of pain early in the diagnostic process. Remember, pain can be related to physical health and psychiatric conditions, as well as a possible reason behind many challenging behaviors.

## Identifying Pain

Identifying pain includes locating the source, determining how the person expresses pain, and what mechanisms they have developed to attempt to cope with the pain. People with communication difficulties who have unresolved pain may develop both healthy and unhealthy coping strategies. One example is a person with Gastroesophageal Reflux Disease (GERD) with associated heartburn. Healthy strategies include: learning not to eat large meals, avoiding certain foods, and learning not to lie down after meals. Unhealthy strategies include (also known as challenging behaviors): refusing to eat meals (a note in the file might read "won't eat red foods"), constantly looking for and asking for food, water or milk, taking food from other people, and not going to bed or getting up in the middle of the night.

### *A scale using facial expressions*

Example: Ask the person to choose the facial expression that best describes how much they hurt:



There are many physical and psychiatric conditions of which pain is a major component. Common conditions requiring a plan for pain management are:

- Degenerative joint disease, arthritis and chronic immobility;
- Migraine headaches, sinus headaches/pressure and other chronic headaches;
- Gastroesophageal Reflux Disease (GERD);
- Premenstrual syndrome (PMS);
- Cancer;
- Anxiety;
- Depression; and,
- Abuse and traumatic experiences.

Some words associated with pain are: **acute** (short term), **chronic** (long term), **sharp, full, boring, aching, burning, constant, intermittent, referred** (pain in one part of the body felt in another), **ischemic** (pain from lack of blood and nutrients to a body part), and **phantom** (very real pain triggered by a powerful memory often in an amputated body part).

Long term (chronic) exposure to pain increases a person's sensitivity, as the person is often in a state of "expecting the pain." This may lead to withdrawal from others, feelings of isolation, loss of control, decreased activity and increased muscle tension with decreased circulation, which results in more pain, both experienced and expected.

**How is a person who cannot speak for him or herself likely to communicate pain?** Any person may have difficulty describing how and what they feel, what is aggravating the pain, and what makes it better. Behavioral symptoms of pain may be: facial grimacing (#1 symptom), crying, screaming, aggression, guarding, rubbing or holding body parts, change in vital signs (increased blood pressure and/or pulse), change in activity level, and increase in existing challenging behaviors. These are signs that should cause us to seek immediate intervention. Unfortunately, similar changes in behavior in a person with ID or other developmental disabilities are often misidentified as psychotic symptoms leading to the increased use of medication to control behavior. This may happen regardless of an existing medical diagnosis associated with pain and in the absence of syndrome-specific psychiatric symptoms.

It takes a team to identify how, what, where, and when a person communicates pain and to discover what is most likely to comfort a person. Team members, particularly those who know the person best, are responsible for sharing the information collected with and about the person with all of the person's healthcare providers.

The fact that pain is often overlooked and/or misdiagnosed indicates a need for staff and family training, physician awareness, and a plan for ongoing assessment in order to address the impact of pain. Finally, in order to promote success, it is important to remember that a physician cannot effectively treat pain without a complete picture.

## Checklist for Identifying Pain

**Q:** What **health or medical conditions** does a person live with which could cause or contribute to chronic pain? (For people in residential settings, check the Chronic Condition List and the Medical History Summary and discuss the situation with the Primary Care Physician.)

**Q:** What **areas** of pain are identified? What **type** of pain is it? (use words that describe the sensations)? **When** does it occur? **How long** does it last? Can the person use the **facial expression** scale?

**Q:** Has the person been **physically examined** for pain? **Who** completed the exam? If yes, request a **body chart** with the specific pain areas clearly stated.

**Q:** Describe any **injuries, illnesses, or trauma** in the past of the person, indicating the need to evaluate further for pain.

**Q:** Does the person experience difficulty **doing certain tasks** that they once performed with ease? If yes, describe.

**Q:** Does it **take longer** for the person to perform each task than in the past? If yes, describe.

## Physical Assessment

If a person has any diagnoses associated with pain and is behaving in a way that you might suspect pain, further physical assessment must be completed. A physical assessment is the next step after identifying pain and includes an **Individualized Pain Assessment** (see below). This process is designed to define more clearly the what, where, and how of causes, feelings and management of a person's pain and may be completed by people providing support. A **formal pain assessment** must be completed by a physician, nurse, and/or physical therapist. Once the initial assessment is done, a **Pain Management Plan** is developed with the individual and their team and ongoing assessment is carried out, as required, to keep that individual comfortable.

When a person is experiencing chronic pain, touch is often aversive. The person's ability to tolerate touch should be noted as part of the assessment. Observe and evaluate each area of the body; watch for change in facial expression, body language, or loss of function that would indicate pain or discomfort. The following are a few common examples of loss of function: person refuses or is unable to stand, open a jar, button clothing; has difficulty putting on shoes or other clothing; or, resists participating in activities they previously enjoyed.

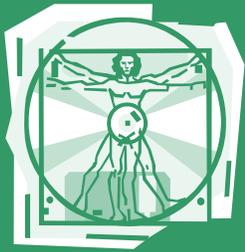
What makes a physical assessment a successful experience?

- This is best done by a person known and trusted by the person in pain.
- Maintain a caring attitude and relationship.
- Use kind and gentle touch.
- Consider the person's need for privacy and physical/emotional comfort.
- If the person refuses to be assessed, then employ alternative methods such as observation as the person goes about their normal routine (e.g. while dressing, bathing, and other personal hygiene activities).
- Physicians are a valuable resource for other possible alternatives.

**REMINDER:  
NO ONE MAY TOUCH AN INDIVIDUAL WITHOUT HIS OR HER CONSENT!**

## Individualized Pain Assessment

Each person's body is proportioned differently. Follow this format, that anyone who supports the individual can follow for an individualized pain assessment. Draw an imaginary line down the center of a person's body. Each side of the body generally looks like the other. This is called symmetry. For example, one foot is a copy of the other foot in appearance and movement. Significant differences in size, color, temperature, movement and loss of function point to abnormality, injury or disease process that may be associated with pain. Fill out a chart of the person's body to clearly portray potential pain sites. Information to collect is provided on the next two pages.



## Individual Pain Assessment Potential Pain Sites

**Head** Possible problems: sore throat, toothache, headache, sinus pain, ear pain, and/or difficulty swallowing. What signs or symptoms are present which may stem from one of these?

**Neck** Ask the person to look at an object (choose something interesting and hold it at various away from the person, first to the right, then to the left). Did the person turn their whole body or did they move their neck and head with ease and flexibility?

**Shoulders** How far can the individual raise their arms? Does one shoulder drop lower than the other? Can they do wide arm circles? Are there any areas of tenderness when touched? Can they reach for a favored object when held over their head? To the far right? To the far left?

**Elbows** Can the person freely bend their elbows? Can they repeatedly flex their arms? Does the person have full range of motion of the elbows? Can they flex, extend, and rotate their elbows?

**Wrists** Ask them to extend, flex, and rotate their wrists. Does the person have full range of motion or indicate pain upon movement?

**Hands & Fingers** Can the person make a clenched fist without grimacing? Does the person have full use of their fingers? Can they pick up a coin from a flat surface?

**Chest** Chest pain may be indicated by one or more of the following: heartburn, rib pain, palpitations or heart pain, arm pain and/or lung irritation from infection or obstruction. A person may tell us that he/she has pain by rubbing his/her chest, holding the chest, rubbing his/her back, arm, shoulder, neck, difficulty breathing, or heavy breathing after simple physical exertion.

## Back

Can the person bend over or turn side to side with ease? Does the person grimace or appear to be in pain when walking or getting up out of a chair to a standing position?

## Abdomen

Is the abdomen larger than usual or hard? Does the person protect or clutch a specific area of the abdomen? Has the person had difficulty having a bowel movement?

## Hips

Does the person rise easily from a sitting position? Can he/she flex the hip without grimacing? Does the person favor one side when walking?

## Genitals

Does the person have painful urination, frequent urination or avoid urination? Does he/she grab or scratch the genital area? Is there any discharge noted? How does their urine smell? What is the urine color?

## Legs

Is walking impaired? Are there any areas of tenderness? Are there any skin lesions or areas of redness? Are both legs identical in size, color, shape? Is one leg warmer than the other?

## Knees

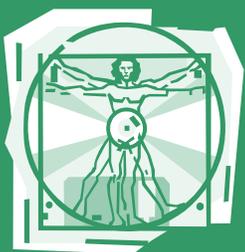
Observe the person walking. Does the individual bend his/her knees when walking? (This may be best seen walking up stairs.) Pain may be evidenced by holding knees stiffly, hesitating when walking up stairs, limping and/or vocalizing distress.

## Ankles & Feet

Are they symmetrical? Are there any obvious changes in the shape of the feet; e.g. bunions, hammertoes, swelling? Can the person bear weight equally? Does the pain differ with or without shoes? Are the nails trimmed and healthy? Do they refuse to wear shoes?

## Other Symptoms

Are there any changes in the person's sleep patterns— too little or too much sleep? Has there been a change in appetite? Has there been a visible change in the person's ability to perform daily activities?



Once this information is gathered and organized, it should be presented to the physician to enhance his/her understanding of the possibility of pain, to enhance a formal pain assessment, and to clarify the need for a pain management plan.

## Pain Management

Pain prevention is an active form of health promotion. This means using prevention strategies, managing co-occurring physical health and psychiatric conditions, and treating pain at the same time. Effective pain management relies upon clear and accurate observation of the individual. These observations are presented to physicians, nurses, and therapists in real terms including how the person expresses symptoms of pain verbally and behaviorally and the way pain affects the person's daily life.

Once pain is identified and assessed, the individual, people who support them, and the physician should discuss possible pain management strategies and develop a plan. When one or more pain management strategies have been prescribed, begin using a pain management journal. This is a means to effectively monitor the techniques and assist the team, including the physician, with what has been implemented, to determine what is working and what is not.

Information in the journal may include: diagnosis, frequency, intensity, and duration of symptoms; behavior related to pain and changes in behavior; the individual's evaluation of the pain and pain relieving strategies; and staff observations and suggestions. Review the journal with prescribing physician and at all team meetings.

**REMEMBER:  
ALL PAIN PREVENTION AND MANAGEMENT  
TECHNIQUES SHOULD BE DISCUSSED WITH A PHYSICIAN**

### General Pain Prevention Techniques

These techniques strengthen the body to prevent and manage pain both before and when it occurs. They also help the brain to interpret pain with less sensitivity, reduce the impact of stress and increase confidence in handling pain. All are helpful no matter the cause. Some examples are:

- Balanced diet
- Physical exercise
- Relaxation exercises
- Meditation
- Massage
- Adequate rest
- Stress Management



## **Pain Management Techniques (Non-Medication)**

Intervene with these techniques when pain occurs. They are best used in conjunction with the General Pain Prevention Techniques for the greatest effect. Some examples are:

- Ice/Heat
- Ultrasound
- TENS: an electronic nerve stimulator
- Vibration
- Address environmental causes
- Cushioning and splinting
- Distraction– work, music, humor, various leisure activities
- Visualization and guided imagery
- Biofeedback
- Breathing exercises
- Acupressure



## **Pain Management Techniques (Medications)**

The goal for effective pain management with medication is to relieve pain while minimizing side effects. All medications used to treat pain have side effects, including over-the-counter (OTC) drugs. The non-medication approaches enhance our own body system to treat pain (endorphins are the body's pain defense). Over use of medication turns off the body's own natural defenses. Use the simplest dosages for the shortest amount of time. For chronically painful conditions, long-term use of medication may be necessary and the non-medication techniques become even more important. Establish a plan to re-evaluate the medication. Documentation of administration of pain medication and keeping the pain journal are key to successful assessment of treatment. Some examples of medication are:

- Aspirin
- Tylenol
- NSAID (Non-Steroidal Anti-Inflammatory Drug)
- Local Injection
- Opioids
- Cox 2 inhibitors

## **Ten Steps For Living A Healthy and Pain-Free Life**

1. Build a support team including the person and all those people, past or present, who have a vested interest in helping the person have a healthy and pain-free life.
2. Determine, if needed and desired by the person, who will help speak or will speak for him/her. Also, who will coordinate information given and received?
3. Evaluate the environment and adapt it to eliminate any areas that cause pain or difficulty for the person.
4. Complete an individualized pain assessment based on history, diagnosis and observation.
5. Present the information to the Primary Care Physician, nurse, any necessary specialists, and/or physical therapist.
6. Obtain/develop a formal pain assessment and pain management plan.
7. Develop a pain management journal. Document all pertinent information including signs and symptoms of the person's pain, effective interventions and how to support the person effectively.
8. Implement the pain management plan and document the results.
9. Train the person, family, staff, and all interested others who actively support the person to implement the plan.
10. Evaluate and change methods as needed.

This booklet was written by:  
Ginny Focht-New, APRN, BC, CDDN  
Dawn Marie Kelly, RN, CDDN

With the assistance of:  
Gerry Allerton, RN, CDDN  
&  
Philadelphia Coordinated Healthcare Staff

Technical assistance for this publication was provided by:  
Susan A. Koniwczny  
PCHC Administrative Assistant

The information in this booklet is to increase your awareness of these medical conditions. It is not intended to replace medical advice. If you believe you or someone you support has this condition, please seek the advice of a physician.



## **PCHC Mission Statement**

Philadelphia Coordinated Health Care's mission is to enhance access to community physical and mental health care through education, public health outreach, advocacy and empowerment as well as to improve health care outcomes for individuals with intellectual and developmental disabilities.

## **Guiding Principle**

It is more important than ever, in the current health care environment, that we focus on integrated health care so that people with I/DD achieve wellness.



A Core Program of



Philadelphia Coordinated Health Care  
1601 Market Street  
5th Floor  
Philadelphia, PA 19103

Phone: 215-546-0300

Fax: 215-790-4976

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