

End of Life Symptom Management Comfort Tracker

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The goal of this tracker is to help you create tight symptom management for your dying loved one to provide the highest quality of daily living every single day (the goal of great end of life care). These are the 5 categories that as a hospice nurse, I have identified that family caregivers need to assess every day and when they do, it will ensure that any issues are identified and "managed" to ensure that the person is experiencing the best end of life journey possible.

HOW TO USE YOUR TRACKER

Every day go to the tracker and answer the 5 Daily Categories. If you note anything that is out of the "comfort" range (anything scoring 4 or above- except for eating), call your hospice nurse and let her know. The care plan will need to be adjusted in order to ensure your loved one is comfortable. The hospice nurse does NOT know there is an issue unless they are notified. Call them! If you are not sure if it is something you need to tell them - CALL THEM! It is better to let them decide.

Keep in mind that pain is subjective. A pain of 6 for one person, may be a pain of 3 for another. Let your loved one share what their pain level is using the 0-10 pain scale. (1 being no pain and 10 being the most intense pain imaginable.) The rule of thumb is to keep pain at a 4 or below for optimal comfort.

*****Staying ahead of the pain***** Pain that gets too far is hard to bring down. Stay ahead of the pain by doing frequent pain assessments.

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YOUR LOVED ONES COMFORT GOALS

In each category, have your loved one (or you) put a rating for each day based on the 0-10 comfort scale. 0 Being fully comfortable and 10 being the most uncomfortable. Please note that eating will not require intervention as someone is eating less and less. It is very helpful to see the decline in food intake though to be an indicator of the advanced end of life process so you and your loved ones can prepare accordingly.

PAIN MANAGEMENT:

Monitor your loved one's pain level and response to the prescribed pain medication daily and even several times a day, as pain at the end of life can increase quickly. The pain dosage that works well currently, may not be adequate for good pain control in the future. Tight pain assessment and management is key to keeping your loved one comfortable throughout the entire end of life journey. Administer the medication as prescribed, assess the effectiveness by asking your loved one 30-45 minutes after given to rate their pain on a scale of 0-10. Pain should be a 4 or below. Communicate with the hospice team or healthcare provider often, this will ensure that your loved one receives the appropriate dose to manage their pain effectively and maintain overall comfort during end-of-life care. This is one of the greatest supports you can provide to them.

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NAUSEA:

Nausea can rival pain and is present with many end of life experiences, especially if the person had chemo medication. Knowing that nausea travels 3 different pathways to the brain, it is vital to have a compound anti-emetic medication available for your loved one at the end of life. The hospice comfort kit will usually include one. **Make sure to ask your hospice nurse to instruct you on when and how to use it.**

SLEEP:

Good quality sleep is critical to feeling our best every day. Your loved one will require more and more sleep as the body becomes weaker. Make sure to have ample “down time” for them. Stagger visits with friends and family. Keep them short when necessary. Remember that even a visit with a friend can require lots of energy from someone at the end of life. Ask your loved one when they want visits and with whom. Give them back control. Each day, write down how many hours of sleep your loved one got and the quality. If they are not sleeping well, there could be an underlying cause that needs to be addressed such as pain or anxiety.

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EATING:

People at the end of life do not require lots of food. It is best to offer small frequent meals that are of soft consistency such as yogurt, ice cream or pureed foods. Do not pressure, guilt or force food on your loved one- just offer. One of the first tell tale signs that someone is heading into their transition phase is that they stop eating and drinking. This is a natural process, but can be alarming to families when they don't know about it. Remember that this is a natural way that the body starts to shut down and that this is the time to provide maximum comfort with mouth swabs and mouth lubricant. You can repeat this care every few hours or as needed.

MOVING BOWELS:

It is so important to monitor your loved one's bowel movements at the end of life. There will be several factors contributing to high probability of constipation. 1) Decreased mobility, 2) Decreased fluid intake, 3) Use of narcotic medications. Constipation can not only cause great discomfort, it can also become an emergent situation if impaction occurs. Your loved one should be having a bowel movement every 1-2 days. Make sure there is a gentle laxative and stool softener on their medication list. If there is no bowel movement for more than 2 days, call your hospice nurse or medical provider.

The Doulagivers End of Life Symptom Management Comfort Tracker

Add the date & time of occurrence, the scale of the symptom from 0-10 (10 being the worst) and notes about what is happening, how it was managed & next steps

Track for all 5 Symptoms DAILY (input 0 if there are no symptoms):

- 1) **Pain:** closely monitor their pain and medication response multiple times a day, as pain can escalate rapidly. Administer prescribed medication as directed, assess its effectiveness by asking them to rate pain on a 0-10 scale 30-45 minutes after taking it; aim for a pain level of 4 or below.
- 2) **Nausea:** Nausea can rival pain. Have a compound anti-emetic medication available. Ask hospice nurse to instruct you on when and how to use it.
- 3) **Sleep:** Your loved one will require more sleep. Daily, write hours/quality of sleep they got.
- 4) **Eating:** Best to offer small, frequent meals that are of soft consistency such as yogurt, ice cream or pureed foods. Tell tale signs that someone is heading into their transition phase is stopping eating/drinking. This is the time to provide maximum comfort with mouth swaps and mouth lubricant. You can repeat this care every few hours or as needed.
- 5) **Bowel Movements:** High probability of constipation. 1) Decreased mobility, 2) Decreased fluid intake, 3) use of narcotic medications. Goal: every 1-2 days. If there is no bowel movement for more than 2 days, call your hospice nurse or medical provider. Gentle Laxatives may be helpful.

<u>DATE & TIME</u>	<u>PAIN SCALE (0-10)</u>	<u>NAUSEA</u>	<u>SLEEP</u>	<u>EATING</u>	<u>BOWEL MOVEMENTS</u>	<u>NOTES</u>
EXAMPLE: MONDAY 1/23/24	2	NONE	6-8 HOURS	2-3 SMALL MEALS	1 REGULAR BOWEL MOVEMENT	Patient states a small amount of pain. Patient states no nausea, is sleeping well and eating 3 meals a day. Patient states having bowel movements regular formed daily.
MONDAY						
TUESDAY						
WEDNESDAY						
THURSDAY						
FRIDAY						
SATURDAY						
SUNDAY						

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