

Connect You with Better In-home Palliative Care for Advanced Cancer Patients (Light in the Darkness Project)



Personal Hygiene

Goal of Care

- Personal care is a time for showing your love for the patient, also a time to observe any changes in the patient's body.
- If the patient is tired, personal care can be completed at intervals.

Skin Care

- Take precaution when trimming nails to avoid cuts and infection
- Take particular care to wash areas in skin creases (e.g. groin, under the breasts, between toes), and to check for any skin breakage rashes or sores
- Apply skin lotion or any prescribed skin medications if necessary



- Gentle washing and cleaning are encouraged to prevent causing discomfort, pain, skin breakage and bruises



Hair Care

- Keep hair and scalp clean and brush hair gently
- Use mild shampoo e.g. baby shampoo or dry shampoo



- Use pillow made with 100% cotton or silk. Reduce agitating scalp
- Put on a hat or wig/ head scarf, carry an umbrella when being outdoor, to avoid exposing your scalp in the sun



Mouth Care

Weakened immunity often associated with increased risk of getting oral ulcer, oral thrush or infection.

- Good mouth care can stimulate tastebuds and minimise swallowing difficulty
- Use a soft toothbrush or a mouth swab and gentle brushing twice daily



- Regular mouthwashes using 500 mL warm water with a teaspoon of bicarbonate, at least 4 times a day
- Offer foods that aid in increasing saliva, such as sugarless chewing gum, sour candy, mouth wash and saliva substitutes such as sprays and gels



- Frequent sips of water to maintain hydration in the mouth if possible
- Avoid coarse, dry food to minimise the risk of causing mouth sores/ulcers

Eye Care

In advanced illness, there may be changes in the patient's eye health and appearance. It can include dryness, itchiness, bulging of the eye or excessive eye secretions.

- Wipe from the inner corner of the eye to the outer edge
- To remove eye secretions, use a sterile cotton ball moistened with sterile water or normal saline over the lid margins and cover for 5 minutes
- Use a separate pad for each eye



- To relieve discomforts, use appropriate eye drops

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Dietary & Nutritional Issues

Goal of Care

- The goal is to reduce food-related discomfort and distress.
- Fixation on the amount of food being eaten and force feeding will create stress and tension between carer and patient.

When assisting with eating and drinking

- Meal time is a social event that encourages family bonding ; try to eat together
- Respect the patient for his/her choice of food and intake quantity to allow autonomy and independence
- Carer should not be disheartened when the patient refuses to eat the food that was prepared for them. Patient generally has different energy output and nutrition absorption, as well as changed dietary choice or loss of appetite
- Take medications on time so that symptoms such as pain or feeling sick are treated and don't stop you from eating

Encourage eating and boost appetite

- Eat when hungry. Most people are hungrier early in the morning, breakfast can be treated as the main meal of the day
- Try to include a variety of food in daily diet. The fragrance of fruits like tomato, pineapple, apricot can encourage appetite. Carer can incorporate fruits like orange, lemon, peach, mango and apple or their juices into meals
- Eat smaller meals, more often. E.g. Have 6 to 8 small meals and snacks per day instead of a few main meals
- Avoid cooking smells and serve foods cool or at room temperature if smells make the patient feel sick

- Ensure good oral hygiene, mouth sores, ulcers, ill fitted denture, tooth decay or gingivitis can discourage eating

Dysphagia (swallowing difficulty)

- Ask for assessment by speech pathologist
- Be careful while eating and ensure patient is fully awake
- Position them sitting upright with the head not leaning back when meals or drinks are taken and for at least 30 minutes afterwards
- Take small mouthfuls and eat slowly, swallow each mouthful before taking another
- To reduce risk of aspiration, serve soft, pureed, moist foods and thicken fluid such as soups, dips, fruit, creamy desserts and mashed vegetables with gravy or sauce for easy eating



- Use a straw or small spoon to help feed the liquid
- When patient cannot swallow or coughs after swallowing, stop feeding. This can cause more harm

Weight loss

Weight loss is common and is unavoidable, accompanied by fatigue and frailty.

- Ask for dietary review by dietitian
- Changes in body's function and activity may mean different nutritional needs.
- Choose high energy, high protein foods and drinks
- Include nourishing supplement drinks such as Ensure and Sustagen (diabetic formula available, consult your dietitian) if food intake is poor. Drinks can be just as nutritious as food and are often easier for a tired person



Report to nursing staff if a person:

- Nauseate
- Minimum oral intake for a few days continuously
- Changes in eating or drinking habit
- Coughs or chokes during or after eating, drinking or taking medication
- Has the feeling of food sticking in the throat
- Food pooling, dribbles or has food escaping from the mouth



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Home Safety & Community Resources

Goal of Care

- Staying independent is encouraged among patients.
- Allow the patient the autonomy to decide the kind of care or therapies they want to receive.
- Creating a safe home environment can be achieved by accepting advice from multi-disciplinary team of your local healthcare team.
- Personal care provided by external carer can only be safely executed when there are correct and suitable equipment at home, to minimise any chance of the patient and carer injuring themselves.

Access of Safety Equipment

A large range of specialised devices are available to tailor individual needs.

- **Personal safety** : install a call bell at home or a personal alarm carried with the patient



- **Mobility aids** : use walking frames, wheelie walkers, wheelchairs when the patient is feeling tired or weak



- **Seating** : pressure care cushions, height-adjustable chairs, recliners, tilted chairs



- **Home safety** : install hand rails at the bedside, bathroom and other areas, and place anti-slip mat in the bathroom, easy-grip utensils/ easy-pour kettles



- **Personal care** : shower stools or chairs, bath seats, over-toilet frames, urinals, commode/ slipper pan, continence pads



- **Bedding and lifting equipment**: back rests, tables and trays, pressure area care mattresses, hoists, hospital beds



Occupational Therapy & Physiotherapy

- Occupational therapy aims to optimise function and independence in people who participate in essential daily tasks. The term 'occupation' is used to describe all the everyday things we do in our life roles. Symptoms such as fatigue, breathlessness and pain can be managed through the use of the equipment recommended by occupational therapist
- Physiotherapy aims to improve quality of life, by helping individuals recover from injury, reduce pain and stiffness, increase mobility and prevent further injury. Treatment are specifically tailored to the condition of the patient. Services are available at home, in the community and in hospital. Their role includes :
 - Respiratory, neurological, lymphatic, orthopaedic, musculoskeletal, pain and haematological condition management
 - Mobility aids and physical aids
Non-pharmacological pain relief such as body positioning
 - Muscle and joint mobility strengthening exercises
 - Education for carers on how to safely mobilise and transfer the patient
- A referral to the occupational therapist or physiotherapist in the community can be made through a GP, non-GP specialist or nurse

Other resources:

- To access safety equipment, speak to your occupational therapist or physiotherapist. Their recommendations will determine the types of equipment that are available to you
- If you need financial aid to acquire these equipment, you may wish to seek assistance from various schemes offered by Centrelink, National Disability Insurance Scheme (NDIS), MyAgedCare, Home Care Package or personal superannuation fund
- For further guidance, contact a social worker at the hospital, your community nurse or your GP

Before discharge home from hospital or contact from home to your Oncologist/ GP/ Palliative Care Team

Speak with your healthcare professional in the following situations:

- Prior to returning home, a conversation with the treating team is crucial to discuss the need for referral to other services
- Have difficulty operating the hired safety equipment
- Consider using complementary therapies to help relieve the discomfort
- Write down the service arrangement between you and the hospital. It is always ideal to keep a copy to refer to if/ when you have any concerns
- When there is a change of needs or condition of the patient, the service arrangement may need to be adjusted accordingly

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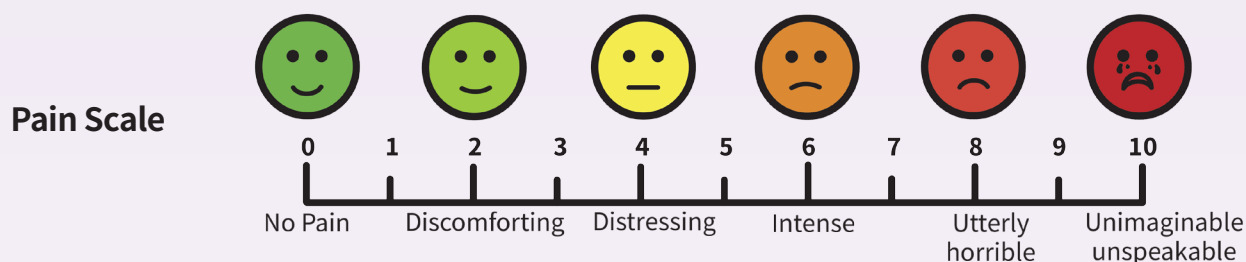
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Pain & Breathlessness

Goal of Care

- Living with Cancer does not mean living with pain.
- Adequate symptom management is achievable with help from health professionals using the multidisciplinary team approach.



Assess the patient's pain intensity level

- Use a pain scale, a tool to help patients self-report the severity of the pain on a scale of 0 to 10: "0" means "no pain"; "10" means the worst possible pain
- Indicate :
 - Time of pain
 - Duration of pain
 - Frequency
 - Type of pain

- Shooting pain
- Burning pain
- Pins and needles
- Tingling
- Sharp pain, stinging
- Muscle pain
- Skeleton pain
- Throbbing pain
- Aching
- Dull Pain
- Cramping
- Pressure like pain

Use of medication

- Take the medication as prescribed, do not wait for the pain to become intolerable
- If the medication is no longer prescribed for your condition, any remaining prescriptions should be returned to the chemist for safe disposal and avoid accumulation at home
- Use of opioid is common at ALL stages of cancer. Not only in terminal phase
- When morphine is properly used, it is not addictive and does not cause death. Understand the myth of morphine, refer to 'Light in the Darkness' booklet
- Long- acting pain relief, must be taken 12 hours apart
- Short-acting pain relief, usually refer as break-through pain relief; it is quick effect and is used as top-up
- For advice on how to minimize the adverse effect or for regular monitoring of the symptom, consult your palliative care team or GP
- Record truthfully and accurately of how you took the long-acting and short-acting pain killers, and show the record to your healthcare professional

Apart from the use of medication, most pain can be relieved or controlled via :

- Radiotherapy
- Physiotherapy
- Complementary therapies
 - Relaxation
 - Meditation
 - Massage
 - Acupuncture
 - Hypnotherapy
 - Music Therapy
- Reposition the patient carefully
- Gentle massage
- Take deep breaths
- Apply heat packs / cold packs

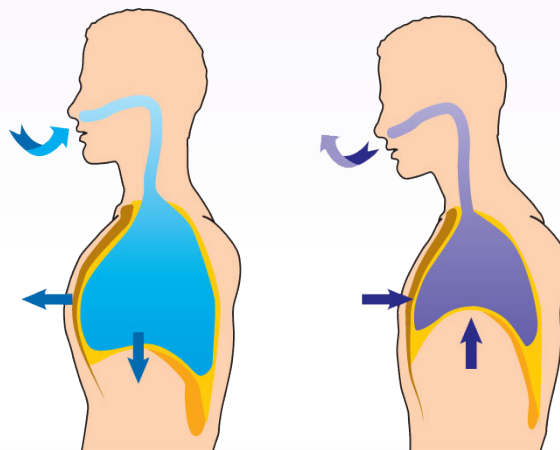


Breathlessness

This can be triggered by multiple reasons including anxiety. Discuss management plan with the treating team.

To alleviate breathlessness :

- Stop & reposition, sit upright or lean against something helps
- Breathe slowly, with pursed lips 3 seconds in, 3 seconds out



- Open a window or use a small fan and direct it at the patient's face, this will stimulate the trigeminal nerve that tricks the brain and helps with breathing
- Take breathlessness relief medication as prescribed
- Relaxation exercises – put on some calming music, offer gentle foot/ hand/ shoulder massage

Oxygen via a mask or nasal prongs is not routinely needed and required a doctor's order to be used. If used, follow instructions.

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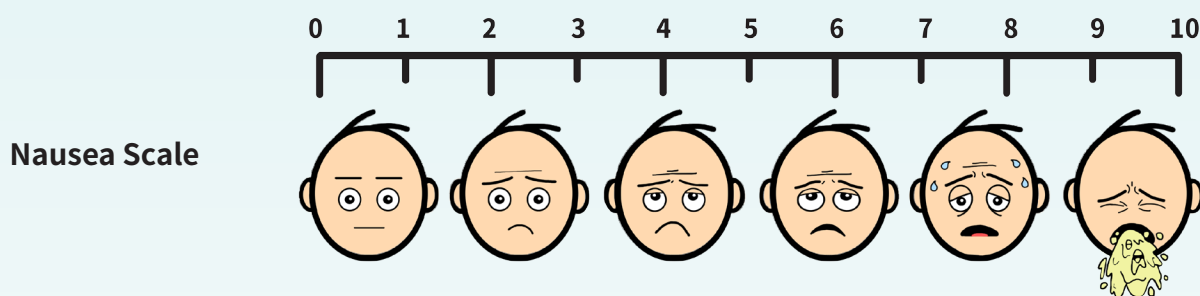
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Nausea & Vomiting

Goal of Care

- Nausea and vomiting can be caused by many reasons and is not just cancer treatment alone. It can be triggered by multiple factors such as smells, tastes, sights or movements, as well as sensations such as pain, and emotions like anxiety.
- Hydration is more important than amount of food intake.
- Carer should not overly focus on oral intake as the stress can increase symptom and burden on patient.



Nausea

- The cause of nausea can be related to the stage of disease, medications, chemotherapy, radiotherapy, constipation or an imbalance of chemicals within the body
- On chemotherapy treatment days, eat a small meal or snack before treatment
- Ensure a vomit bag is within easy reach in case they vomit



- Take vitamin B complex
- Use acupressure device such as the anti-nausea bracelet



- If anti-nausea medicines are prescribed, check to see if they have been taken as directed
- Make use of the following complementary therapies or activity that can help reduce the misery of chronic nausea
 - Take regular sips of water with lemon juice or a piece of lemon added, soda water, ginger ale, lemonade, or energy drinks

- Combine breathing exercise with the use of peppermint, lavender, ginger, fennel seed or lemon essential oils



- Distract yourself with soft music, a favourite TV program, or the company of others
- Keep food or other unpleasant smells to a minimum. Introduce plenty of fresh air
- Do not skip meals or snacks. If your stomach is empty, your nausea may become worse
- Eat food cold or at room temperature to decrease its smell and taste
- Manage posture, avoid lying down straight after eating. If body movement induces nausea, eat something light before trying to sit up
- Lying on the right side (opposite side to stomach) with a pillow positioned into the back and knees drawn up
- Try small amounts of foods high in calories that are easy to digest, and eat several times a day. Food such as porridge, cereals, oatmeal, beans, and more starchy vegetables - potatoes, sweet potato, pumpkin, dairy products - ensure/ Sustagen, yogurt, custard. Minced meat/frothed meat and eggs can also be added
- There are multiple medication to manage nausea. Take your anti-nausea medication as instructed by your treating team. Do not stop taking medications on your own
- While waiting for your anti-nausea medicine to work, relax and take slow, deep breaths

Vomiting

- Vomiting has additional effects including exhaustion, dehydration and absorption of medications given
- Inform your treating team as soon as possible to review care plan. Note down :
 - the triggers
 - frequency
 - colour
 - time
 - volume
- Food intake is not recommended when patient is experiencing vomiting as eating can worsen the condition
- Rinse the mouth, clean the teeth and take small sips of water or suck on an ice cube after vomiting or before eating or between meals
- Gradually re-introduce a wider variety of drinks and a small amount of plain food, such as a slice of dry toast
- Salty, tart and sour foods may be easier to take
- Try chilled tomato or diluted fruit or vegetable juice
- Hot foods may be harder to tolerate, eat food at room temperature
- Certain relaxation and meditation exercises might help reduce induced vomiting. Patient can seek advice from a psychologist in the community or at the hospital



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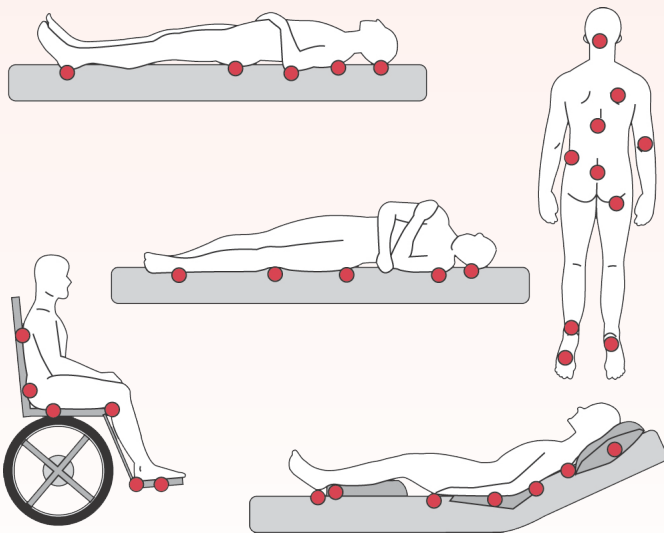
Pressure Area Care

Goal of Care

- Goal is to prevent pressure injury.
- Adequate pressure area care can help reduce and/or delay development of pressure injury.

Pressure Injury Prevention

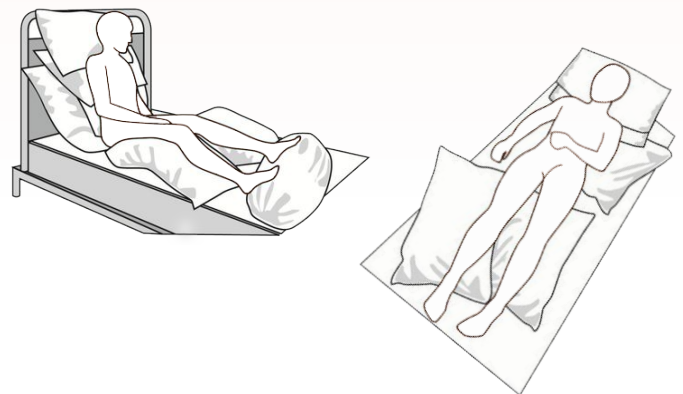
- Pressure injury caused by ongoing and continued pressure to the skin over a bony prominence (refer to the image below)



- People with poor mobility and/or bedbound are at risk for skin breakdown
- Not all skin breakdown is preventable

To prevent pressure injury :

- Maintain good skin integrity
- Moisturise full body, pay extra attention to at risk areas
- Keep bedding tidy and dry
- Maintain good personal hygiene
- Repositioning or mobilising every 2-4 hours
- Gentle massage on areas without broken skin
- Wear comfortable clothing
- Use pressure relieving devices or place cushions or pillows to reduce pressure spot. Consult with occupational therapist



Pressure Area Wound Care

- Inform GP or health professionals
- Referral to local general community nurse for wound assessment and appropriate wound care plan
- Aware sign of infections such as fever, exudate, odour and colour

Fluid Retention/ Lymphedema

- It is a common symptom for those living with impaired immune system
- Eat a well-balanced diet
- Maintain mobility and exercise
- Raise the affected area when sitting or lying down. If the person is experiencing oedema in their feet, ankles, or legs, elevate them to ease their symptoms
- Avoid standing for long periods or sitting with your legs crossed
- Do not reduce the amount of water or other fluids you drink without talking to your doctor
- Talk with your doctor about whether physical therapy or occupational therapy may be helpful
- Speak with health professionals to measure a suitable compression stockings or elastic sleeves to assist symptom management



Contact your GP, the palliative team specialists or community nurse if you noticed the following :

- Increased breathing difficulty
- New areas of oedema
- Worsening oedema
- The patient is experiencing pain
- A change of skin colour or temperature
- Fluid seeping out of the skin

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