

Love Matters Most

A Caregivers Guide



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“The role of a caregiver might be compared to a candle. A candle can help illuminate an experience, provide a path in the darkness and give courage to explore. The light can accompany individuals as they negotiate a sometimes scary and treacherous path. The journey may still be dark, but the light can make it less terrifying.”

-Doka (1993)

THE HOSPICE TEAM

HOSPICE WORKS TOGETHER AS A TEAM TO MEET THE PHYSICAL, EMOTIONAL, AND SPIRITUAL NEEDS OF THE PATIENTS AND FAMILIES IN OUR CARE. YOU AND THE PATIENT'S PHYSICIAN ARE A PART OF THIS TEAM. WE WANT TO BE SENSITIVE TO THE WIDE VARIETY OF NEEDS THAT MAY DEVELOP DURING THE TIME WE ARE INVOLVED WITH YOU.

THE FOLLOWING ARE THE PRIMARY TEAM MEMBERS AND HOW THEY CAN ASSIST WITH YOUR CARE AND CONCERNS.

NURSE

A HOSPICE REGISTERED NURSE ADMITS A PATIENT INTO HOSPICE SERVICES. A PRIMARY NURSE WILL BE ASSIGNED FOLLOWING THE FIRST HOME VISIT. A PRIMARY NURSE WILL COORDINATE THE PATIENT'S CARE, ALONG WITH OTHER NURSES PARTICIPATING IN THE CARE OF THE PATIENT, FAMILY AND/OR SIGNIFICANT OTHER, THE PATIENT'S PHYSICIAN, AND THE HOSPICE TEAM.

THE HOME CARE NURSES ARE THE TEAM MEMBERS WITH WHOM YOU WILL PROBABLY HAVE THE MOST CONTACT. THEY ARE ALL KNOWLEDGEABLE AND CARING PEOPLE.

SOME PRACTICAL AREAS OF INVOLVEMENT **may** INCLUDE:

- INITIATING THE PATIENT'S PLAN OF CARE
- MONITORING THE PATIENT'S CHANGING CONDITION, ESPECIALLY IN PAIN MANAGEMENT, AND REPORTING CHANGES TO THE PHYSICIAN
- TEACHING THE FAMILY ABOUT THE DISEASE PROCESS AND WHAT TO EXPECT
- COORDINATING CARE WITH THE OTHER HOSPICE TEAM MEMBERS
- SUPERVISING HOME HEALTH AIDES WHEN ASSISTANCE IS NEEDED FOR PERSONAL CARE

HOME HEALTH AIDE

HOSPICE HOME HEALTH AIDES ARE SKILLED AT ASSISTING WITH PERSONAL CARE ACTIVITIES. THEY ARE TRAINED AIDES AND HAVE BEEN EDUCATED IN THE HOSPICE PHILOSOPHY OF CARE.

SOME POTENTIAL AREAS OF INVOLVEMENT **may** INCLUDE:

- BATHING, SHAMPOOING AND SHAVING PATIENT
- ASSISTING WITH MOUTH CARE
- PROVIDING SKIN CARE
- CHANGING BED LINENS
- NAIL CARE

SOCIAL WORK

A HOSPICE SOCIAL WORKER IS A PART OF EVERY HOSPICE TEAM AND WILL MEET WITH THE PATIENT AND FAMILY TO ASSIST WITH NON-MEDICAL, ON-GOING NEEDS AND REVIEW NECESSARY ADMISSION PAPERWORK. THE SOCIAL WORKER IS DIRECTLY LINKED NOT ONLY WITH THE PATIENT, BUT WITH ALL OF THE FAMILY MEMBERS. THIS EFFORT IS TO MAXIMIZE THE QUALITY OF LIFE FOR THE PATIENT AND TO ASSIST FAMILIES IN DEALING WITH CHANGE.

SOME PRACTICAL AREAS OF INVOLVEMENT **may** INCLUDE:

- ASSISTING THE PATIENT AND FAMILY WITH THE ADJUSTMENTS TO CHANGES
- HELPING PATIENTS RECOGNIZE THEIR ABILITIES, DESPITE INCREASED LIMITATIONS
- DISCUSSING WAYS FOR CAREGIVERS TO CARE FOR THEMSELVES
- UTILIZING COMMUNITY RESOURCES THAT PROVIDE HELPFUL SERVICES NOT PROVIDED BY HOSPICE
- EXPLAINING ALTERNATIVE OPTIONS IF HOME CARE BECOMES OVERWHELMING
- RESOLVING PROBLEMS WITH INSURANCE, MEDICARE, OR MEDICAID
- OBTAINING GENERAL LEGAL INFORMATION OR PROVIDING REFERRALS FOR MATTERS SUCH AS POWER OF ATTORNEY, BANK ACCOUNTS, SAFETY DEPOSIT BOXES, DEATH CERTIFICATES, ETC.
- ASSISTING WITH DRAFTING OF ADVANCED DIRECTIVES, HEALTH CARE POWER OF ATTORNEY

SPIRITUAL CARE

THE HOSPICE SPIRITUAL COUNSELOR IS AN IMPORTANT MEMBER TO THE HOSPICE TEAM. AS WE ALL WORK TOGETHER TO ENSURE THE QUALITY OF A PATIENT'S LIFE, SPIRITUAL CARE TOUCHES THE INNERMOST SPIRIT OF A PATIENT, ASSISTING THE PERSON TO FIND THE FREEDOM TO ACCEPT ALL PHASES OF THEIR LIFE- PAST, THE PRESENT, AND THE FUTURE.

A SPIRITUAL COUNSELOR IS A THEOLOGICALLY TRAINED INDIVIDUAL AVAILABLE TO THE PATIENT AND FAMILY MEMBERS... YOU WILL FIND THE SPIRITUAL COUNSELOR TO BE ACCEPTING AND OPEN TO ALL BELIEFS. THEY ARE NOT THERE TO REPLACE YOUR OWN MINISTER, RABBI OR PRIEST, BUT TO WORK JOINTLY AND BE SENSITIVE TO WHAT BRINGS YOU STRENGTH DURING THIS DIFFICULT TIME. SPIRITUAL CARE IS FOCUSED ON EACH PERSON AS AN INDIVIDUAL – TO LISTEN TO YOU AND TO LEARN FROM YOU. IT IS OUR HOPE TO JOURNEY WITH A FAMILY AS THEY FIND HOPE AND MEANING BEYOND THE PATIENT'S ILLNESS.

SOME SPIRITUAL AREAS OF INVOLVEMENT **may** INCLUDE:

- NOTIFICATION OF YOUR CLERGY OF YOUR INVOLVEMENT WITH HOSPICE SERVICES
- HELP IN FINDING CLERGY OF A PARTICULAR DENOMINATION, IF THE PATIENT OR FAMILY MEMBERS SO CHOOSE
- IDENTIFYING AND RESOLVING SPIRITUAL CONCERNS AFFECTING THE PATIENT AND FAMILY
- ASSISTANCE IN REFLECTING ON THE MYSTERIES OF LIFE, SUFFERING, DEATH AND AFTERLIFE
- OFFERING A CARING PRESENCE IN TIMES OF NEED OR CRISIS

VOLUNTEERS

HOSPICE VOLUNTEERS ARE A VALUABLE RESOURCE TO OUR PATIENT/FAMILIES. THEY COME FROM DIVERSE BACKGROUNDS AND LIFESTYLE SITUATIONS. A COMMON THREAD OF CARING AND COMPASSION UNITES THEM IN THEIR VOLUNTEERS FOR HOSPICE. THEY ARE A HELP TO US AND OUR HOSPICE FAMILIES, AND AN IMPORTANT PART OF OUR CARE TEAM.

OUR HOSPICE VOLUNTEERS GO THROUGH A TRAINING PROGRAM SPECIFIC TO THE JOB THEY ARE ASSIGNED DURING INTERMITTENT IN-HOME VISITS.

HOSPICE PATIENT CARE VOLUNTEERS ARE AVAILABLE TO ACCOMPLISH THE FOLLOWING:

- STAY WITH THE PATIENT TO RELIEVE THE CAREGIVER AND PROVIDE COMPANIONSHIP
- PROVIDE NEEDED TRANSPORTATION BY SPECIAL ARRANGEMENT
- READ TO, OR WRITE LETTERS FOR THE PATIENT
- ASSIST THE PATIENT WITH PERSONAL HYGIENE
- DO SMALL HOUSEKEEPING CHORES
- PREPARE AND FEED THE PATIENT LIGHT MEALS
- BECOME A FRIEND OF THE PATIENT AND FAMILY

HOSPICE VOLUNTEERS ARE AVAILABLE FOR IN-HOME VISITS THROUGHOUT THE DAY AND EARLY EVENING HOURS. FAMILIES CAN RECEIVE VOLUNTEER SERVICES AS AVAILABLE. HOSPICE ATTEMPTS TO FIT FAMILY NEEDS WITH OUR VOLUNTEERS' AVAILABLE HOURS. IDEALLY, THE SAME VOLUNTEER(S) WILL REMAIN WITH THE FAMILY FOR AS LONG AS THE PATIENT AND FAMILY REQUIRE HOSPICE SERVICES.

HOSPICE MEDICAL DIRECTOR

THE HOSPICE MEDICAL DIRECTOR IS A PHYSICIAN WHO ACTS AS A RESOURCE FOR THE TEAM'S MEDICAL DIRECTION AND QUESTIONS. THE MEDICAL DIRECTOR MAY ACT IN A CONSULTING ROLE FOR A PATIENT'S PRIMARY CARE PHYSICIAN, OR BE THE PRIMARY CARE PHYSICIAN WHEN A PATIENT AND FAMILY REQUEST IT. THE HOSPICE MEDICAL DIRECTOR IS A SPECIALIST THAT UNDERSTANDS THE UNIQUE MEDICAL NEEDS IN HOSPICE.

BEREAVEMENT COUNSELING

FAMILY NEEDS DO NOT END WITH THE DEATH OF A PATIENT. THE TIME OF BEREAVEMENT THAT FOLLOWS CAN BE VERY DIFFICULT. HOSPICE WANTS TO OFFER SUPPORT AS YOU ADJUST TO A NEW LIFE WITHOUT THE PRESENCE OF THE PERSON YOU CARED FOR AND LOVED. OUR PERSONALIZED PROGRAM CAN HELP EASE THE PAIN AND PROMOTE THE CHANGES NECESSARY TO CONTINUE A MEANINGFUL LIFE.

A HOSPICE BEREAVEMENT COUNSELOR IS SPECIALLY TRAINED TO ASSESS YOUR BEREAVEMENT NEEDS AND TO ASSIST YOU IN UNDERSTANDING THE

GRIEF PROCESS. THE COUNSELOR IS SENSITIVE TO YOUR PAIN AND REALIZES THAT IN YOUR GRIEF YOU CAN EXPERIENCE A VARIETY OF FEELINGS. TOGETHER YOU WORK TOWARD INNER HEALING.

WE OFFER INDIVIDUAL AND/OR FAMILY COUNSELING AND ALSO BEREAVEMENT SUPPORT GROUPS; YOU MAY DECIDE WHICH IS MOST COMFORTABLE FOR YOU.

Availability 24 Hours a Day

A HOSPICE NURSE IS AVAILABLE TO YOU BY PHONE 24 HOURS A DAY. THE ON-CALL NURSE RECEIVES A DAILY UPDATE ON ALL PATIENTS WE SERVE AND WILL HELP TO ANSWER YOUR QUESTIONS.

SOME EXAMPLES OF WHEN YOU MAY NEED TO TALK TO AN ON-CALL NURSE ARE:

- IF YOU HAVE QUESTIONS ABOUT MEDICATIONS
- IF A PATIENT'S CONDITION HAS CHANGED (I.E., CAN NO LONGER SWALLOW MEDICINE, IS NO LONGER RESPONSIVE, HAS A DIFFERENT BREATHING PATTERN
- IF YOU HAVE QUESTIONS ABOUT PAIN CONTROL OR OTHER SYMPTOMS
- IF YOU BECOME INCREASINGLY ANXIOUS, FEARFUL OR UNSURE

Calling the Physician

PATIENTS AND FAMILIES ARE ASKED TO CALL THE HOSPICE NURSE BEFORE CALLING THE PHYSICIAN. THE HOSPICE NURSE CAN POSSIBLY ANSWER YOUR QUESTION, HELP YOU DECIDE WHETHER TO CALL THE PHYSICIAN, OR CAN CALL FOR YOU. **If you do speak with the physician** AND HAVE NOT TALKED TO THE HOSPICE NURSE, PLEASE NOTIFY THE HOSPICE NURSE SO HOSPICE WILL KNOW WHAT HAS OCCURRED.

Concerns about Hospitalization

WE URGE YOU TO CALL US FIRST WHEN QUESTIONING IF A PATIENT NEEDS TO GO TO THE HOSPITAL. IN MOST CASES, IT IS POSSIBLE FOR THE HOSPICE NURSE TO VISIT AND HANDLE THE SITUATION IN YOUR OWN HOME. TRANSPORTING A SERIOUSLY ILL PERSON TO AN UNFAMILIAR SETTING CAN BE TRAUMATIC. **However**, IF THE SITUATION CANNOT BE DEALT WITH IN THE

HOME AND THAT PATIENT NEEDS TO GO TO THE HOSPITAL, THE HOSPICE NURSE CAN ASSIST YOU TO MAKE SURE THE TRANSITION IS AS SMOOTH AS POSSIBLE FOR THE PATIENT. STAFF CAN ALSO ADVISE YOU ON INSURANCE REQUIREMENTS SO THAT INSURANCE COVERAGE IS NOT INTERRUPTED.

PHYSICAL CARE

THE FOLLOWING INFORMATION INCLUDES SOME VERY BASIC PROCEDURES FOR YOU TO FOLLOW IN DELIVERING COMFORT CARE FOR THE PATIENT. ADDITIONAL TEACHING WILL BE PROVIDED AS CARE-SPECIFIC NEEDS ARISE FOR YOUR LOVED ONE. THESE SKILLS, COMBINED WITH THE LOVE AND COMMITMENT OF FAMILY AND FRIENDS, CAN PRODUCE THE VERY BEST RESULTS.

MOUTH CARE

CLEANING A PERSON'S MOUTH IS IMPORTANT TO COMFORT. SOME MEDICINES AND DISEASES LEAVE THE MOUTH DRY AND OR SORE. ROUTINE CARE WILL HELP TO PREVENT INFECTION AND IRRITATION IN THE MOUTH. IT SHOULD BE DONE AT LEAST ONCE TO TWICE DAILY:

Needs:

TOOTHPASTE OR DILUTED MOUTHWASH
SOFT TOOTHBRUSH
TOOTHETTES
CUP AND BOWL
LIP BALM (VASELINE/CHAPSTICK)

Procedure:

1. IF A PATIENT IS ABLE TO PROVIDE THEIR OWN MOUTH CARE, HE/SHE SHOULD BE ALLOWED AND ENCOURAGED TO DO SO.
2. IF A PATIENT IS UNABLE TO PROVIDE THEIR OWN MOUTH CARE, YOU CAN ASSIST BY BRUSHING THE PATIENT'S TEETH WITH A SMALL AMOUNT OF TOOTHPASTE AND A SOFT TOOTHBRUSH. ASSIST THE PATIENT TO A SITTING POSITION, OR, IF LYING DOWN TURN HIM/HER TO THE SIDE.
3. IF A PATIENT HAS DENTURES, THEY SHOULD BE REMOVED FOR CLEANING. BRUSH THE DENTURES INSIDE AND OUT WITH A SOFT BRUSH. ALLOW THE DENTURES TO SOAK FOR A WHILE IN WATER OR

DENTURE CLEANER. ASSIST THE PATIENT TO RINSE THE MOUTH WITH WATER OR MOUTHWASH.

4. IF THE PATIENT'S MOUTH IS IRRITATED, OR IF THEY ARE NOT ABLE TO ASSIST WITH THEIR OWN MOUTH CARE YOU MAY CLEAN THE MOUTH WITH A TOOTHETTE (RESEMBLES A LOLLIPOP). THE SPONGE-LIKE TIP BECOMES SOFT WHEN MOISTENED WITH WATER OR DILUTED ALCOHOL-FREE MOUTHWASH AND CAN BE USED IN THE PATIENT'S MOUTH.
5. TO PREVENT THE PATIENT'S LIPS FROM CRACKING OR DRYING, APPLY SOME LIP BALM. THIS CAN BE APPLIED THROUGHOUT THE DAY.

SKIN CARE

GOOD SKIN CARE PREVENTS BEDSORES AND ADDS TO A PATIENT'S COMFORT. IT ALSO PROVIDES AN OPPORTUNITY TO TOUCH THE PATIENT, WHICH IS AN EXPRESSION OF LOVE AND CARE.

Needs:

NON-ALCOHOL LOTION

EXTRA PILLOWS

EXTRA LIFT SHEET OR SHEEP SKIN

Procedure:

1. AS A PATIENT BECOMES WEAKER, THEY HAVE A TENDENCY TO REMAIN IN ONE POSITION FOR LONG PERIODS OF TIME. WHILE THIS IS UNDERSTANDABLE, THEY NEED TO BE ENCOURAGED TO SIT UP AND MOVE AROUND TO PREVENT SKIN BREAKDOWN.
2. IF A PATIENT IS UNABLE TO MOVE ON THEIR OWN, THEN YOU WILL NEED TO ASSIST WITH REPOSITIONING THE PATIENT EVERY COUPLE OF HOURS. THE HOSPICE NURSE OR HOME HEALTH AIDE WILL DEMONSTRATE HOW TO USE A LIFT SHEET OR SHEEP SKIN TO MAKE THE MOVE EASIER. EXTRA PILLOWS WILL BE NEEDED FOR SUPPORT AND TO AVOID PRESSURE AREAS. THE SPINE SHOULD BE STRAIGHT, BUT JOINT AREAS MAY BE MORE COMFORTABLE WHEN FLEXED.
3. A PATIENT'S SKIN NEEDS TO BE MASSAGED TO STIMULATE AND INCREASE CIRCULATION. THIS IS IMPORTANT FOR THE PREVENTION OF BEDSORES. THE HOSPICE NURSE WILL EDUCATE YOU ON THE AREAS MOST SUSCEPTIBLE TO SKIN BREAKDOWN. THEY ARE MOST LIKELY TO APPEAR WHERE THE SKIN IS CLOSE TO THE BONE, SUCH AS HEELS, ELBOWS, AND OVER THE "TAILBONE." GENTLY RUB THESE AREAS WITH

LOTION AND INFORM THE HOSPICE NURSE SHOULD THEY BECOME REDDENED.

4. PATIENT'S SKIN NEEDS TO BE CHECKED REGULARLY (DAILY). AREAS BECOME RAW DUE TO MOISTURE OR FRICTION, ESPECIALLY UNDER THE BREASTS, IN THE GROIN AREA, IN ABDOMINAL FOLDS, AND BETWEEN THE BUTTOCKS. CREAM OR LOTION CAN BE USED TO REDUCE FRICTION OR THE SKIN KEPT DRY WITH A LIGHT DUSTING OF POWDER.
5. PLASTIC RIGHT NEXT TO THE PATIENT'S SKIN ALLOWS HEAT TO BUILD UP. IF YOU HAVE A PLASTIC MATTRESS COVER, PUT A MATTRESS PAD BETWEEN THE COVER AND A BOTTOM SHEET. A SHEEP SKIN PAD WILL ALSO HELP INCREASE AIR CIRCULATION. THE HOSPICE NURSE MAY ALSO SUGGEST THE USE OF AN EGG-CRATE MATTRESS OR AN ALTERNATING PRESSURE PAD TO ASSIST WITH MAINTAINING GOOD SKIN CARE.

PAIN CONTROL

GOOD PHYSICAL PAIN CONTROL IS AN IMPORTANT ELEMENT OF HOSPICE CARE. WE WILL WORK AS A TEAM TOWARD COMPREHENSIVE MANAGEMENT OF PAIN AND OTHER SYMPTOMS TO MAINTAIN A PATIENT'S MAXIMUM COMFORT.

DESCRIBING PAIN

WE RELY ON THE PATIENT TO COMMUNICATE THEIR PAIN OR DISCOMFORT AS CLEARLY AS POSSIBLE TO THE HOSPICE NURSE. MOST PAIN, IF REPORTED HONESTLY, CAN BE CONTROLLED. THE HOSPICE NURSE WILL ASK ABOUT THE LOCATION, DURATION, ONSET, AND SEVERITY OF THE PAIN. THE INTENSITY OF A PATIENT'S PAIN IS TYPICALLY DESCRIBED ON A SCALE RANGING FROM ZERO TO TEN. A RATING OF ZERO MEANS NO PAIN, ONE TO FOUR IS A RANGE OF MILD PAIN, FIVE TO SIX IS MODERATE PAIN, AND SEVEN TO TEN DESCRIBES SEVERE PAIN.

PAIN MANAGEMENT

THE PATIENT'S PRIMARY DOCTOR WILL BE THE PERSON IN CHARGE OF PRESCRIBING ALL MEDICATIONS. THE HOSPICE NURSE WILL ALWAYS KEEP THE DOCTOR INFORMED OF A PATIENT'S PAIN, SYMPTOMS AND CHANGING CONDITION. TOGETHER THEY WILL WORK TO KEEP THE PATIENT AS COMFORTABLE AS POSSIBLE TO ENHANCE THEIR QUALITY OF LIFE.

IN MANY INSTANCES, A NON-PRESCRIPTION MEDICATION IS USED EFFECTIVELY FOR MILD PAIN. COMMON MEDICINE'S, OR BRAND NAMES INCLUDE TYLENOL, ADVIL, AND MOTRIN.

HOSPICE PATIENTS FREQUENTLY USE PRESCRIPTION PAIN MEDICATION FOR MODERATE TO SEVERE PAIN. IT IS MOST EFFECTIVE AND CAN BE TAKEN IN MANY FORMS AND IN VARYING AMOUNTS. YOUR HOSPICE NURSE WILL ALWAYS INSTRUCT YOU IN THE PROPER USE AND RESPOND TO YOUR QUESTIONS OR CONCERNS. HERE ARE A FEW SUGGESTIONS TO KEEP IN MIND:

- ALLOW SEVERAL DAYS FOR THE PATIENT'S BODY TO ADJUST TO THE NEW MEDICATION AND FOR THE DOCTOR AND NURSE TO DETERMINE THE BEST SCHEDULE OF DOSES AND AMOUNT OF MEDICATION NEEDED.
- IT IS EXTREMELY IMPORTANT TO FOLLOW THE MEDICATION SCHEDULE DEVELOPED FOR THE PATIENT. IF DOSES ARE SKIPPED MAXIMUM COMFORT CANNOT BE MAINTAINED.
- PAIN CONTROL IS OFTEN HELPED BY A PLEASANT AND PEACEFUL ENVIRONMENT. COMPANIONSHIP CAN BE A POSITIVE DISTRACTION. SOME INDIVIDUALS ENJOY BEING READ TO OR LISTENING TO MUSIC.

GIVING MEDICATION

MEDICATIONS TAKEN BY THE PATIENT ARE FOR PAIN AND SYMPTOM CONTROL. A PATIENT'S COMFORT IS ALWAYS OF GREAT CONCERN AND IMPORTANCE, WHETHER IT BE PHYSICAL, EMOTIONAL OR SPIRITUAL.

Needs:

AMPLE MEDICATION
MEDICATION SCHEDULE

Procedure:

- MOST MEDICATIONS ARE IN PILL FORM AND NEED TO BE TAKEN WITH WATER OR ANOTHER LIQUID, SUCH AS JUICE, MILK OR POP. THE PATIENT SHOULD HAVE ENOUGH LIQUID TO SWALLOW THE PILL

COMPLETELY. A FEW SIPS OF THE LIQUID BEFORE PUTTING THE PILLS INTO THE MOUTH FREQUENTLY PREVENTS PILLS FROM “STICKING.”

- IF THE PILLS ARE TOO LARGE OR BECOME TOO DIFFICULT TO SWALLOW, THEY CAN FREQUENTLY BE CRUSHED; HOWEVER, ALWAYS CHECK WITH THE HOSPICE NURSE TO BE SURE THE EFFECT OF THE PILL WILL NOT BE CHANGED BY CRUSHING. THE POWDERED MEDICINE CAN THEN BE MIXED WITH JUICE, ICE CREAM, APPLESAUCE, PUDDING OR SOME OTHER FOOD.
- IF THE PATIENT CONTINUES TO HAVE PROBLEMS SWALLOWING PILLS, MANY MEDICINES COME IN DIFFERENT FORMS. YOUR HOSPICE NURSE CAN DISCUSS THIS MATTER WITH THE DOCTOR AND PERHAPS THE MEDICATION CAN BE OBTAINED IN A LIQUID FORM, SUPPOSITORY OR A CREAM.
- AS A PATIENT’S DISEASE PROGRESSES AND HE/SHE BECOMES WEAKER, THE HOSPICE NURSE AND DOCTOR MAY DISCUSS STOPPING SOME MEDICATIONS, EXCEPT THOSE FOR COMFORT.

CONTROLLING INFECTIONS AT HOME

AVOIDING INFECTION IS IMPORTANT FOR THE PATIENT AND CAREGIVERS. THE FOLLOWING INFORMATION WILL HELP PREVENT INFECTION OR THE SPREAD OF INFECTION.

HANDWASHING

HAND WASHING IS THE SINGLE MOST IMPORTANT WAY TO PREVENT INFECTION. HAND WASHING SHOULD BE DONE BEFORE AND AFTER ANY CONTACT WITH THE PATIENT, SUCH AS FEEDING, TURNING, OR ASSISTING THE PATIENT WITH TOILETING. HAND WASHING SHOULD ALSO BE DONE AFTER CONTACT WITH PERSONAL ITEMS SUCH AS BEDDING OR CARE SUPPLIES.

IF POSSIBLE, USE A PUMP DISPENSER, IF NOT, A BAR OF SOAP WILL WORK JUST AS WELL. USE A CLEAN TOWEL OR PAPER TOWEL TO DRY HANDS.

CLEANING MEDICAL SUPPLIES

BEDPANS, URINALS, AND COMMODOES SHOULD BE CLEANED ON A REGULAR BASIS WITH SOAP AND WATER. FOR A MORE THOROUGH CLEANING, YOU

MAY USE A 1 TO 10 BLEACH SOLUTION. THIS MAY BE MADE BY MIXING ONE-CUP BLEACH WITH 10 CUPS OF WATER. THE DIRTY WATER SHOULD BE Poured DOWN THE TOILET AND NOT THE SINK.

GENERAL HYGIENE

PERSONAL ITEMS SUCH AS TOOTHBRUSHES OR RAZORS SHOULD NOT BE SHARED.

HANDLING SOILED CLOTHING

PLACED SOILED LINENS IN A SEPARATE CONTAINER OR TRASH BAG UNTIL YOU ARE ABLE TO WASH. AVOID SHAKING THE ITEMS IN THE AIR PRIOR TO WASHING, WHICH WILL SPREAD GERMS. WASH AS SOON AS POSSIBLE AFTER SOILING. IF THE MATERIAL IS COLORFAST, YOU MAY ADD ONE CUP OF BLEACH AND USE HOT WATER WHENEVER POSSIBLE.

FOOD PREPARATION

WASH HANDS BEFORE PREPARING FOOD. TASTING OF FOOD DURING COOKING SHOULD BE DONE WITH A CLEAN SPOON EACH TIME. THE INSIDE OF THE REFRIGERATOR SHOULD BE CLEANED ON A REGULAR BASIS WITH WARM SOAP AND WATER TO CONTROL MOLDS.

VISITORS

DISCOURAGE VISITORS WHO HAVE MAJOR COLD SYMPTOMS OR FLU FROM VISITING. ENCOURAGE VISITORS TO WASH THEIR HANDS BEFORE AND AFTER THE VISIT.

JUST FOR THE CAREGIVERS

IT HAS BEEN OUR EXPERIENCE THAT PEOPLE CARING FOR A LOVED ONE OFTEN HAVE THE TENDENCY TO FORGET ABOUT THEIR OWN NEEDS. HOSPICE FEELS THAT THE CAREGIVER IS JUST AS IMPORTANT AS THE PATIENT. IF YOU DO NOT TAKE CARE OF YOURSELF, YOU TOO MAY BECOME ILL OR STRESSED TO THE POINT OF NO LONGER BEING ABLE TO CARE FOR THE PATIENT.

WE WANT TO ENCOURAGE YOU TO THINK OF YOUR NEEDS TOO. HERE ARE A FEW GUIDELINES:

1. **Get Adequate Rest.** IF YOUR NIGHTTIME SLEEP IS BROKEN DUE TO PATIENT NEEDS, IT WILL BE NECESSARY FOR YOU TO FIND TIME TO REST OR NAP DURING THE DAY. THIS CAN BE DONE WHEN THE PATIENT IS ALSO RESTING. YOU AND THE PATIENT ARE THE PRIORITY. WE ENCOURAGE YOU TO PUT OTHER HOUSEHOLD DUTIES “ON HOLD” IN ORDER TO DO SOMETHING FOR YOURSELF.
2. **Eat Healthy Meals.** YOUR NUTRITIONAL NEEDS WILL BE DIFFERENT FROM THE PATIENT RECEIVING CARE. FOR THIS REASON, CAREGIVERS FREQUENTLY DON’T FIX MEALS FOR THEMSELVES. IT IS IMPORTANT THAT YOU EAT THREE MEALS A DAY. YOU NEED FOOD FOR ENERGY, GOOD HEALTH, AND TO AVOID STRESS.
3. **Take Time For Yourself.** YOU NEED TO BE REFRESHED EMOTIONALLY AND PSYCHOLOGICALLY. IT IS GOOD TO GET AWAY FROM CAREGIVING FOR SHORT PERIODS OF TIME. UTILIZE FAMILY, FRIENDS, AND THE HOSPICE VOLUNTEERS SO YOU MIGHT:
 - TAKE A WALK OUTDOORS
 - PARTICIPATE IN A SPORTS ACTIVITY
 - GO TO LUNCH WITH A FRIEND
 - GO TO THE BEAUTICIAN/BARBER
 - ENJOY A MOVIE
 - TAKE A LEISURELY BATH
 - READ A BOOK
 - TAKE A NAP

4. Accept Help from Others. OTHER FAMILY MEMBERS AND FRIENDS OFTEN HAVE THE NEED TO PARTICIPATE IN CARING FOR THE PATIENT OR ASSISTING YOU IN SMALL WAYS. THE HELPLESSNESS THEY FEEL CAN BE HELPED BY ALLOWING THEM TO BE INVOLVED. LET OTHERS BRING MEALS, RUN ERRANDS, SIT WITH THE PATIENT, OR TAKE CHILDREN OUT ON AN OUTING. YOU NEED TO BE HONEST WITH PEOPLE BY TELLING THEM THAT WOULD BE HELPFUL.

HOSPICE

VOLUNTEERS ARE AVAILABLE TOO AND WANT TO HELP WITH THESE TASKS.

5. Find a “Listening Ear.” IT IS HEALTHY FOR YOU TO TALK ABOUT THE CARE

YOU ARE GIVING, AS WELL AS YOUR HONEST FEELINGS. WE REALIZE DEALING

WITH THE ILLNESS OF SOMEONE YOU LOVE DAY AFTER DAY CHANGES YOUR LIFE

AND USUAL ROUTINES. MANY PEOPLE SAY, “I DON’T KNOW HOW I FEEL.”

THERE IS WORRY, HURT, LOVE, ANGER, AND AT TIMES EVEN GUILT. TALK WITH

YOUR FRIENDS AND SHARE THESE FEELINGS AND CONCERNS. THE HOSPICE STAFF

ARE ALSO AVAILABLE TO LISTEN. THIS IS ANOTHER WAY THE HOSPICE SPIRITUAL

COUNSELORS AND SOCIAL WORKERS CAN BE ESPECIALLY HELPFUL TO YOU.

VOICING YOUR THOUGHTS REDUCES ISOLATION AND KEEPS FRUSTRATION FROM BUILDING UP.

6. Refresh Your Spirit. MOST OF US NEED SPIRITUAL AS WELL AS PHYSICAL AND

EMOTIONAL RENEWAL. PERHAPS IT IS IMPORTANT FOR YOU TO VISIT YOUR

PLACE OF WORSHIP OR LISTEN TO TAPES OF THE SERVICES YOU’VE MISSED.

OTHERS FIND IT HELPFUL TO READ OR LISTEN TO INSPIRATIONAL MUSIC. YOU

MAY NEED TO SET ASIDE SOME QUIET MOMENTS FOR PRAYER OR REFLECTION.

YOU MAY FIND TAKING A WALK OUTDOORS OR WORKING IN THE GARDEN

ENHANCES YOUR SPIRIT. THE HOSPICE SPIRITUAL COUNSELOR IS AVAILABLE TO

ASSIST YOU AS WELL AS YOUR LOVED ONE. A HOSPICE VOLUNTEER CAN

PROVIDE RESPITE FOR YOU AND COMPANIONSHIP FOR THE PATIENT
WHILE YOU
RENEW YOURSELF.

UNDERSTANDING PHYSICAL CHANGES

SOME VERY DISTINCT CHANGES CAN BE NOTED AS A PATIENT'S DISEASE PROGRESSES. WE FEEL THAT EVEN THOUGH THESE CHANGES CAN BE STRESSFUL AND EMOTIONALLY PAINFUL FOR THE CAREGIVER, TALKING ABOUT WHAT YOU MAY EXPECT CAN EASE YOUR FEARS, ALLOWING YOU TO CONTINUE TO GIVE THE SAME SUPPORT YOU HAVE PROVIDED ALL ALONG.

Nausea

NAUSEA AND/OR VOMITING MAY OCCASIONALLY OCCUR. IT WILL HELP TO:

1. KEEP SURROUNDINGS QUIET AND HAVE PATIENT REST.
2. USE CLEAR LIQUIDS ONLY—BROTH, JELLO, TEA, SODA—OR TRY CRACKERS OR DRY TOAST.
3. KEEP MOUTH FRESH AND CLEAN AT ALL TIMES.
4. TALK TO YOUR HOSPICE NURSE ABOUT MEDICATION TO LESSEN NAUSEA.

Constipation

CONSTIPATION IS A PROBLEM MANY OF OUR PATIENTS EXPERIENCE. IT MAY BE CAUSED BY INACTIVITY, PAIN MEDICATION, OR A DECREASE IN FOOD/FLUID INTAKE. THE BODY GENERALLY CONTINUES TO PRODUCE WASTE PRODUCTS EVEN THOUGH THE PATIENT IS NOT EATING MUCH. IT WILL HELP TO:

1. OFFER FLUIDS, JUICES, NECTARS OR JELLO AS TOLERATED.
2. INCLUDE FRUITS AND VEGETABLES IF PATIENT CAN TOLERATE THEM.
3. ENCOURAGE MILD EXERCISES, SUCH AS WALKING.
4. LET YOUR NURSE KNOW IF CONSTIPATION CONTINUES—PATIENT MAY NEED A STOOL SOFTENER, LAXATIVE OR ENEMA.

Diarrhea

DIARRHEA CAN OCCASIONALLY BE A PROBLEM. THERE MAY BE STOMACH CRAMPING AS WELL AS FREQUENT WATERY STOOLS. IT WILL HELP TO:

1. CONTINUE TO OFFER CLEAR FLUIDS.
2. KEEP SKIN AS CLEAN AND DRY AS POSSIBLE.

3. INFORM YOUR NURSE, AS PATIENT MAY NEED MEDICATION TO CONTROL DIARRHEA.

Incontinence

SOME PATIENTS LOSE THEIR ABILITY TO CONTROL THEIR BOWELS OR BLADDER. THE FOLLOWING MAY HELP:

1. BED PANS, ADULT DIAPERS, AND DISPOSABLE OR CLOTH BED PADS.
2. KEEP THE DIAPERS, PADS, AND LINEN CHANGED AS OFTEN AS NECESSARY.
3. KEEP THE SKIN CLEAN AND DRY TO PREVENT SKIN BREAKDOWN.
4. MANY PATIENTS FEEL SOME EMBARRASSMENT ABOUT THIS LOSS OF CONTROL, SO PROVIDE AS MUCH PRIVACY AS POSSIBLE.

Shortness of Breath

SHORTNESS OF BREATH, GETTING AIR IN AND OUT OF THE LUNGS, IS A PROBLEM FOR SERIOUSLY ILL PEOPLE. THIS CAN BE FRIGHTENING TO THE PATIENT (AND TO THE CAREGIVER). TO HELP YOU SHOULD:

1. HELP THE PATIENT TO STAY RELAXED. REMAIN CALM AND TRY TO CALM PATIENT.
2. HAVE PATIENT SIT UP AND LEAN FORWARD WITH ARMS SUPPORTED ON OVERHEAD TABLE OR OTHER ITEM.
3. RAISE THE HEAD OF THE BED OR ELEVATE PATIENT USING PILLOWS.
4. OPEN A WINDOW IF IT IS A COOL DAY OR USE AN OSCILLATING FAN TO INCREASE AIR CIRCULATION,
5. IF PROBLEM PERSISTS, NOTIFY YOUR HOSPICE NURSE. THE PATIENT MAY NEED OXYGEN OR MEDICATION.

Decreases Appetite

ONE OF THE MOST MISUNDERSTOOD AND DIFFICULT THINGS FOR FAMILIES TO DEAL WITH IS A PATIENT'S LACK OF APPETITE OR IN MANY CASES, NO APPETITE. WE'VE CHOSEN TO ADDRESS THIS CHANGE AT LENGTH, BECAUSE IT IS SO STRESSFUL FOR FAMILIES.

AS CHANGES BEGIN TO TAKE PLACE WITHIN THE PATIENT'S BODY, THE HUNGER AND NEED FOR FOOD LESSENS GREATLY. NOTHING TASTES GOOD, CRAVINGS COME AND GO, AND LIQUIDS ARE FREQUENTLY PREFERRED TO

SOLIDS. THIS DOES NOT MEAN THAT EATING SHOULD NOT BE ENCOURAGED, BUT THE PATIENT'S LIMITATIONS AND CHOICES SHOULD BE RESPECTED. THE FOLLOWING SUGGESTIONS MAY BE HELPFUL:

1. HONOR THE PATIENT'S REQUEST FOR CERTAIN TYPES OF FOOD AND DO NOT BE DISCOURAGED IF THEY ONLY EAT A SMALL PORTION.
2. SERVE FOOD IN SMALL PORTIONS ON SMALL PLATES SO AS NOT TO OVERWHELM THE PATIENT.
3. FREQUENT SMALL MEALS AND SNACKS MAY BE TOLERATED BETTER THAN THE TRADITIONAL "THREE MEALS A DAY."
4. CONCENTRATE ON FOOD OR LIQUIDS HIGHER IN CALORIES IF LESS IS BEING EATEN.
5. SERVE FOOD IN A COMFORTABLE AND RELAXING ATMOSPHERE.

AS ILLNESS AND WEAKNESS PROGRESS, EATING USUALLY DECREASES. THE BODY BEGINS TO SHUT DOWN THE FUNCTIONS OF WANTING AND DIGESTION TO CONSERVE ENERGY. THIS IS NOT AN UNCOMFORTABLE PROCESS. FORCING A PATIENT TO EAT MAY CAUSE ADDITIONAL PHYSICAL DISTRESS, SUCH AS CHOKING, NAUSEA, VOMITING. ANY QUESTIONS OR CONCERNS CAN BE DISCUSSED WITH THE HOSPICE STAFF.

IT WILL ALSO BECOME EVIDENT IN THE LAST STAGES OF A PATIENT'S ILLNESS THAT THE NEED FOR FLUIDS ALSO DECREASES. WE CONTINUE TO STRESS THAT THIS PART OF THE NATURAL PROCESS OF DYING. AS FLUIDS LESSEN, THERE MAY ACTUALLY BE RELIEF FROM SOME UNCOMFORTABLE PHYSICAL SYMPTOMS. THERE WILL BE:

1. LESS FLUID IN THE THROAT AND LUNGS TO REDUCE COUGHING AND CONGESTION.
2. DECREASED STOMACH FLUIDS THAT MAY REDUCE EPISODES OF VOMITING.
3. LESS NEED FOR URINATION.
4. SWELLING MAY DECREASE, LESSENING FEELINGS OF PRESSURE AND TIGHTNESS.

WHEN FLUIDS ARE REDUCED, THE CONCENTRATION OF NATURAL CHEMICAL ELEMENTS IN THE BODY CHANGES. THIS CAN REDUCE SENSATION IN THE CENTRAL NERVOUS SYSTEM, AND THE PATIENT MAY FEEL LESS DISTRESS.

A PATIENT'S COMFORT AND DIGNITY WILL ALWAYS BE OUR PRIORITY. WE WILL CONSULT AND WORK WITH THE PHYSICIAN AND FAMILY TO MEET THE PATIENT'S NEEDS. STAFF IS ALWAYS AVAILABLE TO TALK WITH YOU ABOUT YOUR FEELINGS, ESPECIALLY REGARDING DIFFICULT ISSUES.

We cannot teach the dying how to die. If we are there, however and if we are paying attention, they will teach us.

- Judith Viorst

ONE TO THREE MONTHS PRIOR TO DEATH

WITHDRAWAL – A PATIENT DOES NOT MAKE A CONSCIOUS DECISION TO WITHDRAW FROM THE WORLD AND THE PEOPLE AROUND THEM. IT JUST HAPPENS.

Responses – CONTINUE TO KEEP THE PATIENT WELL INFORMED, ESPECIALLY OF FAMILY MATTERS AND FORMER AREAS OF INTERESTS. THEY MAY NOT RESPOND, BUT THAT DOES NOT MEAN THEY ARE NOT HEARING THE INFORMATION. IF THE PATIENT DOES APPRECIATE VISITORS, SHORTER CONTACTS (10 – 15 MINUTES) WILL BE LESS TIRING. IT IS GOOD TO ALLOW THE PATIENT TO MAKE THEIR OWN CHOICES.

INCREASED SLEEP – THIS IS THE BEGINNING OF A TIME WHEN A PERSON WITHDRAWS FROM EVERYTHING OUTSIDE OF ONE'S SELF AND GOES INSIDE – TO "REVIEW" THEIR LIFE, SORT THINGS OUT, AND HOPEFULLY COME TO PEACE WITH THE LIFE THEY LIVED. WITH THIS COMES INCREASED SLEEP (OR THE APPEARANCE THAT THE PERSON IS SLEEPING). A MORNING NAP IS ADDED TO THE AFTERNOON NAP. THE PATIENT SPENDS MORE TIME IN BED OR ALL DAY IN BED.

Responses – WE WANT TO ENCOURAGE YOU TO ALLOW THE PATIENT TO SLEEP MORE AND RESPECT THEIR NEED TO BE ALONE. THEIR "AWAKE" TIMES WILL BE MORE BENEFICIAL AND MEANINGFUL TO YOU AND TO THE PATIENT.

LESS COMMUNICATION – DON'T TAKE IT PERSONALLY IF THE PATIENT DOES NOT WANT TO TALK. THEY HAVE LESS ENERGY AND FOCUSING ON A

CONVERSATION CAN BE DIFFICULT. WORDS ARE SEEN AS BEING CONNECTED WITH THE PHYSICAL LIFE THAT IS BEING LEFT BEHIND.

Responses – YOU MAY WISH TO BE SILENT AND ALONE WITH THE PATIENT DURING THESE TIMES. HOLD THEIR HAND OR LIE BESIDE YOUR LOVED ONE, COMMUNICATING THE COMFORTING ASSURANCE YOUR PRESENCE BRINGS.

DECREASED FOOD – THE PATIENT’S METABOLISM WILL CONTINUE CHANGING, FOOD IS NO LONGER BEING PROCESSED TOWARD ENERGY AND HEALTH, SO IT IS PERFECTLY NATURAL THAT EATING SHOULD DECLINE AND GRADUALLY STOP. THIS SHOULD NEVER BE CONFUSED WITH STARVATION. AT THIS PARTICULAR TIME IN THE PATIENT’S LIFE, IT IS PART OF A BODILY PROCESS OF “LETTING GO.” A DIFFERENT ENERGY IS NOW NEEDED THAT USUALLY FLOWS FROM A PERSON’S SPIRITUAL BELIEFS. THIS WILL SUSTAIN THE PATIENT.

Responses – OFFER SUGGESTIONS OF SMALL FOOD OR SNACKS AT INTERVALS THROUGHOUT THE DAY. DON’T FORCE FOOD. LET THE PATIENT BE IN CONTROL.

ONE TO TWO WEEKS PRIOR TO DEATH

MENTAL CONFUSION – YOUR LOVED ONE MAY BECOME INCREASINGLY CONFUSED ABOUT TIME, PLACE, AND IDENTITY OF CLOSE AND FAMILIAR PEOPLE. THIS BECOMES APPARENT AS LESS OXYGEN IS AVAILABLE TO THE BRAIN. THE PERSON OFTEN TALKS TO PEOPLE AND ABOUT PLACES AND EVENTS THAT ARE OF THE PAST OR UNKNOWN TO OTHERS. THEY MAY BE DISTURBED BY DREAMS OR SEE AND CONVERSE WITH LOVED ONES WHO HAVE DIED.

Responses – YOU MAY WANT TO LISTEN CLOSELY TO THE PATIENT, BECAUSE HE OR SHE MAY SAY A WORD OR PHRASE THAT CONTAINS SIGNIFICANT INFORMATION OR REQUESTS. REMIND YOUR LOVED ONE OF WHERE THEY ARE, THE DAY AND TIME, WHO IS PRESENT IN THE HOME AND WHO IS TALKING TO THEM. THIS IS BEST DONE IN A CASUAL, CONVERSATIONAL MANNER. YOUR PRESENCE AND FREQUENT TOUCH IS REASSURING AT THIS TIME.

RESTLESSNESS – AS THE OXYGEN SUPPLY TO THE BRAIN DECREASES, THE PATIENT MAY BECOME RESTLESS AND/OR AGITATED. YOU WILL NOTICE THEM

POSSIBLY PICKING OR PULLING AT THEIR BLANKETS OR BEDCLOTHES, AND DEMONSTRATING RANDOM ARM MOVEMENTS. THERE IS A SEEMING AIMLESSNESS TO ALL PHYSICAL ACTIVITY.

Responses – YOU MAY WANT TO TALK CALMLY AND ASSUREDLY WITH THE PATIENT SO AS NOT TO STARTLE OR FRIGHTEN THEM. REASSURE THE PATIENT OF YOUR PRESENCE. SOFT MUSIC OR A BACKRUB MAY BE HELPFUL.

INCONTINENCE – THE PATIENT’S BODY BECOMES RELAXED, SOMETIMES DUE TO THE DYING PROCESS, SOMETIMES DUE TO COMFORT MEDICATIONS. IT IS NOT UNCOMMON FOR A PATIENT TO LOSE CONTROL OF BOWEL AND BLADDER FUNCTION.

Responses – IT IS IMPORTANT TO EXPLAIN TO THE PATIENT THAT WHAT HAS OCCURRED IS A RESULT OF MEDICATIONS BEING TAKEN OR OF THEIR WEAKENED CONDITION. THIS IS AN EMBARRASSMENT TO THE PATIENT AND THEY SHOULD NEVER BE BLAMED. KEEP CHUX OR WATERPROOF PADDING UNDER THE PATIENT. ADULT DEPENDS OR ADULT DIAPERS CAN ALSO BE USED (ALWAYS REFER TO THEM AS “ADULT”). THESE PROTECTIVE PADS SHOULD BE CHANGED, WHEN SOILED, TO KEEP THE PATIENT COMFORTABLE. GENTLY WASH THE GROIN AND RECTAL AREAS AFTER EACH URINATION OR BOWEL MOVEMENT.

BRATHING CHANGES – YOU MAY NOTICE THAT YOUR LOVED ONE’S BREATHING PATTERNS CHANGE FROM TIME TO TIME. IT CAN BECOME IRREGULAR, WITH PERIODS OF NO BREATHING FOR 10 – 30 SECONDS. THESE PERIODS ARE REFERRED TO AS “APNEA”. THIS SYMPTOM IS VERY COMMON AND INDICATIVE OF A DECREASE IN CIRCULATION AND BUILDUP IN BODY WASTE PRODUCTS. RESPIRATION MAY INCREASE AND THEN AGAIN DECREASE, PRESENTING NO DISCOMFORT TO THE PATIENT.

Responses – IF THE PATIENT IS RESTING COMFORTABLY, ALLOW THEM TO CONTINUE TO REST. YOU CAN RAISE THE HEAD OF THE BED IF THE PATIENT BREATHES MORE EASILY THIS WAY, OR OFFER TO CHANGE THEIR POSITION.

BODY TEMPERATURE and PULSE – AS THE PATIENT’S BODY CONTINUES TO BE UNABLE TO MAINTAIN ITSELF, THE PULSE BEAT WILL USUALLY INCREASE SIGNIFICANTLY FROM A NORMAL OF 80 TO UPWARDS OF 150 BEATS PER MINUTE. AS THE HEART “WEARS DOWN”, THE BEAT WILL THEN BEGIN TO DECREASE AND SLOW DOWN UNTIL IT CAN NO LONGER BE FELT OR

DETECTED. THE BODY TEMPERATURE CAN ALSO FLUCTUATE BETWEEN HOT (FEVER) AND COLD DUE TO THE BODY'S INABILITY TO CONTROL ITS OWN TEMPERATURE. PERSPIRATION CAN INCREASE, OFTEN WITH CLAMMINESS. AS CIRCULATION SLOWS DOWN, THE PATIENT'S ARMS AND LEGS WILL BECOME COOL AND MAY BE BLUISH IN COLOR, ESPECIALLY THE NAIL BEDS.

Responses- BLANKETS CAN BE PROVIDED OR REMOVED AS NEEDED FOR THE PATIENT'S COMFORT. NEVER USE AN ELECTRIC BLANKET AT THIS TIME. SPONGE THE PATIENT WITH A COOL WASHCLOTH IF THIS PROMOTES COMFORT. CHANGE PERSPIRATION-SOAKED GARMENTS AND BED LINENS. TYLENOL (LIQUID OR SUPPOSITORIES) MAY BE ORDERED FOR THE PATIENT IF THE PATIENT'S TEMPERATURE RISES TO A LEVEL OF DISCOMFORT.

SPEECH, VISION, HEARING – AS A PATIENT MAKES EFFORTS TO COMMUNICATE WITH YOU, YOU MAY EXPERIENCE A SENSE OF FRUSTRATION AS THEIR SPEECH MAY BECOME DIFFICULT TO UNDERSTAND. THE LACK OF UNDERSTANDING MAY MAKE YOU FEEL AS THOUGH YOU ARE NOT “PLEASING” THE PATIENT. VISION CAN ALSO FAIL AND YOUR LOVED ONE'S EYES MAY BECOME DRY, SUNKEN OR GLAZED OVER IN AN APPARENT STARE. THE LAST SENSE TO BE LOST IS HEARING, AND IT MAY REMAIN ACUTE UP UNTIL THE TIME OF DEATH. NEVER SAY ANYTHING IN THE PATIENT'S PRESENCE THAT WOULD MAKE HIM OR HER FEEL UNCOMFORTABLE OR UNEASY.

Responses- IF YOU HAVE DIFFICULTY UNDERSTANDING A PATIENT'S SPEECH, LET THEM KNOW YOU ARE HAVING DIFFICULTY AND IT IS DUE TO THEIR WEAKNESS. YOU MAY WANT TO HAVE A LIST OF BASIC NEEDS THAT THEY CAN RESPOND TO WITH “YES” OR “NO”. REASSURE THE PATIENT THAT SOMEONE WILL ALWAYS BE AROUND TO PROVIDE THEIR CARE. IF IT IS APPARENT THAT VISION IS FAILING, KEEP THE PATIENT WELL INFORMED AS TO WHO IS PRESENT, AND OF THE DAY AND TIME. A WARM DAMP CLOTH CAN BE USED TO REMOVE ANY EYE SECRETIONS, AND EYE DROPS MAY BE GIVEN IF NECESSARY. KEEP THE ROOM AS LIGHT AS THE PATIENT WISHES, EVEN AT NIGHT. CARRY ON ALL CONVERSATIONS AS THEY CAN BE HEARD, BUT DON'T ASK UNNECESSARY QUESTIONS OF THE PATIENT IF VERBAL COMMUNICATION IS DIFFICULT OR IMPOSSIBLE. SOOTHING MUSIC MAY BE ENJOYED, AS WELL AS CONVERSATION FROM FAMILY AND FRIENDS. THIS IS AN EXCELLENT TIME TO EXPRESS LOVE AND CARING. THOUGH IT IS ALSO A GOOD WAY TO BE WITH A PATIENT BY GIVING A GENTLE MASSAGE OR SIMPLY HOLDING THE PATIENT'S HAND.

DAYS TO HOURS PRIOR TO DEATH

THE LAST FEW DAYS OF A PATIENT'S LIFE CAN SOMETIMES BE MORE "TOLERABLE" IF YOUR ATTITUDE IS ONE OF LETTING GO AND RELEASING YOUR LOVED ONE FROM THIS LIFE. BOTH OF YOU ARE FACING A SEPARATION AND CAN FREQUENTLY WORK ON THIS PAINFUL TASK TOGETHER. WE ENCOURAGE THAT YOU GIVE YOUR LOVED ONE "PERMISSION TO DIE". IN THIS WAY YOU RELEASE THE PATIENT FROM THE STRUGGLE OF FEELING "I KNOW I CAN'T STAY AND I DON'T FEEL LIKE I CAN LEAVE." LET THE PATIENT KNOW YOU'LL MISS THEM, BUT YOU WILL BE OKAY. SAYING "GOOD-BYE" IS YOUR FINAL GIFT OF LOVE, AND IS ONE OF THE GREATEST GIFTS YOU HAVE TO GIVE. SAYING "GOOD-BYE" CAN BE DONE IN MANY DIFFERENT WAYS:

- LYING IN BED WITH THEM
- HOLDING YOUR LOVED ONE'S HAND
- RECALLING MEMORIES
- SAYING "I LOVE YOU," "I'M SORRY," "THANK YOU," "WE'LL MISS YOU, BUT IT IS OKAY TO GO," "WE'LL ALWAYS LOVE YOU AND WE'LL BE OKAY."

DON'T HIDE YOUR TEARS OR APOLOGIZE FOR CRYING. TEARS EXPRESS YOUR LOVE AND CAN HELP YOU LET GO.

DURING THESE FINAL HOURS, YOU WILL NOTICE THAT THE SIGNS WE HAVE ALREADY TALKED ABOUT WILL BECOME MORE INTENSE AS DEATH APPROACHES. REMEMBER, THAT MOST OF THESE CHANGES OCCUR WITHOUT ANY DISCOMFORT TO THE PATIENT. IF YOU HAVE ANY QUESTIONS, YOU ARE ENCOURAGED TO CONTACT HOSPICE. WE WANT TO BE AVAILABLE TO YOU, AS WELL AS THE PATIENT.

PRONOUNCED CHANGES

SURGE OF ENERGY- THIS MAYBE MORE DIFFICULT TO OBSERVE IN SOME PATIENTS THAN IN OTHERS, BUT FREQUENTLY IT APPEARS THAT WHEN YOU BELIEVE THE PATIENT IS GETTING CLOSE TO DEATH, THEY SUDDENLY SEEM A BIT STRONGER, THIS MAY BE APPARENT THROUGH AN INCREASE IN

ALERTNESS, OR CLEARER SPEECH, OR SOME INTAKE OF FOOD AND/OR LIQUIDS. THEY MAY EVEN WISH TO SIT UP FOR A SHORT PERIOD OF TIME TO VISIT. MANY EXPLAIN THIS “NEW ENERGY” AS BEING A SPIRITUAL ENERGY THAT HAS ARRIVED FOR THE TRANSITION THAT IS ABOUT TO TAKE PLACE. FOR SOME, THIS “SPIRITUAL ENERGY” IS USED FOR A TIME OF PHYSICAL EXPRESSION BEFORE MOVING ON.

Responses- RESPOND TO THE PATIENT’S WISHES. HE OR SHE WILL KNOW WHAT THEY CAN OR CANNOT DO. TREASURE THAT MOMENTS AND BE REASSURING OF YOUR LOVE.

RESTLESSNESS- THIS MAY INCREASE SHORTLY BEFORE DEATH DUE TO A LACK OF OXYGEN IN THE BLOOD.

Responses- IF YOU FEEL THIS RESTLESSNESS IS UNCOMFORTABLE OR DISTURBING TO THE PATIENT, HIS OR HER CONDITION CAN BE EVALUATED BY THE HOSPICE NURSE. OXYGEN OR MEDICATION CAN POSSIBLY BE RECOMMENDED. THE BEST MEDICINE IS YOUR PRESENCE, OR THAT OF A FRIEND OR FAMILY MEMBER.

CONGESTION- ORAL SECRETIONS MAY BECOME MORE PROFUSE AND COLLECT IN THE BACK OF THE PATIENT’S THROAT. YOU MAY HAVE HEARD FRIENDS REFER TO A “DEATH RATTLE”. THIS SYMPTOM IS A RESULT OF A DECREASE IN THE BODY’S INTAKE OF FLUIDS AND INABILITY TO COUGH UP NORMAL SALIVA PRODUCTION. THE NOISE COMES FROM THE PASSAGE OF AIR THROUGH THESE SECRETIONS, AND IS GENERALLY MUCH MORE TROUBLESOME TO FAMILIES THAN TO THE PATIENT.

Responses- ELEVATING THE HEAD OF THE BED WITH PILLOWS OR OBTAINING A HOSPITAL BED WILL MAKE BREATHING EASIER. ICE CHIPS, A STRAW, AND COOL, MOIST, WASHCLOTHS WILL RELIEVE FEELINGS OF DEHYDRATION. SOMETIMES A DROPPER IS HELPFUL IN GIVING VERY SMALL AMOUNTS OF FLUIDS.

BODY CIRCULATION- AS THE PATIENT’S CIRCULATION CONTINUES TO DECREASE; YOU MAY NOTICE THE HANDS AND FEET BECOMING PURPLISH IN COLOR. THE KNEES, ANKLES, AND ELBOWS MAY APPEAR BLOTCHY.

Responses- NOT MUCH CAN BE DONE FOR THE PATIENT, OTHER THEN TO PROVIDE TOUCH, PRESENCE, AND MESSAGES OF YOUR LOVE.

HOW WOULD YOU KNOW DEATH HAS OCCURRED?

SIGNS OF DEATH INCLUDE:

- NO BREATHING
- NO HEARTBEAT
- LOSS OF CONTROL OF BOWEL AND BLADDER
- NO RESPONDING TO SHAKING
- EYELIDS SLIGHTLY OPEN
- EYES FIXED ON A CERTAIN SPOT
- JAW RELAXED AND MOUTH SLIGHTLY OPEN

PLEASE CALL HOSPICE, IF YOU FEEL DEATH HAS OCCURRED OR HAVE QUESTIONS / CONCERNS ABOUT ANY CHANGES. DO NOT CALL POLICE OR AMBULANCE.

AT THE TIME OF DEATH HOSPICE WILL SEND IN A STAFF PERSON TO ASSIST THE FAMILY. WE WILL CONFIRM IF DEATH HAS OCCURRED, MAKE NECESSARY PHONE CALLS, AND BE AVAILABLE TO OFFER SUPPORT. IT IS AT THIS TIME THAT CARE CHANGES FROM THE PATIENT TO THE CAREGIVER TO THE FAMILY. IF YOU PREFER TO SPEND TIME WITH YOUR LOVED ONE BEFORE CALLING HOSPICE, YOU ARE FREE TO WAIT UNTIL REQUESTING THE NURSE'S ARRIVAL.

EASING THE BURDEN

Pre-Arranging a Funeral

MOST INDIVIDUALS HAVE LOOKED AHEAD AND PRE-ARRANGED THEIR FUNERAL. FOR OTHERS IT IS STILL A DIFFICULT TASK TO BE DONE. FAMILIES FREQUENTLY FIND HAVING THIS ACCOMPLISHED PRIOR TO A DEATH IS A RELIEF. THE FEWER DECISIONS FAMILY MEMBERS HAVE TO MAKE AT TIMES OF CRISIS OR STRONG EMOTIONS, THE BETTER. IT ALSO ALLOWS THEM TIME TO BE WITH EACH OTHER TO FIND SUPPORT AND COPE WITH THEIR GRIEF.

SOME ADVANTAGES TO PRE-ARRANGING A FUNERAL ARE:

- IT ALLOWS INVOLVEMENT OF THE PATIENT, IF THEY WISH, AND GIVES THE FAMILY COMFORT KNOWING THEIR LOVED ONES WISHES ARE HONORED.

- IT ENSURES YOU HAVE EXACTLY THE KIND OF FUNERAL YOU WANT AND PROVIDES TIME IF YOU CONSIDER THE NEED TO MAKE CHANGES.
- IT IS EASIER TO MAKE ARRANGEMENTS IN AN ATMOSPHERE THAT ISN'T FILLED WITH GRIEF THAT COMES WITH THE DEATH OF A LOVED ONE.
- IT MINIMIZES THE BURDEN OF DECISIONS THAT HAVE TO BE MADE AT THE TIME OF DEATH.
- IT LESSENS FAMILY CONFLICTS ABOUT FUNERAL PLAN.

WE AT HOSPICE RECOGNIZE THAT EVERY PATIENT AND FAMILY IS UNIQUE. PRE-ARRANGING A FUNERAL MAY BE CONTRARY TO ONE'S BELIEF SYSTEM OR PERSONAL CHOICE. IT IS JUST AN OPTION FOR YOU TO CONSIDER.

Your Funeral Director

THE FUNERAL DIRECTOR WILL MEET WITH THE FAMILY TO DISCUSS ARRANGEMENTS. IN ACCORDANCE WITH LAW, CUSTOM AND ESPECIALLY FAMILY WISHES, THEY HELP YOU MAKE CHOICES TO MEET YOUR SATISFACTION. FUNERAL DIRECTORS MUST ALSO UNDERSTAND VARIOUS RELIGIOUS FAITHS, RESPECT THE INHERENT DIGNITY OF MANKIND, AND BE WILLING TO DEDICATE THEMSELVES TO A PROFESSION THAT DEALS WITH PEOPLE IN A TIME OF EMOTIONAL NEED.