

Palliative Care

Patient and Family handbook

Your guide to the J.W.Whittle
Palliative Care Unit

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I. Welcome to the J.W. Whittle Palliative Care Unit

Welcome to the J.W. Whittle Palliative Care Unit (Unit). Our aim is to provide you with the best care possible. Our services are specially designed to improve your quality of life and sense of well being. The experienced palliative care team will work with you, your family and other health professionals to provide you with high-quality care; care that includes providing physical, psychological, emotional and spiritual support.

We have prepared this handbook to answer some of the questions you may have about the Unit. If you need additional information, please speak with a member of the palliative care team. We will be glad to help you.

The Unit is located at the Repatriation Centre, 88 Davey Street, Hobart. The Unit was opened in 1993 when it was part of the Repatriation Hospital. It is named after Sergeant J.W. Whittle, who was awarded the Victoria Cross in the First World War.

The Unit has 10 private rooms and is designed to provide a quiet atmosphere in which you and your family can benefit from the individualised care and support of the palliative care team.

Our Goal

Our goal is to provide excellent palliative care.

The palliative care team recognises that the journey through an illness can be a physical, psychological, social, spiritual and cultural process that is experienced uniquely by each person and each family.

Our Privacy Practices

We are committed to protecting your personal and medical information. When you are admitted to the Unit, we will need to collect personal information to enable us to provide you with the care you require. Our team works closely with other health care professionals to provide you with high quality palliative care. Your medical record helps us and others to provide you with the most effective support. All information is kept secure and managed in accordance with the Personal Information Protection Act 2004.

You will be provided with more information about this on admission to the Unit and a copy of the **Personal Information and Your Privacy** leaflet will be provided.

Your Rights and Responsibilities

We want to encourage you and your family to communicate openly with the palliative care team.

- Ask questions if you do not understand something about your treatment.
- Discuss your treatment plan with your doctor and nurse.
- Feel free to talk to your doctors and nurses about any concerns you may have.
- Ask for an interpreter if you are deaf or hearing impaired or if English is not your first language.
- If possible ask one family member to interact with your health care team. This person can pass along information to other family and friends.

For further information refer to the **Patients Rights and Responsibilities** leaflet in your room.

Our Statement on Treatment and Care

Palliative care is best described as *active supportive care*. The principal aim of treatment is to enhance quality of life on a day-to-day basis.

- The palliative care team will at all times involve you and your family in the planning and delivery of your care. The views of your family members and carers are also important and every effort will be made to establish these. However, it is important to note that views expressed by family members and carers will not override your views. No discussion will take place between the palliative care team and your family members and carers if you are unwilling for such a discussion to take place.
- Treatment such as antibiotics, intravenous fluids, and blood transfusions may be used, when appropriate, after discussion with you. If you decide not to continue with such treatment, your decision will be respected.
- In the event that you experience a sudden unexpected collapse, active support and care is continued to ensure that you are comfortable and free of distress.
- Active resuscitative care, which includes cardiopulmonary resuscitation, is generally not appropriate for patients at the Unit and as a result the Unit does not have the full range of resuscitation equipment which is found in acute care hospitals.
- The palliative care team will make every attempt to ascertain your wishes on or prior to admission to the Unit. If you wish to have active resuscitative treatment as part of your ongoing care, the medical staff will arrange for your care to be undertaken by a more appropriate service.

Once your condition is medically stable you will be assessed to establish the best options for your ongoing care. This often means that you will be discharged home; but in some cases alternative supported accommodation may need to be considered, such as residential aged care.

Palliative Care

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. It includes control of pain and other symptoms, and psychological, social, cultural and spiritual support. It aims to maximise quality of life, emphasising comfort rather than cure. This is achieved by coordinating medical, nursing, social work and other allied services where possible in the environment of the person's choice.

The World Health Organisation (2002) describes palliative care as:

“... an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and supports patients and families through the progression of the illness;
- intends neither to hasten or postpone death;
- integrates 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

- will enhance quality of life; and may also positively influence the course of illness
- is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy; and
- includes those investigations needed to better understand and manage distressing clinical complications.”

2. Your Stay

Our aim is to help you get settled and to feel comfortable as quickly as possible.

Admission to the Unit

On the day of your admission please bring with you:

- Medications;
- Toiletries;
- Day clothes, if appropriate;
- Nightclothes (including dressing gown and slippers);
- Medicare and private health insurance details/card; and
- Special items that may provide comfort for you e.g.: special pillows, family photos, heat packs, music, videos, makeup, etc.

On admission to the Unit you will be asked to provide some personal information. We will provide information about the routines of the Unit and orientate you and your family to the Unit layout. The palliative care team will interview you and your family and plan your care based on this information.

You will be provided with an ID band, this shows your name and medical record number.

The receptionist will ask if you are electing to be a private patient on admission. This will allow us to make a claim towards the cost of your care from your health insurance fund. If you have any questions regarding financial concerns please ask to speak to the Nurse Unit Manager or Social Worker.

Accessing the Unit

The J.W. Whittle Palliative Care Unit is located on the lower ground floor of the Peacock Building, Repatriation Centre, 88 Davey Street, Hobart.

Vehicle access is via Davey Street. Entry is via the driveway between Hampden Road and the Barrack Street intersection. Limited parking is available 24 hours per day. Parking vouchers are available at the Unit's reception desk.

Access to the Unit is via the car park. This access is locked after 6pm until 6am daily. To enter, press the video call bell located on the wall to the left of the entrance. If we are busy, it may take a while for us to answer.

Your Room

You will be assigned a single room with ensuite facilities shared with one other patient. All rooms open onto a courtyard. We will show you how to use the call bell in your room and bathroom. Someone will respond as soon as possible when you use it.

Advance Directives/Advanced Care Plan

Advance directives/advanced care plans are documents you create to describe the extent of medical treatment you do or do not want to receive if you are unable to communicate your wishes. Bring any advance directives with you to the Unit. Please ask us if you require more information about making an advanced directive.

Medications

All your medications should be brought with you on admission to the Unit or a list of those you are presently taking should be given to the admitting doctor. Do not take any medications you bring from home unless this has been discussed with the medical or nursing

staff on the Unit. Whilst you are in the Unit the nurses will provide your medications to you.

Complementary therapies

Complementary therapies are available to patients in the Unit, and are offered by professional practitioners and trained volunteers.

Complementary therapies are a group of diagnostic and therapeutic disciplines that are used together with conventional medicine, and include:

- Aromatherapy;
- Massage;
- Reiki;
- Music Therapy; and
- Art Therapy.

Complementary therapies can be useful in improving symptom control and promoting a sense of wellbeing by:

- Reducing stress levels;
- Creating a peaceful and relaxing atmosphere; and
- Assisting you and your family to adjust to living with a life-limiting illness.

We encourage you to advise the doctor and nurses of all complementary or alternative therapies you are using on admission so that advice and information can be shared. Sometimes complementary therapies interact with conventional medicines, or have the potential to lead to harm. If this is the case the medical and nursing staff will make every effort to ensure that you are fully informed about these possibilities. Family members will be included in this discussion.

If you wish to find out more, please talk to a member of the nursing or medical team.

Meals

Three meals are served daily: breakfast is at 8am, lunch is at 12pm and dinner at 5pm. Each day, you will receive a menu of food choices for the next day. We attempt to offer foods that you will be able to eat and enjoy. If you want to discuss your diet or if you have special food requirements please discuss these with us. If family members or friends wish to bring food in for you they are welcome to, but please let us know.

There is a dining area where you and your visitors are welcome to dine together, and a BBQ in the courtyard outside the lounge room that family members are welcome to use.

We are not able to provide meals for visitors, however there is a sitting room with tea and toast making facilities, and a microwave to reheat food brought from outside. A drinks machine is available in the Unit. There is a vending machine with drinks and snacks on the ground floor of this building which can be accessed during business hours only. Please ask us for directions.

Alcohol

Patients may be able to consume alcohol in moderation following doctor's advice, but visitors are not permitted to consume alcohol on the premises.

Safety

The following policies are for your safety:

Electrical appliances

Radios, hair dryers and other electrical appliances from home are not permitted because

they may pose an electrical hazard. Please ask a staff member if there is something you need, as the Unit has most commonly used appliances for loan.

Fire

If you hear a fire alarm, stay where you are until we direct you. The Unit periodically conducts fire alarm testing and drills and we will advise you of this.

Clothing and Laundry

There is a small wardrobe and drawers for clothing in each room. We encourage patients who are well enough to dress in day clothes during the day. There is a washing machine and dryer available for emergency laundry use only. Family and friends are requested to take washing home.

Valuables

We encourage you to only bring essential items to the Unit. Leave large sums of money, keys, jewellery, personal papers and other valuables at home. You require only a small amount of money for drinks and papers. We cannot accept responsibility for any loss or damage.

Music and Videos

The Unit has a selection of books on tape, CDs, DVD's and videos which you are welcome to use. There is no charge for these. Each room is equipped with a television and a small radio/CD player. We also have board games, jigsaws and reading materials available. Please ask us to assist you.

Newspapers

The Mercury can be purchased from Reception.

Overnight Stay for Family/Friends

Facilities are available if you would like a family member or friend to stay overnight. Please talk to us to make arrangements.

Telephones

Incoming calls can be directed to your room if you are well enough to take the call, otherwise messages can be taken. Outgoing calls can't be made from your room. There is a public phone located on the Unit.

Smoking

Smoking is not permitted within the Unit. Under the Public Health Amendment (Smoke free Areas) Act 2001 smoking is not permitted inside the Unit; within 3 metres of an entrance or exit; or within 10 metres of any air intake or ventilation equipment.

The Unit does have special dispensation for patients who wish to smoke to do so in the garden. Please be considerate of other patients and visitors. Visitors are required to go to the areas outside the garden wall, and beyond the front entrance. Please ask us if further clarification is required.

Visiting Hours

We encourage your family and friends to visit. Visiting hours are only restricted by your condition and needs. If your family and friends are unsure about whether to visit they should phone before coming to the Unit. Family and visitors should check at the reception

or at the nurses' station prior to visiting.

Parking for Visitors

Limited parking for visitors is available 24 hours a day at the front of the Unit with access from Davey Street. Visitor parking bays are identified. Parking vouchers are available at the Unit's reception desk. Metered parking is also available on Davey Street and Hampden Road.

Pets

Your pet may be able to visit you whilst in the Unit. Please talk to us about this. We also have staff dogs who visit the Unit from time to time.

Children

Children are very welcome to visit you on the Unit. There is a play area in the main lounge, and the Unit garden is enclosed from the street. We would ask that children are supervised and do not disturb other patients and visitors.

Quiet Room

There is a small sitting room near reception where your visitors may take quiet time out, or meet with a social worker, doctors or other staff.

Discharge

We will work with you and those close to you to make sure that when you leave the Unit you continue to receive the best possible care. Before your discharge, plans will be put in place to ensure appropriate support will be provided for you at home. This may include:

- referral to the community nurse and the community palliative care team;
- notifying your general practitioner; and
- making arrangements for providing medications if required.

These will be further discussed as your discharge day approaches. If you require ongoing care in another facility (including residential care) this will be discussed with you and your family as required.

Compliments and Complaints

We value your comments and suggestions on any aspect of your stay. We care about the quality of your time spent in the Unit.

If you have any concerns please discuss these with contact your nurse or the Nurse Unit Manager. We value and appreciate your feedback.

For further information refer to the **Do you have a suggestion, complaint or compliment** leaflet that is included in your room.

3. Your Palliative Care Team

Care in the Unit is provided by a highly skilled multidisciplinary team of specialist doctors, nurses, and social workers; and pastoral care, music therapists and allied health professionals; with support from hospital assistants, administrative staff, volunteers and other staff as required. We work in partnership with other professionals involved in your care, such as your GP, community nurse and consultant.

We will introduce ourselves to you, and we will be wearing name tags.

Your own doctor, spiritual advisor, and minister/priest are also welcome to visit and support while you are in the Unit.

Doctors

While you are on the Unit, you will have a team of doctors involved in your care. A palliative care Medical Specialist will supervise your care. The Unit has a Registrar who is a doctor now specialising in palliative care. In addition, medical students from the University of Tasmania Clinical School may also be present on the Unit.

Nurses

Registered nurses are a critical link between you and other members of the health care team. Nurses assess your condition, plan, carry out and evaluate your daily care, administer medications and other treatments. They provide education and information. They also oversee a team of support staff who are responsible for assisting in the operation of the Unit.

If you have a question or a problem, ask to speak to your nurse or the Nurse Unit Manager.

Social Workers

Social workers assist you to make decisions and exercise choice about things that are important to you. The social worker can support you and your family as your priorities and needs change. If you require assistance, ask your nurse to request a social worker to visit you. The social worker can provide: specialist counselling and support in a range of areas; access to written information and resources; advocacy, liaison and referral to other services; and provision and coordination of bereavement support.

For further information refer to the **Social Work** leaflet provided in your room.

Allied Health Professionals

If required, access to allied health professionals will be facilitated by the palliative care team. The Unit has access to physiotherapists, dieticians, occupational therapists, speech pathologists and music therapy.

Pastoral Care

Pastoral Care staff provide sensitive spiritual support, sacramental ministries, advance directive consultation and other services for patients and their family members. Your observance of the rituals and sacraments of your faith will be respected, and your religious needs accommodated as fully as possible. To request a visit from a chaplain or a clergy person of a particular faith please ask us.

Volunteers

Specially trained volunteers from the Hospice Care Association visit the Unit each day. They

will wear a blue nametag indicating that they are a volunteer. The volunteers provide company and support for patients, family and visitors and also assist staff. Some will offer hand and foot massages. They can help you and your visitors feel more comfortable. They will act with discretion and treat discussions with you confidentially.

Contact

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