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Your Comfort Matters

In keeping with United Hospice of Rockland's (UHR) mission, we will make every effort to relieve your suffering, maximize your comfort, and improve your quality of life. We will always accept that any pain you experience is whatever you say it is, existing whenever you say it does.

As someone receiving services from UHR, you can expect:

- Your reports of pain will be believed
- To receive education about pain and pain relief measures
- A concerned team who responds quickly to reports of pain
- You and your family will be included in the plan of care

As someone receiving services from UHR, we expect that you will:

- Report pain when it first begins
- Work with your team to develop a pain management plan
- Report any problems that you think the pain medications may be causing so we can help you to make it better
- Tell us if you are having any difficulty getting your medications or if you have any concerns about taking the medications

Matters of the heart and mind can cause pain and distress as well as increase any pain that you may have. At UHR, we will respect your personal, spiritual and cultural beliefs. Counseling services, including spiritual care, are available to you and your family to help you cope with the impact of your illness.

Please call us ***any time of the day or night*** if:

- Your pain is not adequately relieved
- You experience an increase in your pain
- You experience a new pain or discomfort
- You experience side effects that may include constipation, drowsiness and/or nausea and vomiting
- You have any questions regarding pain management

Quality of Life

Unrelieved pain has many negative consequences. Pain can interfere with your ability to sleep, decrease your mobility, increase anxiety and fear, diminish your appetite and cause you to lose interest in interacting with others. If you are not able to move around due to pain, you can develop pressure sores, blood clots or pneumonia. We want to work with you and your loved ones to minimize your pain and thereby improve your quality of life.

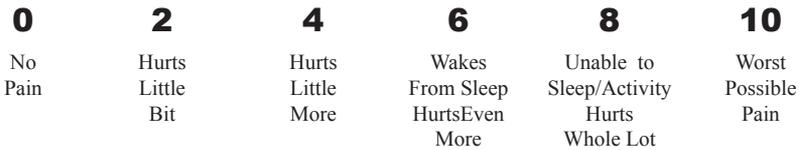
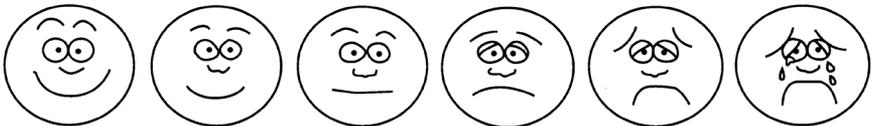
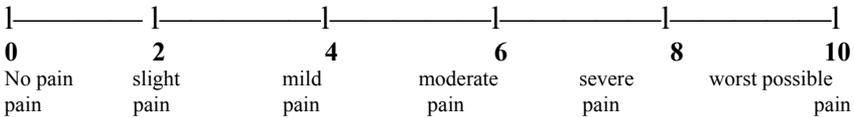
Some people are hesitant to take pain medications. There are many reasons. Some of them include:

- Fear of taking medicine before it is really needed. People are often concerned that the medicine won't be effective if they take the medicine when they have mild pain. Stronger medications and larger doses are available, as you need them. We will always work with you and your physician to ensure your comfort.
- Fear of side effects. Not all individuals experience side effects. We will anticipate and help you prevent or control any side effects that occur.
- Fear that you will be thought of as "weak" or "bothersome". We depend on you to tell us how we can best help you. We need to know if you are experiencing pain. Every person has the right to be comfortable and free of pain. It is much easier for us to control your pain before it becomes unbearable.
- Fear that reporting pain means that your illness is getting worse. In fact, when pain is not controlled, other serious problems can occur. Good pain management will improve your quality of life.
- Fear that some medications should not be taken together and could be potentially dangerous. The hospice nurse and pharmacist will make every effort to avoid drug interactions and will make adjustments as needed.

Working Together

You and your loved ones are the best judges of how you feel. We will be best able to help you manage your pain if you can provide us with some information about your pain. This includes:

1. Where does it hurt?
2. How often do you have pain?
3. Is it constant or does it come and go?
4. What does it feel like? Some descriptions might include throbbing, shooting, sharp, dull cramping, aching, burning or tingling.
5. How severe is it? There are two different scales we use. We may ask you to give us a number to rate your pain or to point to a picture that can show us how much pain you have. See the scales below:



6. Does the pain stop you from sleeping or wake you up?
7. Does the pain stop you from doing what is important to you? (Tell us what you are unable to do.)
8. What makes the pain worse? It might include moving, walking, breathing, coughing, lying down, after a meal, etc.
9. Have you taken any medications that help your pain? If so, what are they and how often do you take them?
10. How much do these medicines help? Do they make the pain a little bit better or do they get rid of the pain?
11. Are there other things that help your pain besides medications?

What Can Be Done to Treat Your Pain?

Often pain can be prevented or controlled. There are things that you might be able to do to help yourself. These include prayer, massage, relaxation, distraction (doing or thinking about something other than your pain), listening to music or putting heat or cold on the spot that hurts. (Be careful not to burn yourself. Never go to sleep on a heating pad.)

There are many medications that can be prescribed by your doctor. The medications that will be used will depend upon the description of the type of pain you are experiencing. The two main categories of medications are narcotic and non-narcotic.

For mild pain, over-the-counter (does not need a prescription from a physician), non-narcotic medication such as Tylenol, acetaminophen, ibuprofen, naprosyn or aspirin may be effective. Some of these medications must be taken with food to protect your stomach. Sometimes these medications are prescribed *with* narcotic medications.

Narcotics are prescribed for moderate to severe pain.

For people who have occasional pain, medicines can be taken as needed. Sometimes this is also known as taking breakthrough medicine or taking medicine on a PRN basis.

For others with persistent pain, medications should be taken at regular times (at standard intervals around the clock) to prevent pain from becoming worse. It is much easier to prevent pain or control the pain than to stop it once it is very severe.

Sometimes long-acting medication is prescribed. This type of medication is usually given every 8 or 12 hours. **DO NOT CRUSH** long acting pills because you will get the entire dose at one time. (Some long-acting medications might have **SR** or **LA** after their name on the outside of the bottle.)

Some long-acting medication comes in the form of a patch that is placed on a flat body surface such as the chest, back, or upper arms. If applying a patch on a hairy part of the body the hair

should be clipped-not shaved. Prior to applying the patch, clean the area with plain water. **DO NOT USE** soap, lotion, oil or alcohol. Patches are usually used for people who are unable to take medications by mouth, people who are cognitively impaired and live alone or people who are experiencing nausea and vomiting. The site of the patch should be rotated each time the patch is changed. The nurse will instruct you on how often to change the patch. This is usually done every 48-72 hours. The absorption rate of medication given through a patch can be affected if a fever occurs. Please call your nurse if you develop a fever.

There may be times when extra medicine is needed. This is sometimes known as breakthrough medication. If breakthrough medication is being taken 3-4 times a day on a regular basis, please call your nurse. This may be a sign that the long-acting medication needs to be increased.

Do not stop taking medications abruptly. This could cause uncomfortable symptoms such as shaking or sweating.

In addition to or instead of the medications discussed above, other types of medications may be ordered for you based on the description of your symptoms. Some of these medications are anti-inflammatory medications. They are often used to treat bone pain. Anti-depressants and anti-convulsants are medications that have been found to be helpful for relieving nerve related pain.

In order to thoroughly evaluate your pain and the effectiveness of any medication prescribed, it is important to keep a pain diary. The information in a pain diary includes:

- The date and times you took medicine(s)
- How severe your pain was when you took the medicine (use number scale or faces scale)
- Indication if the relief you got from the pain medicine

See the back of this guide for a copy of the pain diary. Your nurse can give you additional copies.

Side Effects

Most side effects can be prevented or controlled. The most common side effects are:

Constipation: Narcotic pain medications slow down the movement of your intestines. This will cause constipation. If possible, drink lots of fluid and eat foods high in fiber. Stool softeners and laxatives are generally required 1-2 times a day to produce a bowel movement every 2-3 days. These medications need to be taken even if you are not eating a lot and even if you are having daily bowel movements. If you have diarrhea, report this to your nurse.

Sleepiness: You may become sleepy when you first start taking a narcotic. Your body is getting used to the medicine you are taking. You may also feel confused or fuzzy and may feel like you are not thinking clearly. This will get better soon. If the dosage of the medication is increased, this may occur again until your body gets used to it. If you feel sleepy, avoid activities such as driving, cooking, climbing stairs without assistance or using machinery. **Do not drink alcohol while taking narcotics** unless you check with your doctor first. If your sleepiness does not go away within 3-4 days, please let your nurse know so that he/she can evaluate if adjustments need to be made.

Dry mouth: Rinsing your mouth and drinking a lot of fluids will make you feel better. You may also suck on hard, sour candy to help with the dryness.

Nausea/vomiting: This is sometimes a problem when you begin or increase your pain medicine. Medication can be prescribed that will help.

Safety

All medications should be taken as directed. Do not share your medicines with anyone. Keep them in a safe place out of the reach of children

Things to remember:

- Tell your nurse or doctor exactly what your pain is like.
- Keep the diary at the end of this booklet.
- Take your medicines regularly to prevent pain.
- Take your bowel medicine to prevent constipation. Call your doctor or nurse if you do not have a bowel movement for three days.
- Tell your nurse or doctor about any changes

Your comfort matters to us. Good pain management is a gift to yourself and your loved ones.

Pain Diary

My Pain Rating Scale:

Directions: Rate your pain before you take pain medicine and 1-2 hours later

Date/ Time	Pain Rating 1-10	Medicine I took	Pain rating one hour after taking pain medicine	How I felt after taking pain medicine (side effects)	Laxative medicine taken? BM?	Other Comments



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