

Patient Resource Guide:

Preparing for the End

INTRODUCTION

Many patients and families want to be able to prepare as best they can for the end of life. While no two end of life experiences are the same, there is a similar pathway traveled by most patients in the final stretch of life with similar symptoms experienced. Gaining an understanding of what may occur can help with setting appropriate expectations and goals for these moments.

COMMON OCCURRENCES AT THE END OF LIFE

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| Social Withdrawal | It is common for the patient to become less concerned/engaged with others and the surrounding environment. Initially interest in news events or television programming may decrease but followed by decreased interest in social interactions with friends, and finally a decreased acknowledgement of family and loved ones. |
| Decreased Appetite | Lower energy requirements and diminished appetite and thirst are common at the end of life. This is often more difficult for those closest to the patient due to concerns the patient is starving and experiencing distress. Often, a gradual decreased interest in eating, even favorite foods, is experienced by the patient. It is important to follow the patient lead, and not force food, drink or create increased stress by attempting to do so. |
| Increased Sleep | The patient will spend more and more time sleeping; it may be difficult for them to keep their eyes open. This is a result of a change in the body's metabolism as a result of the disease. Tell family to spend more time with the patient during those times when he/she is most alert; this might be the middle of the night |
| Confusion | The patient may become confused about time, place and the identity of people around him/her. He/she may see people who are not there, such as family members who have already died. Sometimes patients describe welcoming or beckoning. While the patient may not be distressed, it is frequently distressing to family or health care professionals. Gently orient the patient if he or she asks. There is no need to 'correct' the patient if he or she is not distressed. |
| Restlessness | The patient may become restless and pull at the bed linens. These symptoms are also a change in the body's metabolism. Talk calmly and assuredly with the patient so as not to startle or frighten them. If the patient is a danger to himself or others, you may prescribe sedating neuroleptics (e.g. chlorpromazine), or neuroleptics (e.g. haloperidol) in combination with benzodiazepines (e.g. lorazepam), to help the patient rest |

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| Decreased Senses | Clarity of hearing and vision may decrease. Soft lights in the room may prevent visual misinterpretations. Never assume that the patient cannot hear you, as hearing is the last of the five senses to be lost. |
| Decreased Bowel and Bladder Control | often not a problem until death is very near. Invite family to participate in direct care; the nurse can help place absorbent pads under the patient for more comfort and cleanliness, or a urinary catheter may be used. The amount of urine will decrease and the urine become darker as death becomes near. |
| Common Physical Changes | <ul style="list-style-type: none"> • Blood pressure decreases; the pulse may increase or decrease. • The body temperature can fluctuate; fever is common. There is increased perspiration often with clamminess • The skin color changes: flushed with fever, bluish with cold. A pale yellowish pallor (not to be confused with jaundice) often accompanies approaching death. • Breathing changes also occur. Respirations may increase, decrease or become irregular; periods of no breathing (apnea) are common. • Congestion will present as a rattling sound in the lungs and/or upper throat. This occurs because the patient is too weak to clear the throat or cough. The congestion can be affected by positioning, may be very loud, and sometimes just comes and goes. Elevating the head of bed and swabbing the mouth with oral swabs give comfort and can be done effectively by family. • The arms and legs may become cool to the touch. The hands and feet become purplish. The knees, ankles and elbows are blotchy. These symptoms are a result of decreased circulation. |

Please do not hesitate to discuss concerns about changes in physical, mental, emotional or spiritual state of being with the hospice agency to ensure all resources are made available. Hospice services extend beyond medication management of symptoms, often providing access to a comprehensive network to provide support however needed by the patient and/or family.