

Information for clients, families and carers

Latrobe Community Health Service
Palliative Care Service



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**Community
Health** Service

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Information for clients, families and carers

Edition January 2010

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We would like to gratefully acknowledge and thank those who provided feedback and comments including Linda Martin on behalf of her husband Terry Martin, Tania and Shane Bennett and LCHS Ambulatory Care staff.

Introduction	3	Managing Symptoms	7
What is Palliative Care?	3	Constipation.....	7
The Palliative Care Service.....	3	Dehydration.....	8
Contacting the Palliative Care Service	4	Depression	8
Equipment	4	Fatigue.....	9
Complaints.....	4	Lack of Appetite.....	10
Advance Care Plan.....	5	Nausea and Vomiting.....	11
Medication	6	Pain	12
Disposal of Medication.....	6	Breathlessness	13
Medication Supplies.....	6	Non-medical Strategies	14
Emergency Medications	6	Herbal Treatments.....	14
Expensive Medications	6	Relaxation Techniques.....	14
Syringe Drivers.....	6	Massage.....	14
		Heat and Cold Therapy	14
		Other Strategies	14
		Pastoral Care and Counselling Support.....	14

Introduction

Latrobe Community Health Service operates a community based Palliative Care service for people residing in Latrobe City. There is no cost for this service.

WHAT IS PALLIATIVE CARE?

Palliative care is a type of health care for clients and their families facing life-threatening illness. Palliative Care plays a crucial role in improving quality of life through control of symptoms, the provision of psychosocial and spiritual care and bereavement support from diagnosis to the end of life for people with a life threatening illness.

THE PALLIATIVE CARE SERVICE

The Palliative Care Service can provide support in helping you to develop a plan that will ensure your needs are met as best as possible. The staff are skilled in assisting you to understand what resources and support you may require now and what resources you may need in the future. They can also provide you with assistance in connecting you to other support services and networks in your local community.

The team is considered to include:

- Specialist Palliative Care nurses who can help you to manage symptoms at home by visiting regularly; assessing your health care concerns, and coordinating care with other members of the team
- General Practitioners/Family Doctors who are willing to make home

visits

- District nurses who can help provide practical nursing support
- Personal carers with home care programs who may help with bathing and domestic chores
- Carer respite staff offering short-term patient care for several hours, overnight or even several days
- Volunteers who can visit, provide support, and help you to feel less isolated at home
- Counselling staff who can provide emotional and psychological support

It is important to remember that you are the most significant part of the team. Being able to openly share your concerns and asks questions can assist the staff in providing the best possible care and identify the most appropriate resources needed.

The intent of the Palliative Care Service is to have a comprehensive assessment and planning process in place so that you and your family are well supported and resourced to manage at all times.

General Practitioners/Doctors

It is imperative that your treating Doctor has agreed to work with the Palliative Care Service to help manage and oversee your needs. Your doctor will play an integral role in coordinating your care and prescribing medications if required. The Palliative Care Service will liaise with your doctor on referral to establish the best way to communicate on an ongoing basis.

Referrals

The Palliative Care Service has access to other services such as counselling and grief and bereavement practitioners, podiatrists, physiotherapists, dieticians, occupational therapists and support groups. The staff will discuss the need for referral with you as part of your care plan and can assist with access to these services if required.

CONTACTING THE PALLIATIVE CARE SERVICE

The Palliative Care Service offers a 5 day a week service from 8.30am to 5.00pm.

During business hours (Monday – Friday 8.30am – 5.00pm) please contact the Ambulatory Care office on (03)5136 5444 and let the staff know that you wish to speak with the Palliative Care Nurse. If the staff are not available at that time they will contact you as soon as possible.

After Hours Contact

The Palliative Care Service will discuss with you about who you should call if you need urgent help at home during the day or on evenings and weekends. A plan will be put in place with you to ensure that you have adequate support and contact details as necessary.

The Palliative Care Service offers a 24 hour telephone after hour's service to discuss any concerns you may have if an urgent situation arises. The staff who provide the after hours service also work during the day so we ask that you only use this service if the matter is urgent and cannot wait until the next day.

Most calls can be managed over the phone with good advice however, we can also provide an after hours home visit but only if the service assesses and prioritises that it is required and it is safe for staff to do so.

It is suggested that you keep information about emergency contacts in a spot that is easy to find such as on the fridge door.

EQUIPMENT

The Palliative Care Service can also provide assessment for equipment such as wheelchairs, walkers, bath boards and other medical equipment to help family caregivers provide safe care. The Palliative Care Service will provide you with directions and instructions if you need any items as there is a requirement that staff are present when equipment is picked up or dropped off.

COMPLAINTS

Latrobe Community Health Service views feedback as an opportunity to review and improve the quality of our services.

If you have any concerns about the service you are receiving we would encourage you let us know. If you want to put a complaint in writing then you can do this by either completing a Community Feedback Form or in a letter. If you wish make a complaint either over the phone or face to face then we encourage you to speak with one of the Palliative Care team or by contacting the Ambulatory Care Manager on (03)5136 5444.

Advance Care Plan

Advance Care Planning is about asking and supporting people to think about, and plan for, their wishes as they approach the end of life. Advance Care Planning is intended to assist people to:

- Think about the type of care that they would want taking into consideration their own values
- Talk to their Doctor and the Palliative Care Service about their concerns about the dying process and to request information to help them make decisions about their future care
- Talk to their families and/or friends about their wishes and desires
- Identify some one who can make decisions for them if required
- Address other matters to do with their death, such as organ donation, wills and funerals

It is important that you plan in advance for any problems that might occur. Putting family members and/or friends in the position of having to make decisions without knowing what you want can be very challenging and difficult.

A written Advance Care Plan can assist in communicating the person's wishes to family members and the treating team. You can communicate these choices by appointing a Medical Enduring Power of Attorney (ME-POA) or in some cases your wishes can be documented in a Refusal of Treatment Certificate (RTC).

Your Doctor and Palliative Care Service can provide you with more information and guidance on what you need to do and how you can complete an Advance Care Plan.



Medication

At some point you may require medication to assist with managing symptoms.

DISPOSAL OF MEDICATION

It is not uncommon for there to be a change in medication. Any unused medications should be returned to the Pharmacy for safe disposal. The nursing staff are not able to return this medication on your behalf.

MEDICATION SUPPLIES

Try not to leave ordering medications too late. If you only have a few days worth of medication left, phone your Doctor or speak with the Palliative Care Service to arrange for another prescription.

EMERGENCY MEDICATIONS

Your Doctor and the Palliative Care Service may organise for medicines in the form of injections to be left in your home to manage a 'just in case' situation if you have discomfort that is not relieved by medicines taken by mouth. If this is the case, the medicines must be stored in a safe, cool and dry place. The Palliative Care Service can provide support in teaching carers how to administer this medication.

EXPENSIVE MEDICATIONS

Some medications are not covered under the Pharmaceutical Benefits Scheme (PBS) and you may not be able to afford to purchase these medications. If this is the case and your Doctor has confirmed the need for the medication the Palliative Care Service can advise and refer you for assistance. Please discuss this with the Palliative Care Service.

SYRINGE DRIVERS

A syringe driver is a small battery powered machine that is designed to give you your medications over a 24 hour period. It is often used when a person cannot take medications by mouth due to feeling sick or swallowing problems. The Palliative and/or District nursing staff will check this daily and provide you, your family or carer with support and advice on its use.



Managing Symptoms

CONSTIPATION

Constipation can occur for a number of reasons and can have a significant negative impact on your day to day life. When you are constipated, you may not feel like eating and you may feel pain and/or abdominal bloating. You may at times experience nausea which can change the way for feel about eating.



Constipation:

1. Small lifestyle changes may encourage regular bowel movements:
 - Drink as much fluid as you can and try to do as much physical activity as possible
 - Try to use your bowels at the same time each day. It is sometimes useful to try and have a bowel movement half an hour to an hour after meals.
 - Eat foods that are high in fibre including dried fruits and fresh vegetables.
 - Avoid eating foods such as cheese and fried foods that may be constipating
 - If you are taking medication for pain, it can be useful to take the medication before using your bowels
 - It can be useful to have your knees slightly raised in a seated position when using your bowels
 - Privacy whilst using your bowels can also assist in relaxation to aid bowel movements.
2. If you have been prescribed medications such as Morphine for pain then it is a good idea to speak with your doctor or the Palliative Care Service about having laxatives prescribed to help prevent constipation.

Managing Symptoms

DEHYDRATION

Dehydration is an excessive loss of water from the body. Two of the most common causes of dehydration are vomiting and diarrhoea. It is quite common for someone in the advanced stages of a life threatening illness to drink smaller amounts of fluid. Sometimes there seems to be no specific cause yet dehydration may still occur. It is quite well accepted that people don't necessarily become uncomfortable without large amounts of fluid and they can be satisfied with small sips of fluid or ice chips.

what you can do

Dehydration:

1. If you are experiencing nausea, vomiting or diarrhoea then let the staff know as dehydration can occur quickly and rapid treatment of these causes can reduce the severity.
2. Drink fluids you enjoy – water, juice, or sip on ice chips, however, avoid fluids that are high in acid such as orange juice, as they may irritate the mouth.

DEPRESSION

Depression can be a serious medical condition that impacts on the way a person thinks and feels. Depression is more than just feeling low in that it can sometimes last for weeks or months. Fortunately, there are a number of strategies including medication and therapy that can assist in treating depression.

what you can do

Depression:

1. It is important that you look after yourself by having a balanced diet, ensuring you have adequate sleep and if you are able to continue exercising.
2. Ensuring that you have social and emotional support is vital so try not to become isolated. Being able to talk with someone about how you are feeling can really improve the way you are feeling.
3. If you are taking antidepressant medications then remember to take them regularly and don't become discouraged if you don't feel better immediately as they can sometimes take several weeks to start working.
4. Being depressed can distort the way you view life so it is important to try and not make significant decisions while you are depressed.

Managing Symptoms

FATIGUE

People with chronic and/or life threatening illnesses can often feel extremely tired and lack energy. These feelings do not subside with sleep or even rest and can go on for long periods of time. Fatigue can impact on your daily life and can cause significant difficulties such as a lack of concentration, feeling overwhelmed and constantly running out of energy. Fatigue can cause problems with what we might consider the basic activities in life such as having a shower, getting dressed or walking short distances. Fatigue can be caused by a range of issues such as depression, poor symptom control such as pain and the side effects from some treatment

what you can do

Fatigue:

1. Prioritise the activities that are most important to you so that you have the energy to complete them and pace yourself throughout the day.
2. It is important that you have adequate rest and sleep. Make sure you don't drink stimulants such as alcohol or coffee before bed.
3. Make sure you do some gentle exercise which can sometimes help you feel a little more invigorated.
4. Attempt relaxation strategies.



Managing Symptoms

LACK OF APPETITE

It is not uncommon to experience a lack of appetite at some time. There are a number of reasons for loss of appetite including pain, constipation, medication side effects, mouth conditions and depression.

When someone has a life-threatening illness which is advanced there are some other abnormalities that can occur which contribute to weight loss i.e. it can be more than just not eating much.

what you can do

Lack of Appetite:

1. It is normal to want a person to eat and drink however for someone in the advanced stages of an illness they often do not experience thirst or hunger the way healthy people can. Even though carers and loved ones might feel better encouraging the person to drink or eat forcing them can make them feel stressed or even more unwell.
2. Even when someone is in the advanced stages of an illness they are often the best person to make decisions about whether they want to drink or eat – it is common for someone who is unwell to feel quite full after only a few mouthfuls of food.
3. Avoid giving the person large meals instead offer them frequent smaller meals throughout the day.
4. It is common for people to feel nauseated from the smell of cooking and it is often best to avoid spicy and/or rich foods if the person cannot tolerate them.
5. Meal times can be a time to share so try not to worry or get frustrated if the person loses interest in food or doesn't like what they have been given.

Trying to make your loved one eat only makes you feel better...

Managing Symptoms

NAUSEA AND VOMITING

It is common to experience nausea and vomiting in the advanced stages of a life threatening illness. Nausea is the sensation of feeling sick in the stomach and can sometimes make you feel like vomiting. Not everyone experiences nausea and vomiting together and it is possible to have one and not the other.

Nausea can be caused by a number of issues including side effects from medication, being constipated, anxiety and as a side effect from some treatments.

It is important to manage nausea and vomiting appropriately so that it doesn't cause other problems such as weakness, weight loss, confusion and dehydration.

Try to remember how you feel when you are ill

Nausea and Vomiting:

1. Be aware of what you eat and drink:
 - Rather than eat 3 large meals a day, try eating smaller meals more frequently
 - Try and avoid the smells of cooking and reduce rich, fatty, spicy and acidic foods – instead try and eat more mild food such as dry toast or biscuits
 - Make sure you keep your fluids up by drinking frequent but small amounts (sipping slowly can help)
 - Sometimes drinking fluids before and after meals can help
 - Try sucking on ice cubes, ice blocks or hard sugarless lollies.
2. If you have vomited:
 - Try and clean out your mouth as soon as possible by either rinsing or brushing your teeth
 - Avoid using mouthwashes that contain alcohol as these can have a drying and irritating effect on the mouth
 - Try to replace lost fluid by drinking a little more even if it means sipping slowly over a longer period of time
3. Medication for nausea and vomiting:
 - There are certain medications used to treat nausea and vomiting and these are referred to as "antiemetics."
 - Medication can be given in advance if we know when nausea and vomiting may occur for example with certain treatments such as chemotherapy or when experiencing movement such as airplane or car travel.
 - If the nausea and vomiting make it difficult to take a tablet form of medication then there are other ways that medication can be administered such as a patch on the skin, an injection or via the rectum.
 - The Palliative Care staff will discuss with you and your Doctor having different forms of medication available if the person is having difficulty taking oral tablets.

Managing Symptoms

PAIN

It is important to remember that every single person experiences pain differently and that there are a whole range of reasons a person might be experiencing pain such as particular injuries or breaks in bones, surgery, irritation to nerves or bones from a tumour, joint or muscle problems related to decreased activity or other diseases such as arthritis. It is not always the case that a person will experience pain but it is relatively common for someone with an advanced life threatening illness to experience some form of pain.

Pain is what the person says it is. Because pain can be experienced differently by each individual it is important to note that there are other factors that can influence the person's experience of pain such as stress, depression and anxiety.

Assessing pain accurately is the best way to try and manage it. If we understand the origins of the pain and what is causing it then we have a better chance of keeping it under control.

what you can do

Pain:

1. Ensure early treatment of pain:

In most cases, pain can be managed. What is critical is that you are up front with your doctor and the Palliative Care Service from early on so that medications and treatments can be tried and reviewed as appropriate so that pain doesn't get to the point where it is out of control. Pain that is not managed well can impact significantly on a person's life and create other problems such as depression, difficulty in sleeping and difficulty in social interactions.

2. Medications for pain:

If you have been prescribed medication for pain then it is important that you take it on a regular basis as it has been ordered and that you don't miss doses.

The critical thing with pain medication is that you need to try and be a step ahead all the time as taking medication only when the pain occurs will probably not be as effective.

Remember that pain is experienced by everyone differently and therefore the individual's response to medications may also be different. Breakthrough medications can be prescribed by your doctor to take in between regular medications if the pain occurs between doses – your Doctor and the Palliative Care Service will discuss this with you if required.

Many people have concerns about taking medications known as opioids such as Morphine as they think they might become addicted or they might hasten the advance of the disease.

Managing Symptoms

BREATHLESSNESS

Breathlessness is best described as an uncomfortable feeling of not getting enough air in to your body. Breathlessness can sometimes be associated with pain and may sometimes be slower or faster than your normal breathing pattern. Breathlessness can be caused as a result of a number of reasons including stress and anxiety, complications from tumours, lung issues such as pneumonia, anaemia and muscle weakness.

what you can do

Breathlessness:

1. Reducing anxiety and stress can be very important – this can be assisted by medication, relaxation strategies and specific breathing techniques.
2. Keep good air circulation in the home including opening windows and using fans and try and keep a low humidity environment. Avoid cigarette smoke and anything that you may be allergic to that could worsen your breathlessness.
3. Managing and limiting physical activity i.e. don't climb stairs unless absolutely necessary and make sure that you rest frequently. Sitting upright can help breathlessness – recliner chairs and pillows are very useful in this situation.

Opioids can be a very effective means of controlling and managing pain and it is important that you have a discussion with your Doctor and the Palliative Care Service about the benefits of this type of medication.

3. Transcutaneous Electric Nerve Stimulation (TENS):

Some people's pain responds to a small machine called a TENS. This very small unit is a power pack that emits a non-harmful electrical current through electrodes that are placed on the skin. There are several reasons why a TENS should not be used including if there are problems with the person's skin such as an infection or if the person has a pacemaker. It is best to discuss this option with your doctor and the Palliative Care Service.



Non-medical Strategies

There are a range of non-medical strategies that can assist in managing symptoms of advanced illness. Generally these non-medical techniques can be used in conjunction with your medication and other medical treatments. It is important that you discuss these with both your Doctor and the Palliative Care Service. Below are listed a number of these strategies.

HERBAL TREATMENTS

There are a number of herbal treatments that can assist in particular with nausea and vomiting. These include ginger and peppermint. Both of these can be taken in tablet form but can also be taken in liquid form such as ginger beer and peppermint tea.

RELAXATION TECHNIQUES

Relaxation techniques can sometimes assist a range of symptoms such as nausea and vomiting, stress and anxiety and breathlessness. There are a range of techniques including deep breathing, progressive muscle relaxation, distraction techniques and guided imagery. If you would like further information about these techniques the Palliative Care staff will be able to assist you in sourcing this information.

MASSAGE

Massage can be extremely helpful in reducing stress and anxiety but also to assist in encouraging blood flow around the massaged areas of the body. Massage can be hugely beneficial if performed correctly. Please speak with the Palliative Care Service for further

information and/or resources.

HEAT AND COLD THERAPY

Heat and Cold Therapy can assist in reducing pain. There are a variety of aids that can be used such as ice and gel packs, heat pads and warm baths. There are a number of safety issues that need to be considered when using heat and cold therapy so it is best to discuss this with the Palliative Care staff prior to use.

OTHER NON-MEDICAL STRATEGIES

Acupuncture and Hypnosis are two other non-medical strategies that can sometimes assist with pain, nausea and vomiting and stress and anxiety. If you are interested in either of these techniques then it is important that you discuss these with your Doctor and the Palliative Care Service.

PASTORAL CARE AND COUNSELLING SUPPORT

The Palliative Care Service can assist you in dealing with some of the concerns that you may have including stress and anxiety. However, the team also have access to more specialised services such as counselling and grief and bereavement services and pastoral care services. Being able to discuss how you are feeling can be extremely helpful in reducing stress, anxiety and depression. The Palliative Care team will discuss these options with you as required

My Notes

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My Contacts

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