IRT Group Palliative and End of Life

Information Pack

October 2021

Dear resident, family and friends

We aim to ensure that you have all the information you need about palliative and end-of-life care to enable informed care and create understanding of what to expect.

At IRT, palliative care:

- is aimed at preventing suffering, improving comfort and addressing psychological, spiritual, cultural and social needs
- provides care that is based around your and/or your loved one's wishes and which involves you throughout all stages wherever possible
- aims to ensure residents die with dignity and achieve the end-of-life experience desired, wherever possible
- is based on best practice and evidenced-based guidelines and participation in regular reflective practices to continuously improve palliative care.

We anticipate you may require different information at different times depending on the stage of your or your loved one's palliative care journey. To this end, the enclosed Palliative Care Information Pack provides you information about:

1. End-of-life care – information providing guidance when end of life is approaching, including what to expect at the end of life.
2. Namaste information – Namaste is offered to residents with end-stage dementia and other life-limiting illnesses. The approach focuses on the person. Complete and return the My Sensory Checklist if this is of interest.
3. Palliative care survey – this form helps IRT to consistently improve the services and end-of-life care offered to residents and families. Complete and return this survey if you wish.

We also offer a number of support services at the end of life with a range of different end-of-life recognition programs at IRT's aged care centres. It is at your discretion to access and participate in these services and programs. The services and programs include:

1. The supply of a palliative care trolley in the final days of life. It enables the family to stay close to their loved one and spend quality time with them in their room, while also offering the resident comfort. This trolley may include: comfort aids; a Namaste box of the resident's personal mementos; refreshments for the resident and their family; and other religious, cultural or spiritual artefacts.
2. The end-of-life recognition programs that may be practiced at IRT's aged care centres include:
    - Purple flower signage, which is placed on a resident's care suite door in the final days of life to allow the family privacy while allowing others the opportunity to pay their last respects should they wish.

- Butterfly signage, which is placed on a resident’s care suite door when a resident has passed, indicating to staff, other residents and families that the resident is deceased.
- A condolence/memorial book with a candle or flowers is placed on a table in the foyer/reception area of the aged care centre on a resident’s passing, allowing staff and others to write their condolence messages.
- A guard of honour service is held on a resident’s passing enabling the family, staff and other residents to bid farewell to the resident as they leave the IRT community. The departed resident is adorned with a special quilt as the undertakers leave the aged care centre, departing through the aged care centre’s front door.

Please speak with your Care Manager to understand which programs are offered at your aged care centre. We invite you and your loved one to consider which of these end-of-life recognition programs you would like observed.

At IRT we wish to support you through this time to ensure you or your loved one’s care is based around your wishes and aims to ensure you or your loved one dies with dignity and achieves the desired end of life, whenever possible. Please speak to the Care team or Care Manager if you have any questions about the enclosed information pack.

“You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.”

– Dame Cicely Saunders, founder of The Hospice Movement

Yours sincerely

Nia Briguglio
EGM – Aged Care Centres

Cardio Pulmonary Resuscitation (CPR)

Information for residents, customers, representatives and family

IRT's position on Cardio Pulmonary Resuscitation (CPR)

IRT understands it has a duty of care to its residents and customers, while also recognising that death is inevitable and a natural part of life. Our approach to life-prolonging measures such as CPR is guided by these two principles.

IRT has taken the position that our employees will not perform CPR on all residents/customers who are found unresponsive and not breathing normally (i.e. residents/customers who have suffered cardiac arrest).

However, in some emergency situations designated employees working in our aged care centres or providing home care services may perform CPR. An ambulance will always be called if CPR has been commenced.

When CPR will not be performed

Our employees will not perform CPR in the following circumstances:

- The resident/customer has a palliative approach in place, nearing the end of their life. (see *CPR in an emergency situation*, for residents with Advanced Care Planning documents)
- The resident/customer has expressly communicated their wish not to be resuscitated under any circumstances, via an Advance Care Directive or Statement of Choices.
- The cardiac arrest does not appear to be the result of an emergency situation.

CPR in an emergency situation

Employees who are trained in CPR are supported to perform CPR in the following circumstances:

- The cardiac arrest appears to be the result of an emergency - such as an accident, fall, choking event or medical episode - as distinct from a natural ending of life.
- The cardiac arrest does not appear to be the result of an emergency but the employee knows the resident/customer has expressly communicated their wish for CPR to be performed in all cases, via an Advance Care Directive or Statement of Choices.

IRT aged care centres and home care employees do not have access to Automatic External Defibrillators. If CPR is commenced an ambulance will always be called and defibrillation will only be performed by ambulance officers.

Advance care planning

IRT supports all residents/customers to be given the opportunity to complete an Advance Care Directive (ACD). A Statement of Choices (SoC) can be completed by the resident/customer's substitute decision-maker where the resident/customer does not have capacity to make decisions relating to their advance care planning.

ACD is a legally enforceable document, whilst a SoC helps guide decision making at a future time when the resident is unable to communicate their own wishes. SoC is not a legally enforceable document.

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RESIDENTS AND RELATIVES NEWSLETTER

Issue 14, September 2020

Palliative Care

What is Palliative Care?

‘Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.’

- Palliative Care Australia

‘shifting from a ‘cure’ to a ‘care’ focus, especially in the last 6-12 months of life’

- The Royal Australian College of General Practitioners

Aims of Palliative Care

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness

An Advanced Care Plan is recommended for all residents to ensure their values, hopes and goals in relation to their health are known particularly if they may lose the capacity to communicate or make decisions towards the end of their life

Palliative care should be planned and discussed well in advance once a person is diagnosed with a life-limiting illness (including dementia) at any age and at any stage of their illness. Palliative care does NOT just apply to 'end of life or 'terminal phase' care.

Good palliative care can significantly reduce both physical suffering and emotional distress.

The main objective of palliative care is to minimise the impact of the progressing illness so that residents can have the maximum function, symptom relief and comfort possible within the limits of their illness.

Good palliative care is not different from good clinical practice in any field—it includes holistic assessment (of both the physical and psychosocial dimensions of need), pharmacological and other interventions tailored to the resident, and regular review to ensure care is adapted to the changing needs of the resident and their family as death approaches.

The medical practitioner and nursing staff will discuss with family the prognosis, goals of care and advance care planning, which are important elements of palliative care.

The decision to adopt a palliative approach reflects a recognition that the goals of care are shifting from managing disease and prolonging life towards optimising the quality of remaining life. It acknowledges that intensive efforts to prolong life are unlikely to be beneficial and may not be wanted by the resident.

If a resident requires management of complex problems that are beyond the skills of their usual healthcare provider(s), referral may be made to a specialist palliative care service. They can assist with management of symptoms or complex psychosocial or spiritual distress, and in situations when communication is challenging or there are difficulties with decision-making.

Increasingly, residents are choosing to remain in the aged care facility rather than being transferred to hospital or hospices for the final phase of life. This is possible in most cases as aged care facilities are able to identify residents who may benefit from introduction to palliative care for end of life care. Palliative care specialists are also able to be consulted within the aged care home setting to assist with optimising management during this phase of life.

Common Symptoms in a Palliative Resident

Psychological Symptoms	Physical Symptoms
Depression Anxiety Delirium Confusion	Pain Nausea/ Vomiting Constipation Shortness of breath Oral Problems Anorexia, weight loss & Cachexia Fatigue/ Tiredness

Psychological Symptoms

Depressive disorders

- Not a normal part of dying although distress and sadness may occur
- Monitoring for symptoms including suicidal thoughts is required as well as appropriate treatment (counselling, antidepressants) may reduce suffering for the person

Anxiety

- May be due to the fear of death, separation/loss and impact on the family
- Can accompany a depressive disorder
- Can be associated with other symptoms (e.g. shortness of breath)
- Management with an antidepressant if required may be helpful
- Anti-anxiety medications (e.g. lorazepam) may be helpful short-term or intermittently

Delirium (acute confusion or altered consciousness)

- More common as death approaches and should be recognised and treated early
- May fluctuate causing symptoms such as disorientation, disorganised thinking and behaviour, agitation, memory disturbances, hallucinations, delusional beliefs, sleep disturbances
- Causes include medications, infections, organ failure, pain/discomfort, metabolic disturbances, withdrawal states (e.g. from opioid medicines)
- Management may include antipsychotics (e.g. risperidone, olanzapine, haloperidol)

Physical Symptoms

Pain management

- Regular, thorough and ongoing assessment should be conducted, to ensure adequate pain management.
- The medical practitioner will discuss expectations with the person, including the degree of pain relief which may be expected, potential adverse effects, and effects on mobility and social activity
- The treatment of pain does predominantly involve pain relieving medication. However, psychological support, and non-pharmacological management is important.
- This includes counselling, treating depression, and non-pharmacological measures such as physical therapy (hot and cold therapy), mind-based techniques (mindfulness, meditation, relaxation), massage, aromatherapy and music therapy amongst others.
- When choosing a pain-relieving medication, the choice depends on the type and severity of pain, also considering the person's preferences, condition (kidney and liver function), and potential adverse effects.
- Mild pain is managed with paracetamol, or nonsteroidal anti-inflammatory drugs (NSAIDs) if suitable for the person. If not effective, then opioids are used for moderate to severe pain.
- Treatment with opioids does not mean that the end of life is near. With improved knowledge about the management of pain, opioids are often used in many types of chronic pain.
- Morphine is an opioid often chosen because it has many different forms and is available as short and long acting tablets or capsules, oral liquids and injections. However, there are other opioids that may be used.
- Opioids are effective for most types of pain, however, are less useful in nerve pain which can be involved in the palliative process, where other agents may be required, such as anti-epileptic medications or antidepressants.

Physical Symptoms continued...

Nausea

- Nausea, with or without vomiting can commonly occur. It may be caused by medications (opioids for example, commonly cause nausea), constipation, or may occur as part of the disease process.
- Treatment is recommended to increase comfort, and if an anti-nausea agent is needed, regular doses are more effective than when required (PRN) administration.
- Uncontrolled nausea and vomiting can cause severe discomfort and can interfere with eating and administration of medication.
- Nausea can be induced by anxiety and the trial of behavioural therapies (e.g. Relaxation, cognitive and behavioural therapy) may be useful
- Residents with nausea and vomiting from external pressure on the stomach, or from delayed emptying can benefit from consuming small amounts of food/drink regularly. If residents cannot tolerate solid food, they may benefit from liquids or pureed foods
- It is not often possible to identify or specifically correct the underlying cause of nausea and vomiting. Often the cause is multi-factorial.
- Whether causes are known or not, the burden of any pharmacological intervention must not outweigh its potential benefit.

Constipation

- Management of constipation is important as if left unmanaged it can lead to pain, bloating, nausea and vomiting, overflow incontinence, faecal impaction and occasionally bowel obstruction and colonic perforation.
- Constipation can lead to problems such as delirium, agitation, depression and anxiety.
- It can also affect the absorption of medications.
- Usually the cause is a range of factors, and all should be addressed – including diet, hydration, and medications which cause constipation.
- The most commonly used laxatives and best initial choice for people in palliative care are stimulants – e.g. Coloxyl with Senna.

Shortness of breath (dyspnoea)

- Management of constipation is important as dyspnoea is the experience of difficulty in breathing. It is frightening for the person as they can feel they are suffocating, short of breath, unable to breathe, or drowning.
- Oxygen can be given to those who have a low saturation of oxygen in their blood (i.e. hypoxic)
- Dyspnoea is otherwise treated with oral or injectable opioids like morphine
- A benzodiazepine can also be given if the person is anxious, e.g. lorazepam or oxazepam

Oral Problems

Dry lips

- Avoid lip balms containing alcohol

Dry mouth (xerostomia)

- Can cause loss of quality of life and contribute to difficulty swallowing food and medications
- Causes include damage to salivary glands (e.g. by radiotherapy), medications, and mouth breathing
- Requires meticulous mouth care to moisturise, e.g. mouthwashes and other mouth care products

Swallowing difficulty

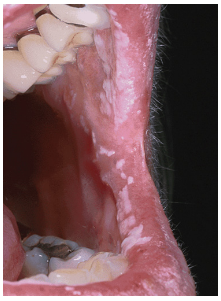
- May require speech therapist assessment and change of diet consistency however while aspiration is a potential complication, resident choice to eat or drink as they please should be respected
- Oral lubricants may be helpful particularly if cause is associated with dry mouth

Mucositis

- Inflammation of the mucosal surfaces of the mouth which may cause ulceration accompanied by difficulties with eating, drinking and taking oral medications
- Initially the only symptoms may be loss of appetite or altered taste
- Treatments include mouthwashes, topical anti-inflammatory agents or analgesic mouth solutions

Infections

- e.g. oral thrush – treated with topical antifungals unless severe requiring oral treatment



Anorexia, weight loss and Cachexia

- Anorexia (lack of appetite) and weight loss are common and can cause significant concern to residents, their family and carers.

Common misconceptions include 'death by starvation', however lack of appetite may be due to the dying process rather than the dying process being due to the person not eating

- Cachexia (extreme weight and muscle loss) occurs in the late stages of almost every chronic illness, and cannot be reversed by increasing calorie intake
- Stabilising weight by increased feeding does not postpone dying in most cases (particularly cancer)
- Ceasing to weigh a resident may be discussed

Fatigue

- Can be more distressing to the person than pain - affects ability to function, increases loss of independence
- May be seen by family/carers as the person 'giving up' and it is important to understand this as a possible symptom of a palliative care resident.
- There is limited evidence on the benefit of medications for fatigue, e.g. dexamethasone.

Stopping Medications

An important activity in palliative care is to regularly review the resident's medication to rationalise treatment. This may involve modifying or stopping medications.

Medication may be withdrawn if it is no longer considered beneficial or appropriate for the patient in the palliative context, and/or are not desired by the resident. For example, a resident who is in the terminal phase and is bedbound may warrant cessation of their medications for osteoporosis due to their low risk of fractures and potential risk of adverse effects like gastric upset due to their prolonged lying position.

As the resident's condition declines, there is usually a greater focus on medications that offer immediate benefit (e.g. to relieve pain or shortness of breath in respiratory disease) while medications that have been prescribed for long-term benefit may become less important and can be stopped.

Where possible, it is important to involve the resident with these decisions to understand whether they feel their medications are beneficial and if they wish to continue taking them.

Review of medications will also require a balance between the benefits and harms/burdens of each medication. Residents with advanced disease are at a greater risk of adverse effects due to old age, altered organ function and/or weight loss, which may be a reason to cease or reduce medication dosages.

End of Life Care

In the normal dying process, a period of deterioration often occurs in the weeks leading up to the terminal phase. In those who do not have a malignancy, the period of deterioration can be longer and more variable. The following usually occur:

- Progress of disease e.g. tumour enlargement, progressive weight loss, increasing oedema (swelling), worsening symptoms
- Loss of strength and energy leading to spending most of their time in bed. Going to the bathroom can even become exhausting.
- Increasing periods of sleep
- Less interested in food and drink. Most oral intake may consist of fluids.

The terminal phase refers to the last days of life- when the person is actively dying.

The person is usually:

- Totally bedbound and requires increasing care
- Poorly responsive or unconscious, with limited response to stimuli
- Unable to swallow
- Has reduced or no urine output
- Undergoes changes in breathing pattern
- Shows signs of peripheral shut down – pale skin, cold hands and feet
- Can become agitated and restless

In managing the terminal phase symptoms, it is important for medical review to:

- Stop medications which are no longer beneficial
- Stop medications which cannot be swallowed
- Change the route of administration to subcutaneous or sublingual.

Note that dry mouth can affect the absorption of sublingual (under the tongue) preparations, which is why subcutaneous options (injections under the skin) are generally preferred.

FAMILY/CARER INFORMATION REGARDING MEDICATIONS IN THE LAST DAYS OF LIFE

When people are in the last days of life, their bodies and vital organs are slowing down and will eventually stop working. The medical term for this is **end stage organ failure.** This is a normal part of the dying process and it happens to everyone while dying.

Our goal now is to provide comfort and support to the dying person and their families/carers. One important part of comfort care is to provide medication that will prevent or relieve discomfort and suffering that may be caused as a result of failing organ and body function.

This information sheet talks about medicines that are given to the person to increase comfort and relieve suffering in their last days of life. Not all people will receive all the medicines discussed here.

You are encouraged to ask the nurses and doctors about what medication/s are being given and how you can be involved, if you would like to be.

The nurses and doctors will be regularly watching your family member/friend for signs of being uncomfortable or distressed. Healthcare staff, while very experienced in caring for people, do not have the deep understanding of the individual that you do.

If you think or feel that your family member/friend is feeling uncomfortable or is distressed, please let the nursing or medical staff know.

Being uncomfortable or distressed may be shown by:

- Facial signs, such as grimacing or wincing
- Groaning
- Stiffening or resisting body movement when being moved into a different position
- Restlessness or agitation
- Bloated tummy (which was not there before)
- Dry heaving or repeated burping

How is medication given in the last days of life?

The most common way to give medication to people in their last hours or days of life is through a small very thin tube that goes under the skin. The medical name for this is **sub-cutaneous injection.**

The tube that goes under the skin is called a **butterfly needle** as the outside of the tube that is taped to the skin, looks like butterfly wings. Medication given through the butterfly needle is given through a machine called a **syringe driver** or **pump.** This is a machine that is able to deliver very small amounts of fluid through a tube every hour.

Most people will not be able to swallow tablets in the last days/hours of life. Medicine that is given under the skin works very well. Small amounts of medication are given every hour. This helps to better manage distressing symptoms and means your family member/friend does not need to have regular injections. The butterfly needle can stay in place for a number of days before needing to be replaced.

What should I do with any medicines when they are no longer needed?

It is important that any medicines prescribed are safely disposed of when they are no longer needed. This includes regular medicines that have stopped (including tablets, liquids, inhalers, eye drops, etc.) as well as those injection medicines used in the last days of life.

What to do?

- Take any medicines to your local community pharmacy, and give them to the pharmacist for free and safe disposal.

What not to do?

- Do not flush medicines down the toilet
- Do not pour medicines down the sink
- Do not throw medicines into the garbage

(adapted from the Return Unwanted Medications (RUM) Project)

Medication for pain and breathlessness

Morphine (pronounced *more-feen*)

Morphine is an important part of comfort care management. Many dying people may be distressed by feelings of pain or breathlessness (feeling like you cannot catch your breath) in their last hours/days of life. Giving small, regular or continuous amounts of morphine works very well to help keep the person comfortable by easing their pain and helping them to be able to breathe more easily.

Morphine is a safe medication that is used by many people every day. Morphine that is given when someone is dying does not shorten life. People are only given the amount of morphine that they need to keep their pain controlled and to be able to breath comfortably.

If you think that your family member/friend is in pain or finding it hard to catch their breath, please let the nursing or medical staff know. It is better to start treatment earlier rather than later.

Medication for restlessness or confusion

Haloperidol or Midazolam (pronounced *hal-o-PEAR-eeh-doll* and *mid-AZ-o-lamb*)

Many people may become confused or restless in their last days of life. The medical word for this is **agitation.** They may be **hallucinating** – talking to people who are not there; unable to be reasoned with and often angry with family/carers and friends, even though there is nothing that has caused their anger. Often it is not possible to help them to settle down because it is what is happening in their thoughts/mind that they are responding to. They do not understand that what they are thinking is not what is really happening.

Two common medications used for settling agitation are called **Haloperidol** and **Midazolam.** Each of these medications can be given to people either as an injection or with other medications through a drip or syringe driver. Medication that is given to manage confusion and restlessness has a relaxing and calming effect. You may find that your family member/friend is more settled and does not wake up as easily. They may only open their eyes or nod occasionally rather than talk to you. Sometimes they may stay asleep even when you talk to or touch them.

Please let the nurses or doctors know if you are worried that your family member/friend is restless or confused. It is better to manage their distress early rather than late.

Medications to control nausea and vomiting

Haloperidol and Metoclopramide (pronounced *hal-o-PEAR-eeh-doll* and *met-o-CLO-pra-mide*)

Not everyone will need to have medication to stop them feeling sick. If your family member or friend has felt sick or vomited previously when given morphine AND they have been started on morphine in their last days of life, please let the doctor or nurse know.

Medications for noisy or rattly breathing

Glycopyrrolate or Buscopan (pronounced *gly-co-PIE-ro-late* or *BUS-co-pan*)

In the last hours of life, a person may begin to make a noisy, 'rattle' sound when they breathe. The noisy rattle comes from a build-up of spit (medical name **saliva**) and mucous that they are no longer able to swallow or spit out. The noise of the rattle is often more distressing to the family or friends than the person who has the rattle.

Medication may be given to dry the mouth and reduce saliva so that fluid does not build up in the mouth. These medications work best if they are given as soon as the noisy breathing begins. The medications can be given as a regular injection or included with other medication and given by a drip or syringe driver.

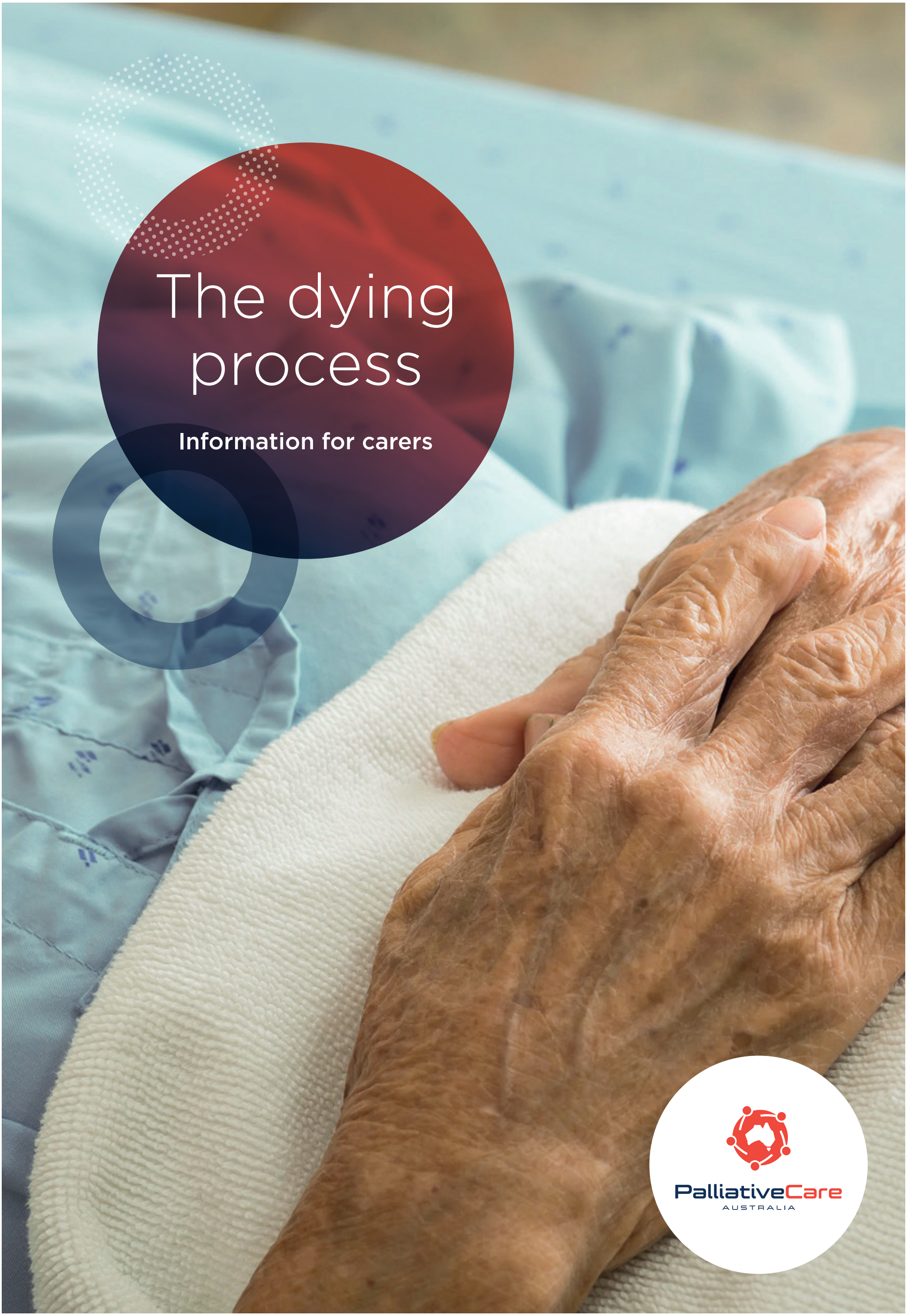
Please let the nurses or doctors know if you begin to hear a 'rattle' sound when your family member/friend is breathing. Starting medication early helps to reduce the build-up of fluids that make this sound.

Last Days of Life

CLINICAL
EXCELLENCE
COMMISSION

The dying process

Information for carers



PalliativeCare
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Not all of us have been present when someone dies, but the moment of death is often peaceful. This brochure may help you understand, anticipate and respond to some of the signs you might notice before, during, and after death.

Caring for a person during the last few weeks and days of their life can be distressing, demanding and tiring. Many different feelings and emotions may surface at this time.

Carers often worry that death will be painful. However, the time before death, and moment of death, are generally peaceful. There is a gentle winding-down that may take several days. The body starts to 'let go' of life. If restlessness does occur, it can be treated.

Not all of the signs mentioned in this leaflet will occur with every person, nor will they occur in any particular sequence. Sometimes these signs appear a few hours before death, sometimes a few days. These physical signs are part of the normal, natural process of a person's body gradually slowing down.

Apart from the signs described here, you may notice other changes that worry you. The palliative care team can assist you by providing information and support.

Please ask for help at any time. The palliative care team expects to have increased contact with you in the last stages of the person's life.

You can bring enormous benefit to the person you are caring for simply by sitting with them, holding their hand and speaking in a calm and reassuring manner. Even if the person does not respond, they can probably hear you. Don't underestimate the value of these simple things. 'Being with' can be more important than 'doing for'.

Changes you may notice and what you can do to help

Appetite and thirst

The person's appetite and thirst may decrease, and they may have little desire to eat or drink. This concerns many carers, but it is a natural process and it is not painful for the person. Sips of water or a moist mouth swab will help provide comfort. You can ask the nurses to show you how to help with mouth care. Attempting to feed someone who is unable to swallow may make them distressed and cause harm.

Sleep and alertness

Changes in the person's body mean that they may spend a lot of time asleep, may be drowsy or difficult to wake up. It is best to talk to the person when they seem most alert, and allow them to sleep when they want to. There is no need to shake the person or to speak loudly. It is best to speak softly and naturally.

Temperature

The body's temperature may change. Sometimes the person's hands, feet and legs may be increasingly cool to the touch, and at other times they may feel hot and clammy. Sometimes, parts of the person's body may become blotchy and darker in colour. This is due to the circulation of the blood slowing down and is a normal part of the dying process. If the person indicates that they feel cold, use light bedding to keep them warm. Too many bed clothes or an electric blanket may make them hot and restless. Provide good ventilation; a fan to circulate the air and cool damp towels can help if the person seems hot.

Breathing

Regular breathing patterns may change. Sometimes the breathing may be fast, and at other times there may be long gaps between breaths. Breathing may be shallow or noisy. This is a normal part of the dying process and is not painful or distressing for the person.

Secretions

As coughing and swallowing reflexes slow down, saliva and mucus may collect in the back of the person's throat, causing a gurgling, bubbling or other noises. These noises can be a concern to carers, but do not usually cause distress to the person. To help improve the situation, you can turn the person on their side or lift their head supported with pillows, so that their head is turned to one side in a comfortable position. Medications can also be given to slow down the production of saliva and mucus and thus improve comfort.

Restlessness

Due to the decrease in circulation of blood to the brain and to other changes happening in the body, the person may become restless or agitated. To have a calming effect, speak in a quiet natural way, lightly massage the person's hand or forehead, or softly play familiar music. Let a palliative care team member know if the person becomes restless or agitated. Medications can be given to reduce the problem.

Incontinence

The amount of urine that the body is producing decreases due to the reduced amount of fluid the person is drinking. The urine may become stronger smelling and darker in colour.

Many carers are concerned that the person will lose control of their bladder and bowels. This does not happen to all people, but if it does, there are pads, easy to use equipment, and special absorbent sheets, to enhance comfort and hygiene. A member of the palliative care team can advise you about what is needed.

You can bring enormous benefit to the person you are caring for simply by sitting with them, holding their hand and speaking in a calm and reassuring manner.

How will you know that death has occurred?

- Breathing stops.
- No heartbeat or pulse can be felt.
- The person cannot be woken up.
- Eyelids may be half open.
- Their mouth may be open.
- Pupils are fixed.

What should you do?

You don't have to contact anyone immediately unless you want to. It is important that you do everything in your own time. You should contact the palliative care team so they can guide and support you at this time. If the person dies during the night you can wait until morning before you notify the doctor or nurse, or you can call them straight away, ideally discuss this with the palliative care team early on so you have a plan you are comfortable with.

The person's body can stay at home for a while, especially if you would like friends and relatives to come and say their goodbyes.

You can sponge away any perspiration or body fluids that worry you. It is not necessary to bathe the person completely, unless you want to. The palliative care team can help you to do this if you would like to.

Turn off or remove sources of heat such as room heaters, electric blankets and hot water bottles. It is also important to straighten the person because their limbs will stiffen, and if you can, replace dentures if they were removed.

When you are ready, and the death certification has been completed by a registered practitioner, you can contact the funeral director who will take the person's body and guide you through any funeral arrangements.

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PalliativeCare AUSTRALIA

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Australian Government
Department of Health

The Art of Dying Well

St Mary's University Twickenham London

DEATHBED ETIQUETTE

Be attentive to what your loved one wants – you are there to support them.

If something concerns you about your loved one, seek out help or advice.

Sitting at the bedside can be exhausting so try to eat, drink and take regular breaks.

Aim to create some personal space around the bed, particularly if your loved one is in hospital.

Don't feel you have to sit in silence – gentle background conversation or music can be comforting.

Organise a regular email or set up a WhatsApp group to update family and friends.

Consider bringing small children for a brief visit and inviting older ones.

Let your loved one sleep – they may be sleeping a lot in the last days.

The dying person may speak about dead relatives coming to meet them – listen and don't be afraid.

Remember those important last words that you, and they, might like to say: 'thank you, I'm sorry, I love you'.

Holding your loved one's hand is often more powerful than words.

Don't be surprised if your loved one dies when you are out of the room – it happens a lot.

Be prepared for a change in breathing patterns – it's normal for your loved one to stop breathing and then restart and this may sound like a gasp. It indicates the terminal phase of their illness.

Be prepared also for their breathing to sound laboured and for a gurgling sound caused by fluid building up at the back of their throat.

Reassure your loved one that they are free to let go – this 'permission' is often taken.

www.artofdyingwell.org

Understanding grief

PalliativeCare
AUSTRALIA

Understanding grief

Grief is how we respond when we experience loss. Grief is a normal, natural and inevitable response to loss and it can affect every part of our lives.

Grief can seem like a roller-coaster ride with ups and downs, or it may feel like we are being battered about like a little boat in a storm. Sometimes it can seem overwhelming and frightening.

Grief allows us to gradually adjust to our loss and find a way of going on with our life without the person who has died.

GRIEF ALLOWS US TO GRADUALLY ADJUST TO OUR LOSS AND FIND A WAY OF GOING ON WITH OUR LIFE

What does grief feel like?

Everyone experiences grief in their own way. There is no 'correct' way to grieve, and no way to 'fix it'.

Feelings

We may experience intense feelings such as shock, chaos, sadness, anger, anxiety, disbelief, panic, relief, or even numbness.

Some people are fearful as they are adjusting to a loss that they may forget or lose connection with the person who has died, or may even feel disloyal.

Thoughts

We may experience confusion and find it difficult to concentrate. It is not unusual for people to have 'extraordinary experiences' such as dreams of the person who has died or to have a sense of their presence. Mostly these are comforting and help us feel close to the person who has died.

We may think we will never get over this, or that we are going crazy. We may think that it is all too hard and wish we were with the person who has died. This is an expression of our pain and sadness.

Physical reactions

Sometimes we may have trouble sleeping. Grief can also lead to physical symptoms such as tiredness, loss of appetite, nausea or pain. If these symptoms persist, check with your doctor to exclude other causes.

Relationships

Relationships can be affected. Sometimes we will be preoccupied or tense, or feel disinterested in other people and things.

Behaviours

We may experience lethargy or over-activity, pay little attention to self care, sleep a lot, desire to resort to alcohol or non-prescribed drugs and other potentially harmful behaviours.

Beliefs

Our beliefs about life may be challenged. Often grieving people wonder why this has happened to them.

How long will it take?

Grief has no timeline. It is not unusual for grief to be felt over an extended period of time, even for many years. At first, people tend to feel grief more strongly. As time passes, we learn to manage the grief.

Sometimes, after a period of feeling good, we find ourselves experiencing sadness, despair or anger. This is often the nature of grief, up and down, and it may happen over and over.

Life will eventually have meaning again, although our loss will always be part of us.

How do we grieve?

Everyone grieves in their own way. There is no right or wrong way to grieve. Some people express their grief in private and do not show it in public. We do not always know how people are grieving simply by what we see.

Some people want to express their grief through crying and talking. Others may be reluctant to talk and prefer to keep busy. Members of the same family can grieve differently. People may behave differently at different times.

It is important to respect each other's way of grieving.

Helping yourself

Grief is like a journey to an unknown destination that you cannot control or plan. Here are some suggestions for getting through the difficult times. Remember though, that you will grieve in your own way.

Privately and personally

You may sometimes prefer to keep your thoughts and feelings to yourself:

- Try not to make big decisions too soon.
- Create a memorial – do or make something to honour the person who has died.
- Continue the relationship with the person who has died by talking to them, looking at photos, visiting special places.
- Develop your own rituals – light a candle, listen to special music, make a special place to think.
- Allow yourself to express your thoughts and feelings privately – keep a journal, draw, collect photos.
- Exercise – do something with your pent-up energy, walk, swim, garden.
- Draw on religious and spiritual beliefs if this is helpful.
- Read about other people's experiences – find books and articles.
- Think about some self care ideas such as meditation, massage or aromatherapy.

SHARING WITH OTHER PEOPLE CAN REDUCE THE SENSE OF ISOLATION AND FEELINGS OF LONELINESS THAT COME WITH GRIEF

With other people

Sharing with other people can reduce the sense of isolation and feelings of loneliness that come with grief:

- Allow people to help you – you will be able to help someone else at another time.
- Talk to family and friends – sharing memories and feelings can be comforting.
- Consider joining a support group.
- Don't feel you must grieve all the time – try some things you enjoy as well, when you feel up to it
- Talk with a counsellor to focus on your unique situation.

Being a carer for someone with a terminal condition can be quite isolating and exhausting. After the person has died, you may find it very difficult to reintegrate into work, groups, clubs or activities you previously enjoyed. Inviting a friend or volunteer to accompany you the first few times may make it a little easier.

Helping others

No one can take away the pain and sadness of grief, but knowing that people care is comforting and healing for grieving people. You cannot fix it, but you can help.

Here are some suggestions for things that might help:

- Keep in touch and be prepared to just listen.
- Be open in showing your concern and care.
- Help in practical ways.
- Express your sorrow about their loss.
- Talk about the person who has died – use their name if culturally appropriate.
- Remember that many people may be grieving, including children, grandparents, friends.
- Make contact again, even if there was no response the first time – sometimes people will want to talk and sometimes they won't.
- Share memories and stories.
- Remember and acknowledge birthdays, death days, anniversaries and other special days.

Sometimes, there are things that are not helpful, such as:

- Avoiding people who are grieving.
- Taking anger personally – often it is simply an expression of pain and grief.
- Saying 'I know how you feel', everyone feels differently.
- Telling them they 'should' be grieving in a certain way.
- Changing the subject or trying to cheer them up.
- Not using the name of the person who has died for fear of reminding them – they won't have forgotten.
- Trying to find something positive in the death.
- Making suggestions to 'replace' the person who has died.

Use your judgement. If you are really worried about someone, ask them if they think they are doing okay.

If you make a mistake, it's never too late to say sorry. If possible, don't allow friendships and relationships to become strained.

Finally, don't allow your inability to fix it stop you from reaching out to a grieving person and don't underestimate the value of ordinary human kindness.

Feeling overwhelmed?

Sometimes, we may need to seek help. Counselling is one option, or you might consider joining a support group.

Although the experience of grief is a normal and inevitable part of life, for some people it can be very distressing. If this happens, professional help is recommended.

Some signs that you may need to seek professional help include:

- a strong sense of meaninglessness that persists over time;
- high levels of insomnia;
- inability to carry on previous relationships;
- deep yearning or searching for the person who has died;
- deep depression or anxiety;
- thoughts of self harm or harm to others.

Specialist palliative care services can help with accessing a bereavement counsellor or social worker. Also, your general practitioner will be able to refer you to an appropriate service.

Where can I find more information?

Palliative Care Australia has a number of information resources available for download. To access these resources go to www.palliativecare.org.au or click on the links below.

National Palliative Care Service Directory: An online searchable directory for a service in your local area.

What is palliative care?: A brochure explaining palliative and end of life care.

How can I support my friend or family member?: Strategies for making a difference to help you help someone you know who is living with a terminal condition.

Several organisations provide information or telephone counselling.

Australian Centre for Grief and Bereavement

1800 642 066
www.grief.org.au

Lifeline (24/7)13 11 14

Kids Helpline (24/7) 1800 55 1800

Mensline (24/7) 1300 78 99 78

Parentline 1300 30 1300

Beyond Blue 1300 22 4636

YOU CAN FIND MORE SUPPORT INFORMATION AND RESOURCES LIKE THIS ON OUR WEBSITE

Contact Palliative Care Australia

t 02 6232 0700 e pca@palliativecare.org.au w www.palliativecare.org.au f Facebook t Twitter

a **Street:** Unit 8/113 Canberra Avenue, Griffith ACT 2603 **Mail:** PO Box 124, Fyshwick ACT 2609

PalliativeCare AUSTRALIA

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Australian Government
Department of Health

Journey of Care

Namaste Information

What is Namaste?

Namaste is a Hindu term which means *'to honour the spirit within'.*

IRT has adopted Namaste as a core pillar in the support of residents with end-stage dementia and and other life-limiting illnesses. The approach focuses on the person.

Namaste incorporates sensory-based care including therapeutic touch, music and sensory experiences with activities customised for each resident away from the hustle and bustle of the aged care centre environment. All activities are designed to achieve resident comfort and pleasure, by honouring the spirit within. The basis of the care is 'the power of loving touch' and as such, necessitates a level of physical contact between staff and residents.

Trained staff integrate sensory stimulating techniques through care delivery and programs during the day.

Namaste also encourages family members and friends to participate in the care activities of their loved one so they can feel a sense of connection to their family member or friend at a time when communication is very limited.

The core elements of Namaste are:

- ***'Honouring the spirit within':*** The guiding principle of Namaste is a respectful and compassionate approach to individuals with advanced dementia and other life-limiting illnesses.
- ***The presence of others:*** Residents in the Namaste program are brought together as a small group with a dedicated worker, so each resident receives individual focused attention.
- ***Comfort and pain management:*** Resident comfort; pain assessment/management are essential to enable residents to relax and engage in the program.
- ***Sensory stimulation:*** Namaste incorporates stimulation of the five senses (touch, hearing, sight, smell, taste). Music, colour, therapeutic touch and massage, aromatherapy oils and food treats are all part of the multi-sensory environment created in the Namaste room.
- ***Meaningful activity:*** The focus is on resident pleasure from individual meaningful attention. Hands and face may be gently washed with a warm flannel and patted dry with a soft towel. Hands and face washing is part of everyone's life experience and usually results in a sense of well-being. Moisturising creams may be applied and staff use this opportunity to make eye contact, connecting individually with the resident. Activities for residents revolve around their individual needs and preferences.
- ***Life story:*** Knowledge of the resident's life story is key to adapting the Namaste activities so that they are meaningful for each person.
- ***Food treats and hydration:*** Staff offer drinks throughout the session (being mindful of any swallowing difficulties). This creates extra opportunities to improve hydration and contribute to the residents' health and well-being.
- ***Namaste worker education:*** Staff are trained in dementia, Namaste, and end-of-life care. The Namaste workers need support to feel confident and participate in specific training to deliver Namaste.
- ***Family/Friends:*** Family and friends are encouraged to take part in the Namaste sessions. Staff can assist them to take part as they feel comfortable and this can add meaning to the visits.

Please contact the Care Manager at your IRT aged care centre if you would like further information regarding Namaste.

Namaste - My Sensory Checklist
Likes and dislikes

Please complete and return to the Care Manager

Favourite music - eg*. Elvis, Christian hymns1*

A scent that helps me feel calm - eg. *Scent of lavender*

My favourite flavours - *eg. Strawberry yoghurt, I don't like sharp citrus fruits*

How things feel to me - *eg. I like to sleep with socks on, I sleep with a fleece blanket*

Things that make me feel uncomfortable - *eg. I would not like to be washed by a man*

Sensory likes and dislikes

Name:				**LIKES**
SIGHT	**HEARING**	**TOUCH**	**TASTE**	**SMELL**

Name:				**DISLIKES**
SIGHT	**HEARING**	**TOUCH**	**TASTE**	**SMELL**

Palliative Care Family/Persons Responsible survey

Please accept our sincere condolences for your recent loss.

At IRT we strive to consistently improve the services for our residents, this includes the palliative and end-of-life care residents receive. We would greatly appreciate it if you could complete this short survey to help us understand and improve the palliative and end-of-life care offered to residents and their families that support them.

Please return the form to the IRT Aged Care Centre where your loved one received care.

IRT Aged Care Centre where your loved one received care

☐

In the last month of your loved one's life, do you feel the staff were able to meet their needs in the following areas:

Pain control	☐ Never	☐ Some of the time	☐ Most of the time	☐ Always
Control of other symptoms	☐ Never	☐ Some of the time	☐ Most of the time	☐ Always
Medication needs	☐ Never	☐ Some of the time	☐ Most of the time	☐ Always
Hygiene needs	☐ Never	☐ Some of the time	☐ Most of the time	☐ Always
Dietary needs	☐ Never	☐ Some of the time	☐ Most of the time	☐ Always
Emotional needs	☐ Never	☐ Some of the time	☐ Most of the time	☐ Always
Comfort needs	☐ Never	☐ Some of the time	☐ Most of the time	☐ Always
Religious / Cultural / Spiritual needs	☐ Never	☐ Some of the time	☐ Most of the time	☐ Always

Do you feel your loved one's end-of-life wishes were observed with respect to:

Their Advance Care Directive or Statement of Choices was followed	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree
They were involved in how their end-of-life care and services were delivered	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree
Where they wished to pass was observed, to the extent possible	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree

Did you feel supported through the palliative and end-of-life care stages across the following areas:

Staff were helpful and comfortable discussing end-of-life care with you and other family members	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree
The palliative care information you were given was relevant and timely	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree
You were kept informed throughout the process	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree
You knew what to expect around the practical aspects of dying	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree
You were offered information on grief and bereavement support	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree
You were aware of the support available to you e.g. palliative care trolley, overnight stay, access to facility after hours	☐ Strongly disagree	☐ Disagree	☐ Neutral	☐ Agree	☐ Strongly agree

Please share any comments or concerns that you may have? For example, did you feel a special need was not met during your loved one's last stage of life or do you feel some aspect of the experience was done well?

Would you like to discuss this survey with a member of the Care Team where your loved one received care? If so please provide the most appropriate contact details and time for us to contact you.

Thank you for taking the time to complete this survey. Full confidentiality of these responses are assured and maintained by IRT. If you have any further questions please contact the Care Manager where your loved one received care.

Please accept our deepest sympathy for your loss.