



Palliative Care
South East

Carer Support Kit

We're all in this together



Contacting us

Nursing Services

24/7

Carer Support



All of your daytime palliative care services, including nursing, can be contacted on one central number:

DAY TIME
03 5991 1300

The following services are only available:
MONDAY – FRIDAY / 8:30am – 4:30pm

- PCSE Office
- Music Therapy
- Mobility/Occupational Therapy
- Counselling
- Social Work
- Volunteers
- Spiritual Care



NIGHT TIME
03 5991 1300

Our night time nursing phone service can support you in the following:

- symptom management
- medication management
- significant changes in condition
- whenever you are having difficulty caring

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At Palliative Care South East, we are here to support you in your caring role as well as providing the physical, emotional and spiritual care we provide to your loved one.

Caring for someone you love when they are seriously ill can be one of the most difficult but also one of the most rewarding things a person will do during their lives. The role of a carer is constant, can be stressful and at times often exhausting. We understand the huge contribution that carers make and the challenges that can be associated with caring for a loved one and the constancy of the carer role.

We have developed this kit to provide you with information, ideas and support to assist in building confidence and reducing the stress associated with the role of carer.

The kit will also be used by our palliative care team to identify additional support you may need and to tailor that support to areas you identify within the kit. Please use it or share it with others who are helping.

Palliative Care South East is made up of a specialist team of nurses, medical staff, social workers, counsellors, occupational therapists, music and art therapists, volunteers and administrative staff and we are all focused on supporting you and your loved one.

We are always here to help, so if you have a question, please call the office or speak to one of our staff when they come to visit. You would be surprised to know, many of the questions you may have, are questions we are used to answering. Many of your fears or worries are common to people who are caring for a seriously ill person, so please don't feel there's anything you can't ask. We are here to help in any way we can.



Kelly Rogerson
Chief Executive Officer
Palliative Care South East

Acknowledgements

We would like to acknowledge the following contributors and supporters of the Carers Support Kit:

- South Eastern Melbourne Primary Health Network
- Victorian Government
- Palliative Care Australia
- Southern Metropolitan Region Palliative Care Consortium
- PCSE Clinical Team



Supporting your language and cultural needs

At PCSE we value diversity.

We are committed to:

- treating people with dignity and respect
- providing person-centred support and care that is flexible and inclusive of individual differences
- acknowledging that all palliative caring situations are unique
- supporting inclusive definitions of family and carers
- improving access to palliative care for the many diverse communities in our region

Please tell us about your cultural or spiritual needs. If you need a spiritual care worker or other specific support, let us know.

Using our service in your language: Interpreting services

We encourage you to speak with us in the language you are most comfortable with.

Let us know if you would like an interpreter present during visits.



Interpreter Service Please call 13 14 50 (free service)

You can speak your own language and ask them to phone PCSE 03 5991 1300.

Introduction to the Carer Support Kit

This Carer Support Kit is designed to support carers through their palliative care journey. The content has been developed with the encouragement and wisdom of carers themselves.

We include the voices of real carers, who often tell us...

“ *If only someone had told me this is what being a palliative carer would be like ...* ”

This kit provides information you may need in your role as carer, but also serves as a reminder for self-care – to look after yourself.

Our commitment to carers

All carers will be supported with education and information to enable them to continue providing care in the home, if that is the client's and their wishes.

We will provide 24/7 access to specialist palliative care advice, to help carers in their role and assist them when unexpected problems arise.

Support for carers is very important

Becoming a carer will change your life in many ways.

There's plenty of resources and support available to help you along the palliative care journey. Accessing this support and making sure you care for yourself is very important.

You will not be alone: our staff and volunteers are here for you. We will also help you to plan for what's to come.

It's important that you have confidence and support to manage care 24/7.
Call us during day or night.



How to use this kit

The kit is divided into a number of different sections: looking after yourself and practical tips; managing pain, symptoms and medications; and resources and links. These are designed as brief guides and conversation starters, for you to reflect on and to discuss in more detail with the PCSE team at different stages of your journey. The kit is also part of our Carer Education services which are available to you.



TIPS & IMPORTANT NOTES
in blue boxes



CONVERSATION STARTERS
in purple boxes

when you will benefit from talking to your PCSE team,
your doctor or specialist – either by phone or during visits



EQUIPMENT TIPS
in green boxes



The kit and single fact sheets can be downloaded from
www.palliativecaresoutheast.org.au

0.1 About Palliative Care South East

Palliative Care South East (PCSE) provides specialist and holistic care for people living at home with a life-threatening illness, and emotional and practical support for family and carers.

Our holistic approach acknowledges that a life-threatening illness affects the whole person and their family and carers in many different ways – physically, emotionally, socially and spiritually.

PCSE takes a team approach to care:





PCSE does not offer the following services.

- emergency call out service
- hygiene, personal care and wound care
- supply of regular prescriptions and daily medications management
- blood thinning or diabetes injections
- blood pathology collection
- chemotherapy, immunotherapy or hormone therapy injections
- intravenous antibiotics or chemotherapy catheter maintenance or dressings
- respite nursing support in home

We can refer or direct you to the appropriate service provider.

0.2 The goals of palliative care

What is palliative care?

Palliative care supports a person to live well at the end of their life.

Palliative care is all about the person living with illness.
Some of the goals of palliative care include:



supporting people to live with dignity



providing holistic care in the home, including social, emotional and spiritual support for families and carers



optimising comfort (pain relief and symptom management)



supporting client care choices and decision-making

Note: The person living with a life-threatening illness is at the centre of any decisions made. They should be respected and allowed to choose the kind of services they want.

Take one day at a time

What does palliative care mean to you?

List some goals of care for you and the person you are caring for.

Examples you may wish to consider...

I want to be with my family at home for as long as possible

I want to continue doing the things I enjoy most

Set simple short, medium and long term goals.

Short term (daily) (e.g. go to park, go to shops, enjoy the day)

Medium term (weekly) (e.g. have family over for dinner, plant that garden bed)

Long term (monthly or 6-monthly) (e.g. plan a little holiday/weekend away; plan for family night out)

As early as possible, talk to the person you are caring for about their wishes for end-of-life care and where they would prefer to die, so you can prepare. As a carer, you might consider what your own wishes might be, and begin the conversations there.

When I die, I would like to be cremated and my ashes placed at Berwick, and hopefully I can be at home for as long as possible.

Have you thought about what you would like?

0.3 Being a carer

Becoming a carer will change your life in many ways. While caring brings many challenges, it can be an extraordinarily rewarding experience; knowing you have helped someone who needs you and that you've made a difference to their quality of life. It can also give you a sense of purpose at a difficult time, and allow you to grow and develop new skills.

We're here to help you when you have questions or have difficult and complex feelings. For example:

- You are likely to have contact with various parts of the healthcare and social support systems – we can help you navigate these and make them work for you
- You might find it hard to balance your social life and start to feel isolated – speak with our counsellors or social workers
- Working or studying may become too difficult – you may be eligible for financial assistance through the Department of Human Services (Centrelink)

There are plenty of other support options available we can direct you to.

Write down your feelings and questions. You might feel better once your questions are answered. Talk to your carer support group.

Role of a carer

Each caring role is different and can last for a short time or a longer time.

What you do as a carer depends on the needs of the person you are caring for and what you can do.

It's very important to recognise what your role entails so that you can get the full support you need, and get access to services, information and financial assistance where possible.

Our PCSE volunteers are available to support you with some of these responsibilities and tasks.

Responsibilities can change from day-to-day and evolve over time, but may include:



coordinating medical care and medication



pain management and wound care



managing finances or financial support



legal arrangements and emergency care plans



emotional and social support (including resolving conflict, communicating with family)



decision-making and advocacy



guidance, organisation and supervision



practical assistance (transport, toileting, grooming, household maintenance, meal preparation, supporting eating)

The carer's role in person-centred care

You probably know the person you are caring for well. Your knowledge, including their views and perspectives, how they like to live, their cultural, spiritual and religious needs, and their financial situation, is important to the PCSE team.

This knowledge will help us to optimise the person's comfort and care, and to ensure their end of life goals are planned for adequately.

There are many resources on becoming and being a carer. Refer to Resources on page 85 or ask one of our team.



0.4 Assessing your needs as a carer

Our dedicated PCSE team will support you in the home to increase your confidence and give you the skills you need. To support you as much as possible, we will complete a support needs assessment with you.

You might review the following questions from time to time, and ask yourself what help you need to enable you to carry out your role as carer.

As a carer, do you need more support with ...

Knowing who to contact if you are concerned
(for a range of needs including at night)?

NURSING

Managing symptoms
including giving
medicines?

Understanding
the illness?

Having time for
yourself in the day?

SOCIAL WORK,
VOLUNTEER

Practical help
in the home?

Dealing with
feelings and
worries?

COUNSELLING,
SPIRITUAL CARE,
MUSIC THERAPY

GP

Looking after your
own physical health

Equipment
for the home

OCCUPATIONAL THERAPY

Financial, legal
or work issues?

SOCIAL WORK

Getting a break
from caring
overnight?

COUNSELLING,
NURSING

Talking about the
illness with the
ill person?

Providing personal
care (e.g. dressing,
washing, toileting)

NURSING,
CARER EDUCATION,
SOCIAL WORK

SPIRITUAL CARE

Your beliefs or
spiritual concerns?

NURSING,
SOCIAL WORK

Knowing what to expect in the future
when caring for the person?

What else do you need support with?

Think about the following and let us know if any of these apply to you.
Feel free to mark those that do and discuss them at your next visit.

	Are you no longer able to be responsible for your family?
	Are you unable to do the things you used to do, including social activities?
	Is there conflict or tension within your family?
	Do you worry about the consequences of death on your family, especially children?
	Are you yourself ill or facing severe illness?
	Have you had to leave work or study?
	Do you need financial support or help to access entitled benefits through Centrelink and other government agencies, including superannuation?
	Do you need support for legal assistance such as powers of attorney, wills and guardianship?
	Do you need information about community care packages?
	Would you like to be referred to the Aged Care Assessment Service to access residential aged care facilities and respite care?
	Would you like to be linked to resources in the community including organisations and support groups that are specific to your needs?

Accept all the help you are offered

1. Looking after yourself and practical tips

We're all in this together

It is important that carers look after themselves as well as the person they are caring for. Your health and wellbeing is a critical part of palliative care, because when your own needs are taken care of, the person you care for will benefit too.

1.1 Self-care for carers

Self-care simply means looking after yourself, which involves getting enough sleep at night, getting some rest during the day when the person you are caring for is asleep, eating healthy food and doing regular physical activity.

Practical things you can do to look after yourself

take some time out during day for ME time	sit outside, have a cup of tea or a bath	do something physical	rest whenever you get the chance during the day	go for a walk	call a friend for a chat	do some bending or stretching
accept offers of help	play with your pet	do yoga or meditation	treat yourself with special food sometime	eat a healthy diet	make a doctor's appt for check up	take a break
do gym or aqua aerobics class	organise a family meeting	talk to someone	be kind to yourself	look for the positives	maintain humour	let your phone go to voicemail

What are some other strategies that work for you?

1.2 Looking after your emotional needs

Supporting someone you care about at the end of their life can cause many difficult and conflicting feelings.

Carers sometimes experience:

-  isolation
-  adjustment to diagnosis
-  complicated family dynamics
-  compounding grief
-  fatigue

It is easy to become fatigued through the physical, mental and emotional load of caring. Not understanding what is happening to the person you care for can be a big stress as well.

It is helpful to talk about your feelings, worries and uncertainties. PCSE can support family and carers with emotional, spiritual and cultural care, and can provide you with strategies and tools to use at home to help understand and process your feelings.

Self-check: Am I coping?

This checklist may help you to determine whether you would benefit from emotional support or counselling at this time.

QUESTION	YES/NO
I am feeling overwhelmed or confused	
It is difficult for me to concentrate or make decisions	
I feel as though I cannot stop crying	
I am using drugs, alcohol or other addictions to cope	
I feel angry, frustrated, guilty or resentful	
I am finding it difficult to sleep or to eat	
I feel low, exhausted, run down and unable to cope	
I feel a sense of anxiety, panic or numbness	
I feel alone and that no one understands me	
I am finding it hard to enjoy life	

Our counsellors are available to help you talk through these feelings. We can work together to understand, respond and resolve current issues.

If you think you need extra support, please talk to the PCSE team or your doctor as soon as you can.



“If only someone had told me this is what being a palliative carer would be like ...”

What if I'm not coping?

IF YOU NEED TO SPEAK TO SOMEONE URGENTLY

Lifeline: 24hrs	13 11 14
Beyond Blue: 24hrs	1300 224 636
Suicide Line (counselling)	1300 651 251
Crises Assessment Team (CATT) ...	1300 369 012
Grief Line: 12 midday – 3.00am ...	1300 845 745
Kids Help Line	1800 551 800
Men's Help Line	1300 789 978
1800 Respect	1800 737 732



Emergency respite for you

Taking respite means taking a break. Sometimes you need a break quickly. You can get respite in different ways (depending on where you live). These include in-home, residential or inpatient respite or the use of day centres and volunteer services.

Commonwealth Respite and Carelink Centres are available as a first point of contact for all carers seeking emergency and urgent respite.

Commonwealth Respite and Carelink Centre Southern Region

1800 052 222

www.carersouth.org.au

1.3 Managing stress

If you become too stressed for too long, your own health and wellbeing is likely to be affected.

The following techniques can help in managing stress.



1.4 Mapping your support network

If you can establish a strong support system around you and the person you care for, you will experience fewer physical and emotional symptoms of stress.

Spend time reaching out and strengthening your friendships and relationships whenever possible. Think about the people in your life who can support you. What can they help you with? Map out people to reach out to when you need different types of support – practical, emotional, or spiritual.

If you have no friends or family available to help you, talk to the PCSE team about some other support options or see the Resources and Links section on page 85.

There are various digital tools available to organise practical help.

Palliative Care Australia has a mobile app, AllowMe!
palliativecare.org.au/allowme/

Gather My Crew is a free online rostering tool that helps friends, family, neighbours and colleagues decide when and how they will help
www.gathermycrew.org/



Carer support groups
Online communities



Community & volunteer groups
Community organisations



Spiritual leaders & communities of faith



Work and business colleagues
Activity or hobby groups
Study associates



Neighbours
Neighbourhood groups



Family



Friends



Pets

1.5 A support group for carers

We encourage carers to come together to support each other. A carer support group provides the opportunity to socialise with other carers who have similar experiences.

You can talk about your caring situation, share your stories and exchange advice and information.

Groups can be a safe place to talk about your feelings and your worries and to hear how other carers have coped with difficult situations.

PCSE hosts a Carer Support Group, a Carer Education program and a Walking Group.

Contact our Carer Educator for further details.

Talk to our Social Workers or Counsellors for more information on support groups, including groups held in languages other than English.

See the Resources section on page 85 for more information on support groups.



“It is a happy group and safe place to share. We all seem to be able to laugh and smile again.”

Providing care for a person living with a life-threatening illness requires planning and team effort. Planning ahead and working with others ensures the best possible care and that you as carer are supported to continue in your important role.

This section includes tips on managing day-to-day care, checklists, charts and lists of questions to ask the PCSE team and doctors.

1.6 Practical tips for day-to-day care

It is important to mobilise the people around you for help in caring– don't be afraid to delegate. This involves asking for help, which some people can find difficult.

Remember:

- asking for help is not a sign of failure
- family and friends want to help
- sometimes people wait to be asked for help

You could also ask people to organise help on your behalf.

Give everyone who has offered to help something specific to do. See the caregiving roster on page 26 – there are plenty of tasks to delegate.

Speak with your PCSE team about extra help or volunteers if you have no one else available.

Organise a family meeting to allow everyone to discuss how they can help. PCSE staff may assist if this is likely to be difficult or involve conflict or misunderstandings.

Some practical advice from some of our carers:

Get used to people coming into your house – both professionals and family and friends

Use a baby monitor or a door chime as a personal alarm bell

Keep all medication together in a plastic container

Use a hot water bottle with fabric cover for pain

Get a drink bottle with a straw

Get lots of pillows

Stock up on sustagen drinks

Hospital discharge never goes as planned

Get a much bigger rubbish bin, double the size, to hold all the waste

Place vomit bags around the house for easy access

Soups make good meals

Other practical ideas for organising help and day-to-day care



Keep a diary of care issues – for family meetings, for the PCSE team, or when others ask for information. You can record progress, last bowel movement, record the area of pain, record medication dose and timing, moods, conversations



Always carry a list of medications (names, dosages, frequency) to any appointment and Emergency/hospital



Follow up on recommended services for help (or ask someone else to do it)



Create a system to keep track of paperwork such as bills, receipts, test results, reports and letters



Discuss flexible work options with your employer

Circumstances may change. Be prepared for change



The health of the person you care for may change or become more complex. Planning for change is important.

Keep a record of changing symptoms and behaviour. Let your PCSE team know.

Set up a caregiving roster

Here is a list of example tasks to delegate to people who agree or offer to help. If possible, set up a roster with set, regular times for others to help.

What else? List other care needs you need support with.

-  Doing household chores such as cleaning, laundry, ironing, shopping or gardening
-  Collecting medications
-  Showering or dressing
-  Preparing some meals or organising home delivery service
-  Driving to appointments and/or attending appointments
-  Making the home safer
-  Managing finances
-  Making legal arrangements
-  Answering phone calls or receiving visitors
-  Picking up children from school or other activities
-  Paying bills
-  Keeping others updated (by telephone or email or blog or social media)
-  Sitting and talking with the person you care for while you take a break
-  Staying overnight, to give you some rest and provide company
-  Help with bed transfers

1.7 Questions to ask

Knowing ahead of time what questions you would like answered during home visits or appointments means you are less likely to forget to ask them when the time comes. Following are lists of questions to keep in mind.

If you are given answers that you don't understand, ask for clarification.



Questions you might want to ask of the PCSE team

Questions about caring

	What skills do I need as a carer?
	Do you think I can care for the person at home?
	Can I get help if I cannot manage?
	How can I best support the person I am caring for?
	How can I assist the PCSE team to talk to the person I care for in a way that respects their personality/culture?
	Who can I talk to if I am concerned about the care the person is receiving?
	If I cannot manage to look after the person I care for at home, how can we come to terms with this?

*Don't be afraid to prioritise what's important –
don't sweat the small stuff*

Questions about practical support

	Can you provide equipment to make every-day living easier at home? (Do fees apply?)
	Are we eligible for disability parking? How do I apply for this?
	Are there any volunteers available to help me? (e.g. to take me to an appointment or to do the shopping)

Questions about finances

	What costs will there be during the illness (e.g. for any equipment required or medications)?
	Is there any way we can get medical equipment (e.g. oxygen) or medications at a cheaper price?
	What financial assistance is available for the person I care for or me (e.g. pensions)?
	Is there someone I can talk to about financial matters?
	How can I help get affairs in order and write a will?

Questions about nursing

	What symptoms may occur in the future and what should I do if they arise?
	Will the pain and other symptoms be controlled in the future?
	What should I do if the person I care for won't eat very much?
	If they eat more will this make them live longer?
	What are the worst days going to be like?

Reproduced with permission from Palliative Care Australia (with minor alterations)

Refer to the booklet Asking Questions Can Help from Palliative Care Australia for more information.



Write down any questions as you think of them. Keep them in a safe place to take to any appointments or have for home visits.

1.8 Advocacy and your rights

Your rights

Your rights as a user of the Australian Healthcare system are contained in the Australian Charter of HealthCare Rights. Your rights as a carer are to be treated fairly and with respect, and not be discriminated against based on age, ethnicity, abilities, sexuality, gender/sexual preference.

You have the right to:



Access



Participation



Safety



Privacy



Respect



Comment



Communication

Note: We value your feedback on our service – complete the Having Your Say Form available from PCSE

Your role as advocate

As carer, one of your important roles on the health care team might be as advocate – to speak on behalf of the person you care for. This might be to:

- ensure their rights and wishes are respected
- ensure they are treated with respect
- ensure their needs are being met
- ensure services are provided in a professional manner
- challenge any barriers or discrimination.

You can be an advocate during an appointment with a health professional or by telephone or email outside of a care meeting.

Get in touch with PCSE if you have any questions or need support to advocate for the person you care for.



Tips for being an effective advocate

Keep a written record of all the information regarding the issue

Know your rights and the rights of the person you are caring for

Choose the most appropriate approach to raise the issue

Be confident

Develop a clear message on what you want

Listen carefully to the discussion and the suggestions and write it down

Public advocate

The Office of the Public Advocate can be contacted to act on your behalf on issues around care.

Telephone: 1300 309 337 or visit www.publicadvocate.vic.gov.au.

Second opinions

You have the right to a second opinion. In summary:

- You have the right to ask a doctor for a second opinion if you are unsure about the doctor's suggested medical treatment or a diagnosis
- Ask the doctor to give you a referral to another doctor or medical specialist
- Ask the doctor to send the other medical practitioner any test results or medical history

Making a complaint

See our brochure on Working Together in Partnership for details on how to make a complaint about a health service to the Office of the Health Complaints Commissioner – www.hcc.vic.gov.au or telephone 1300 582 113.

If the complaint relates to aged care services, refer to Seniors Rights Victoria. Telephone: 1300 368 821 or visit seniorsrights.org.au.

1.9 Preparing for a doctor's appointment

Living with a life-threatening illness often means many medical appointments. Talking to health care professionals can be daunting. Before visiting the doctor, take some time to prepare for the appointment.

Before the visit

	Write a list of all the questions you both have. Don't be afraid to ask 'simple' questions. (Ask for a longer appointment if you have a lot of questions)
	Make a list of all the care issues you want to discuss
	Make a list of all the medications being taken, including complementary therapies. Note the dose and any side effects
	What to bring? (e.g. test results, scans, blood tests) – check with the doctor's receptionist
	Record any recent change in condition or symptoms in the diary



During the visit

	Take notes or record the discussion with the doctor
	Ensure there is two-way communication. Tell the doctor everything you know that is relevant.
	Write down any specific instructions
	Clarify anything you don't understand
	Ask the doctor for printed material or where to find further information
	Ask who you should contact for more help

After the visit

	Review your notes
	Record the next appointment in a diary or calendar
	Call the doctor for test results, if required
	Contact the doctor about changes in the condition or symptoms

1.10 Planning ahead: advance care planning

Making decisions

As a person's condition changes, they may not be able to make or express a decision. This can range from medical decisions to signing forms for financial assistance or gaining access to services. Planning ahead, and appointing a trusted person to act in the role of substitute decision maker can make things easier. This must be done before a person loses capacity to do so. There are legal forms that will assist this. Please speak with the PCSE team if you require more information.

Often the person you are caring for can contact specific institutions such as their bank, Centrelink and aged care provider and provide permission for a specific person to act on their behalf through a nomination process.

Talk with PCSE social work for more assistance and information about these options.





Read PCSE's brochure on Advance Care Planning. Our Advance Care Planning champion will discuss planning ahead with you.



Advance care planning

Advance care planning is an opportunity to talk about a person's values and preferences for their future healthcare.

Planning ahead means that a person with a life-threatening illness gets to determine:

-  where they are cared for
-  where they want to die
-  their will
-  any other care goals including choices in regard to future medical decisions

A written plan ensures there is clarity and consistency in everyone's understanding, and provides the greatest opportunity for wishes to be honoured.

There are two main approaches and tools used in advance care planning:

1. Advance Care Directive – preferences can be written down in a document for healthcare providers
2. Appointing a substitute decision maker (called an Enduring Power of Attorney – Medical Treatment) or Medical Treatment Decision Maker.



2. Managing pain, symptoms and medications

We're all in this together

The following sections are a handy guide to managing pain, symptoms and medications. We want you to have the skills to support your loved one in the home to be able to effectively relieve discomfort and pain.

The information is to be used as a reference only and should not replace the advice of your palliative care team. The PCSE team will discuss relevant issues and symptoms with you in more detail.

2.1 Managing pain

One of the greatest fears of people and their carers is severe and uncontrolled pain.

Many people with a life-threatening illness fear severe and uncontrolled pain but not everyone experiences this.

Understanding pain

- Pain is individual. The treatment approach depends on how a person describes their pain
- Pain can almost always be managed, but is managed best when identified early. Be honest about the extent and nature of pain – being honest does not mean a person is not coping
- Untreated pain can cause or increase tiredness, low mood, worry, anger, poor appetite and stress
- Pain treatments include medication but also heat/cold packs, massage, relaxation and spiritual or psychological (such as music and art therapy)

Pain medications

- Pain relief medications include paracetamol/aspirin, codeine, morphine or other opiates, such as hydromorphone, oxycodone or fentanyl patches
- Morphine is the most commonly used opiate for moderate to severe pain

There are myths and misconceptions around using opiates like morphine, which can cause people to worry. Speak with the PCSE team if you would like to talk about

- addiction
- delaying morphine
- concern about hastening death

What are the side effects of opiates (morphine & similar drugs)?

- Constipation, which can be controlled with laxatives (See Bowel Care on page 37)
- Short-term nausea, sleepiness or confusion, which usually settle down
- If there are continuing, unacceptable side effects, other medications can be discussed

Types of doses

Long-term dose: The doctor may prescribe a regular dose of pain medication that acts over a long period of time, e.g. 12 or 24 hours.

Breakthrough pain: When pain is experienced between doses, you might need a 'breakthrough' pain medication that acts within 30-60 minutes.

Keep a record of the amount of 'breakthrough' medication being used so that the PCSE team can review dosage of baseline medication.



What you can do: tips for carers

- Encourage the person you care for to take an active role in managing their pain
- Keep a pain diary, noting the description and location of pain, for the PCSE team to review and discuss options
- PCSE team do not carry pain medications with them. Staff will help you make sure you have enough medications available

Tell us if you feel that the pain is not being controlled or could be better controlled to increase quality of life.



2.2 Managing symptoms

The information presented here can support you as carer to manage common palliative symptoms at home to relieve discomfort and pain (when appropriate) before contacting a nurse. The guide focuses on day to day care, and does not apply to emergencies. Planning for Emergency Care on page 61 will be discussed with your PCSE team.



Bowel care: constipation and diarrhoea



Confusion



Declining mobility and falls



Changes in eating and drinking



Nausea and vomiting



Fatigue and drowsiness



Fear and anxiety



Mouth care



Shortness of breath



Skin care



Terminal restlessness

You are doing your best



Bowel care

Constipation or diarrhoea are two issues that can cause distress and discomfort – but they can be managed.

Constipation

Constipation is a very common and uncomfortable symptom. It is caused by a combination of reduced mobility, reduced intake of food and fluids, and some medications.

Signs of constipation

- Passing small hard faeces infrequently and with difficulty
- Bowels are opening less than 3 times per week or less than the normal routine

Note: If bowels have not been opened after 3 days, tell your PCSE nurse.

Medications

- DO NOT stop taking any medications because of constipation
- People taking regular strong pain medications should take a regular laxative – TALK to your PCSE team about options
- If persistent, increasing the laxative dose or an enema or suppository might be considered



What you can do: tips for carers

- Increase fluid intake (6–8 cups daily)
- Give prunes at breakfast or prune juice, other fruit juices, plums or rhubarb
- Light massage in a clockwise direction over the abdomen, using warm oil (Note: avoid if there is abdominal tumour)
- Give small, regular meals
- Ensure privacy in the toilet
- Use a small footstool at the toilet to raise the feet
- Try hugging a fat pillow resting on the thighs
- Consider a commode or an over toilet seat – talk to your PCSE team
- Keep upright when trying to pass a bowel motion

Diarrhoea

Diarrhoea is an increase in fluidity and frequency of bowel motions that can be caused by medications (antibiotics), treatments (chemotherapy/radiotherapy), diet or disease. Diarrhoea can be treated, sometimes with medications.



What you can do: tips for carers

- Discuss the issue with your PCSE team
- Increase fluid intake
- Use electrolyte replacement fluids e.g. Gastrolyte or Hydralyte
- Avoid solid food for 24-48 hours to rest the gut
- Follow good hygiene practices (i.e. hand washing) after each bowel action
- Use soft toilet paper and/or moist wipes and use barrier creams on the area

Keep a bowel movement diary to discuss with the PCSE team



Confusion

Confusion is the clouding of thinking which makes someone uncertain of what is happening around them. Confusion can affect a person's ability to think clearly or respond appropriately. A person with confusion may be unaware of where they are or what is happening. They may be very anxious, restless or agitated or express other emotions that are difficult to understand or that seem to be excessive in the circumstances.

Confusion can be caused by:

- disease progression towards the end of life
- parts of disease that affect the brain (e.g. brain tumour, stroke)
- other diseases such as dementia or some mental health conditions
- chemical imbalances from disease or failure of vital organs
- raised temperature (e.g. fever from infection)
- anything that affects the amount of oxygen reaching the brain (e.g. disease of heart or lungs)
- medications (new or higher dose)
- pain or discomfort
- constipation

Confusion can increase in the evening, at night or during changes in routine or arrangements.



Let the PCSE team know immediately about any change of behaviour. There might be other conditions that are contributing to any confused state.



What the nursing team can do

- Some causes of confusion can be cleared up quickly (e.g. full bladder or rectum)
- Review medication (change may be needed)
- Review other causes



What you can do: tips for carers

- Do not argue with someone in their confused state (for example, about their delusion/beliefs)
- Gently remind the person where they are and who you are. Sit with them, taking their hands and talk to them, even if they seem unaware of you. (Be careful: an agitated person may hit out or become aggressive)
- Try to create a feeling of peace and safety. Talk reassuringly about anything you are about to do, even if you think they do not hear or understand you
- Avoid changing surroundings, the position of the bed in the room or other arrangements
- Check that the person is not too hot
- Check the bed and clothes for anything that may be causing irritation
- At night try using a night-light or leave the hall light on and the door open
- Keep the environment free of distracting or distressing noise. Music helps some people to settle. If a windy night or intermittent noise increases the confusion, try masking the noise with familiar sounds such as radio or TV

Declining mobility and falls

It is common for mobility/movement to decrease as illness progresses. There can be multiple causes: side effects of treatment or medication, increased fatigue, muscle weakness due to disease, decline in nutrition and emotional state.

Experiencing a reduction in physical function can be upsetting. People get frustrated by the loss of their independence and their increased need to rely upon family members/carers. The PCSE team can provide advice, support, equipment and aids that will help improve independence and optimise ability to move around.

Tell us about any new changes in functional ability such as moving from one position to another, walking and completing own care (e.g. toileting or showering). We can then work with the Occupational Therapist to explore ways to improve mobility and independence.



What you can do: tips for carers

- Make the living space clutter-free and remove hazards like rugs
- Make sure the lighting is adequate
- Be sensitive to your expectations: the person you care for may not be able to function as before
- Be patient
- Provide support where needed (e.g. assisting with a shower), but also encourage independence as much as possible
- Some mild to moderate exercise can improve or maintain muscle tone
- Look at ways to boost nutrition
- Encourage rest when necessary and avoid pushing beyond limitations

What your PCSE team can do

- Work with our Occupational Therapist, who can:
 - provide new strategies or ways of doing things
 - improve balance and coordination
 - reduce muscle and joint pain
 - choose equipment to support independence
- Assess any underlying and treatable causes (such as medications, disease progression, injury or infection)
- Provide emotional support – if there is an emotional component to the reduced movement, such as depression, then a counsellor, social worker or spiritual care worker can provide strategies and tools you can use at home to help manage the feelings
- Arrange therapies – music therapy is available for relaxation and symptom relief, which can improve sense of wellbeing and overall function

Eating & drinking

Loss of appetite and weight loss are common. The person you care for should choose the size and time of their meals or whether they have a meal at all whenever possible. If this is too difficult, you can make these decisions.

- Nausea, vomiting and constipation can affect appetite
- A dry and sore mouth may affect nutrition – refer to the Mouth Care section on page 47
- Use convenience or pre-prepared foods for ease

Ask family or friends to prepare some meals for the freezer.



Supporting comfort in eating and drinking

- Serve less fluids just before or with meals to avoid feeling full
- Serve meals on smaller plates so it is not overwhelming
- Timing of meals is important: consider having main meals earlier in the day
- Make meal times a social occasion
- Provide small frequent meals / support grazing throughout the day
- Avoid foods that carry heavy aromas
- Encourage food to be eaten slowly

A referral to a dietitian might be useful.



Tastes and flavours

Changes in taste are common. Experiment with different food tastes.

- A 'bitter' taste can be eliminated by reducing red meat. Use more chicken, fish and dairy
- Try foods at different temperatures
- Try adding extra flavour to foods, e.g. salt, pepper, and sugar/sweetener, stock. (NOTE: no additional salt if high blood pressure)

Make sure the person is comfortable when sitting up to eat. A triangular pillow might help in bed.



Ensuring energy intake is adequate

Consider

- Supplement drinks (such as Sustagen, Resource, Proform) and high protein (flavoured) powders can be used in recipes such as puddings and omelettes
- Small tubs of mousse, yoghurt and custard, ice cream, jellies, smoothies and soups
- Infant foods
- Enrich milk drinks with full cream milk powder
- Increase calories in diet by adding eggs and cheese to food

Your feelings are normal

Nausea and vomiting

Nausea is a feeling of sickness and the feeling you could vomit. Nausea and vomiting are unpleasant and distressing symptoms which can occur together or separately

Nausea and vomiting can be triggered by:

- particular smells, sights, tastes or movements
- some medications or treatments (e.g. chemotherapy, radiotherapy)
- body imbalances (dehydration, constipation, obstruction to the bowel, blood chemicals changes)
- emotional reasons like anxiety/worry
- continuous coughing
- worsening of the disease
- pain

Nausea and vomiting can usually be treated or relieved – talk to the PCSE team.



Managing nausea

- Prevent constipation if possible; treat constipation early
- Take any prescribed anti-nausea medications regularly
- Keep a record of symptoms and causes
- Keep room aired and free from unpleasant smells
- Review medications (eliminate unnecessary drugs, review timing)
- Avoid lying down immediately after eating
- Teeth should be cleaned or mouth rinsed before and after eating
- An empty stomach can cause nausea: serve small amounts of foods 5–6 times per day
- Eat cold or warm food if the smell of hot food causes nausea
- Relaxation, music therapy, deep breathing exercises, meditation or an activity can help
- Sucking on ice or icy poles and sip flat, carbonated drinks
- Eat or drink ginger products such as dry ginger ale/beer, ginger biscuits

Managing vomiting

- When vomiting stops, rinse mouth, clean teeth and suck on ice or drink small sips of water
- When possible, drink regular sips of water, soda water, ginger ale, lemonade or energy drinks. Try different temperatures and allow any fizzy drinks to go flat before drinking
- Re-introduce food slowly. Slowly introduce a greater variety of drinks and a small amount of plain food (e.g. slice of dry toast or dry biscuit)
- Refrain from fatty or dairy foods until the stomach copes with the lighter food

If vomiting continues for more than one day, contact the PCSE team.



Fatigue and drowsiness

Fatigue is a very common and upsetting symptom during advanced illness. It is often linked to a lack of appetite and interest in food and involuntary weight loss.

Common causes of fatigue include: cancer treatments, medications, pain, shortness of breath, anaemia (low red blood cells), infection, dehydration, poor diet, depression or advancing disease.

Common symptoms include one or more of the following:

- general tiredness
- feeling drained
- lack of motivation
- feeling that they can't be bothered
- lack of energy
- problems with sleeping
- feeling grumpy, tearful or emotional
- low self-esteem
- feeling a burden to others
- low mood
- poor concentration

There are many treatments to help manage fatigue, depending on the causes.

Managing fatigue and drowsiness

- Serve a healthy diet including fruit and vegetables; consider dietary supplements or drinks
- Plan the day, and plan activities for times when energy levels are highest
- Include regular rest periods during the day. Plan rest days in between outings
- Shower every second day instead of daily
- Gentle exercise and keeping active can help improve energy levels and maintain muscle strength

Some equipment can help decrease fatigue, e.g. wheelchair for outings, raised toilet seat, shower stool



- Ask other people for help with shopping, cleaning and other household jobs
- Break large tasks into smaller goals
- Consider complementary therapies such as music
- Reorganise the environment e.g. rearrange the bed so it's closer to the bathroom
- Some medications can increase levels of fatigue – talk to the PCSE team

Let us know if there are uncontrolled symptoms such as pain, shortness of breath, depression or insomnia. Treating these symptoms can improve fatigue.



Fear and anxiety

It is normal for someone who is sick to feel uneasy, restless, afraid or anxious. Comfort care helps to cope with these feelings.

The person you care for might feel:

- that things are not right
- fear
- worry
- confused
- unable to pay attention, focus or concentrate
- loss of control
- tense

A person's body may express what they are feeling with:

- trouble relaxing or getting comfortable
- needing to move for no reason
- faintness/dizziness
- fast breathing or heartbeat
- shaking or muscle twitches
- sweating
- trouble sleeping
- irritability
- confusion or extreme restlessness (called agitation)



What you can do: tips for carers

Think about what worked in the past. What helps when they have felt anxious or worried?

What happened when this feeling started? Can they do something about that? Did it start with pain, and did they take their pain medication?

You might recommend:

- writing down thoughts and feelings
- gentle exercise
- talking to someone

Support a relaxation activity such as:

- breathing slowly and deeply for a few minutes
- listening to music that calms them
- slowly counting backward from 100 to 0
- yoga or tai chi
- having someone massage hands, feet, arms, or back
- patting a cat or dog
- reading to them

Other ways to help:

- when a person needs to rest, tell visitors to come another time
- make sure medication is taken as prescribed
- limit alcoholic drinks
- limit drinks with caffeine (including energy drinks)

Talking helps

Many people find they can prevent or manage these feelings of worry if they can talk to someone they trust about their fears, to someone close to them or to the medical team.

Medication is available –
talk to the PCSE team.



PCSE has social workers, counsellors and a spiritual care worker available to support:

- feelings that may be causing anxiety (such as fear of dying or worrying about money)
- concerns about illness
- problems with family or friend relationships
- spiritual concerns
- signs and symptoms that the anxiety is changing or getting worse

IF YOU NEED TO SPEAK TO SOMEONE URGENTLY

GriefLine	(03) 9935 7400
Lifeline: 24hrs	13 11 14
Beyond Blue: 24hrs	1300 224 636
Kids Help Line	1800 551 800
Men's Help Line	1300 789 978
1800 Respect	1800 737 732



Mouth care

Mouth and oral problems can be caused by treatments and/or medications. The problems can include dry mouth, coated tongue, bad breath, infections, thrush and ulcers. Maintaining good mouth/dental health will reduce discomfort.

Tell the PCSE team about any signs of mouth or throat soreness.



Saliva

Thick saliva can be reduced by:

- breathing in steam
- juices and ice cubes made of grape, apple, pineapple and papaya.

There are some medications to treat excessive watery saliva.

Dry mouth

- Clean teeth regularly
- Rinse mouth frequently with plain or salt water (1/2 teaspoon salt in 500 mL water), 3–4 times a day, after meals
- Avoid commercial mouthwashes that contain alcohol, which can dry the mouth. Difflam mouthwash, Biotene moisturising gel and Aquae sprays are recommended and available at local pharmacies. Swab around the mouth before meals and at bedtime
- Pineapple/watermelon wedges refresh the mouth
- Suck pieces of boiled lollies or ice chips made with frozen tonic water, cola/lemonade or juice
- Sugarless gum stimulates saliva. Purchase saliva substitutes from your local pharmacy
- Keep lips moistened with lip balm, lanolin or paw paw ointment

Coated tongue

- Clean the teeth and tongue with a soft toothbrush, or
- Mix sodium bicarbonate with some water to form a paste; use the paste on a soft tooth brush to brush mouth and tongue

Tell the PCSE team about any coated tongue symptoms.



Oral thrush

A common fungal infection that appears as white spots on the tongue, inside the cheeks or a yellow coated tongue. This can cause pain, swallowing difficulty and reduce appetite. Your nurse may recommend regular use of a solution called Nilstat (Nystatin) or Fungilin lozenges, which are slowly sucked until they dissolve.

Ulcers

- Rinse the mouth regularly with salt water
- Use Bonjela gel or Difflam mouth rinse if the ulcers are sore

Dentures

- Remove dentures overnight. Use a denture cleanser soaking solution instead of water (which encourages infection)
- Rinse dentures before placing back in the mouth
- Rapid weight loss may cause dentures not to fit properly. See dentist to refit or use denture pads
- If there are ulcers, remove dentures to help promote comfort and healing



Shortness of breath

Shortness of breath is common in people living with a terminal illness. A person can feel they cannot get enough air and breathing can be faster or slower than usual. It is usually caused by disease of the lung, asthma, emphysema, chest infection, pressure from other body organs or anxiety.

Breathlessness is not damaging but it can be distressing. There are many helpful tips and ways to adjust lifestyle to reduce breathlessness and maintain a sense of control.

Speak with PCSE team about options

- Equipment (commode, wheelchair, raised toilet seat, strategically placed chairs)
- Breathing techniques
- Complementary therapies, such as music therapy
- Medications
- Develop an action plan and keep it somewhere easy to find

Oxygen therapy is not usually advised unless ordered by GP. Oxygen concentrator units are available for continuous oxygen use in the home. (Costs may apply.)



What you can do: tips for carers

- Encourage a calm and unhurried approach to activities with regular rests; provide help if required
- Avoid situations that cause anxiety or make shortness of breath worse. Encourage remaining calm at all times
- Reduce clutter in the immediate environment
- Body positions which make breathing easier:
 - sitting upright
 - sitting at a table with arms raised on pillows
 - in a bed supported by pillows or backrest
 - in a chair with arms well supported and legs elevated
- Clothing should be loose around the waist, chest and neck
- Use a fan or provide seating near an open window, door or outside
- Provide fluid to avoid dehydration

Portable oxygen can be arranged for outings. Ensure that the tanks are full and take a spare bottle.



Skin care

Skin can suffer from infection or pressure sores. This can be due to not moving for long periods, accidental or involuntary urine/bowel motions, some treatments, medications and decreased food and fluid.

Caring for skin

There are several ways to improve the condition of skin, and reduce discomfort.

- Protect the skin from cuts/scratches
- Thoroughly clean any cuts or scratches

Tell the PCSE team if any cut or break in the skin becomes painful, red or hot to touch or if there is any swelling



- Electric razors are often safer than blade type razors
- Use sun block/protective clothing to prevent excessive sun exposure
- Avoid tight clothing
- Examine bony parts of the body for redness (e.g. bottom, heels, elbows and hips)
- Change bed position regularly, especially if not moving independently

The use of special mattresses can help reduce pressure.



- Use pillows between bony body parts and surfaces (e.g. between knees when lying in bed)
- Wash skin gently and pat dry when exposed to bodily fluids
- Apply moisturiser frequently to dry skin (e.g. sorbolene or barrier creams)
- If having radiotherapy treatment, refer to skin care guidelines provided by the treating hospital or clinic

Itching skin

Itchy skin can be caused by various factors such as dryness, the disease or medication.

- If the skin is dry, use a moisturiser such as water based cream twice a day (store it in the fridge so it will feel cool on the skin)
- Discuss medications with your doctor
- Protect the skin from damage that could be caused by scratching (e.g. keep nails short, rub rather than scratch)
- Avoid things that irritate the skin (e.g. washing powders, scented soaps, hot water)

Sweating

Sweating is common with advanced disease. This can cause discomfort and affect activities like sleeping.

- Speak with the PCSE team
- Use layers of light non-synthetic clothing
- Keep room cool and well aired
- Use light bedding and use layers to adjust for comfort

The PCSE team can discuss equipment available and show you how to move and transfer someone into/out of bed to reduce skin tears and pressure sores



Terminal restlessness

Terminal restlessness is a type of confusion that occurs in the last days or hours of life. While not common, the signs and symptoms can be particularly distressing for carers and family, but they do not mean that the person is distressed.

Sitting more upright and turned slightly to one side can help.



In addition to the usual symptoms of confusion, the person you care for may:

- have increased physical restlessness or nervous excitement, muscle twitches, or unusual patterns of muscular tensing
- may pick at or continuously handle the bedclothes
- moan or call out
- make sounds each time they breathe out
- react with distress to sudden stimulation (even if they seem unconscious)

Advise your PCSE team and/or your medical team immediately if there are signs of terminal restlessness. Nurses will assess and recommend treatment. Medications are available to stop twitches or muscle contractions. Sedation might be available.



You are not alone

2.3 Managing medications

The following information describes the medications commonly used in palliative care to relieve discomfort and pain. It includes notes on using medications safely, using a syringe driver and giving injections.



Using medications safely

Most medications for managing symptoms need a prescription from the doctor and are bought from a pharmacy. An information leaflet is usually supplied with medication. Read this leaflet as it contains information about the medication, its use and side effects.

Giving medications

All medications are labelled with instructions. Make sure you follow these instructions. The person you are caring for should:

- Take the dose as directed at the times indicated
- Never take more than the recommended dose
- Complete the whole course of medication as per instructions even if they feel better

Seek advice from the doctor, PCSE nurse or pharmacist if there are side effects and/or difficulty taking medication.



APPLY FOR A PBS SAFETY NET CARD

Keep a record of the PBS medicines you buy on a Prescription Record Form (available from pharmacists). If you always use the same pharmacist, you can ask them to keep a computer record instead. Once the threshold is reached, your pharmacist will give you a Safety Net card. Your PBS medicines are then cheaper or free for the rest of that calendar year.

To find out more, call 1800 020 613 or go to www.pbs.gov.au.

Go to the same pharmacy to get prescriptions when possible. Order repeat prescriptions **BEFORE** the medication runs out – allow at least 2 days.



You can always ask questions about medications – ask the pharmacist, the doctor or the PCSE team.

What are the drugs called and what are they for?

How much should be given and when?

How should the drugs be given (e.g. with or without food)?

Should anything be avoided while taking the medications, such as alcohol or driving?

Do the drugs interact with other drugs or vitamin supplements?

What are the possible side effects?
What should I do if the person experiences side effects?

How long will the medications be needed?

What to do if a dose is missed?

When is the use-by date?

How should the drugs be stored?

Storing medications

- Keep medications in a safe place away from children: a cool dry cupboard is a good place. Generally, medication should be stored in the original container
- Some medications should be kept in a fridge – check the label

PCSE team do not carry medications with them. Staff will help you to make sure you have enough medications available in the home.



Good practice with medications

- Never take another person's medications
- Return out of date (expired) or unused medications to the pharmacy for safe disposal

Always tell the doctor and the PCSE team about any other medications used e.g. herbal medications or over the counter medications



Keep track of medications

Use a medication chart to keep an up to date list of the medications being used, and have it available when seeing a health professional or pharmacist.

Ask the PCSE team about using a Medicines Chart. We can give you a template or you can download an app for your phone.



Palliative medications

Palliative medications may be needed to treat or prevent symptoms such as pain, nausea and vomiting, anxiety, shortness of breath and others.

Some treatments work to control or slow down progress of a disease rather than curing it. These include chemotherapy, hormone treatments and radiotherapy. Their key benefit is to improve the quality of life.

What is different about palliative medications?

Standard medications may be used differently for palliative care. For example, using antipsychotic medications to treat nausea, anticonvulsants to treat pain, and opioids to treat breathing difficulties. Ask your doctor, the PCSE team or pharmacist if you have any questions.

There is help available

NOTE: Sometimes it may be difficult to get some medications and some are more expensive if they are not subsidised by the Pharmaceutical Benefits Scheme (PBS). Ask us if you have any problems.

If someone is unable to swallow, there are various other ways to administer medications. If tablets can't be swallowed, options include: syrup form or crush or dissolve medication or give medication by injection



Reviewing unnecessary medications

If someone is living with multiple medical conditions, they are likely using multiple medications. The PCSE team will review all medications, based on assessment of risks, interactions, costs, and prognosis.



Emergency medications

Emergency medications are 'ready-to-go' injectable medications provided to be kept in the home. They are used if symptoms get worse or new symptoms arise or ability to swallow or absorb medications by mouth decreases.

Emergency medications are prescribed for pain, nausea, vomiting, breathlessness or breathing problems, anxiety and restlessness.

The medications are provided 'ready-to-go' to ensure you can keep caring in the home and as a form of 'insurance', in case the need ever arises. The nurses administer them, and carers can be taught to use them also.

Make sure you have enough emergency medications on hand. The PCSE team do not carry medications and they can only give the emergency medications that are already prescribed and stocked in the home.



When to use emergency medications

- Use the usual oral medications (e.g. painkillers) first. If they are not helping, call the PCSE team
- PCSE nurses will review symptoms and administer medications if necessary and review any changes necessary to regular doses
- Keep a record of the medications administered as this is helpful in an emergency

Let the PCSE team know if the person's condition changes. Medications and doses will be reviewed.

Who can give emergency medications?

- The PCSE team gives the initial 'ready-to-inject' emergency medications and can teach carers how to give the injectable medication

If you would like to learn to give the emergency medicines, please talk to the PCSE team. You will be taught about the medications, when they can be given, how to give the injection, how to record that the medications were given and who to contact for support. You will be provided with a care plan and the necessary equipment.

Looking after the emergency medications

- The medications are for the person you care for and should not be taken by anyone else
- Keep medications in a safe place out of reach of children or vulnerable adults
- Medications do not need to be kept in a fridge

Note the expiry date of each emergency medication when you receive them and check them every month. Tell your GP or the PCSE team when the expiry date is close so you can get a new prescription.

Managing a syringe driver at home

As people become more ill, they may not be able to swallow tablets, capsules or liquid. When medications need to be given by injection, a small infusion pump called a syringe driver is used to dispense carefully calculated regular doses of medication over an extended period of time. The driver is managed by the PCSE team.

What you need to know

- The PCSE team will set up the syringe driver and will attend your home on a daily basis to refill the syringe with the required medications
- You will be taught to care for the syringe driver and fix any simple problems
- The nurse will prepare breakthrough medications and explain how/when to use these
- You, as the carer, are responsible for making sure that prescriptions for ongoing medications from the GP are filled by your pharmacy and ready in the home for PCSE staff to use at each visit

Dos and Don'ts: tips for carers



DO: Check the battery daily, by checking that the light on the front of the syringe driver is flashing intermittently.



DO: Only use the recommended DURACELL MN1604 9Volt Alkaline Battery (a spare battery will be supplied).



DO: Check that the tubing is not kinked and the person is not lying on the tubing. Check for leakage from the tubing or the butterfly injection site. Your PCSE nurse will point out the common leakage points.



DON'T: Get the syringe driver wet (do not take into steamy room or shower area). It is not waterproof.



DON'T: Use a mobile telephone within one metre of the syringe driver.

Troubleshooting

Fault	Action
The syringe driver has stopped before the syringe is empty	<div>→ Check that the line is not kinked or trapped</div> <div>→ Fit a new battery</div> <div>📞 CALL PCSE</div>
The light is not flashing	<div>→ Fit a new battery</div>
The medication is leaking around the needle insertion site	<div>📞 CALL PCSE</div>
The syringe is empty before the nurse is due to arrive	<div>📞 CALL PCSE</div>

If you are unsure about managing the syringe driver, contact PCSE.

Fitting a battery

If the battery needs replacing:

- Slide the back cover off the syringe driver and gently tap out the battery. You can access this through the locked box at the back
- Fit a new 9 Volt battery and slide the cover on, holding the battery down

To restart the syringe driver:

- Press the on/off button on the front of the driver. When the screen asks ‘Resume Syringe Driver?’, follow instructions on LED display and press green YES button three times to resume and restart the syringe driver

To stop the syringe driver infusing e.g. if the person has died, remove the battery from the driver and call PCSE.



Giving medications by injection in the home

Sometimes, even when a person is receiving regular medications for their symptoms, they may have more pain or troublesome symptoms that need extra medication. This is given by injection and sometimes these can be administered at home without the nurse.

The PCSE team will teach you how to give injections. You do not have to give these injections unless you are comfortable doing so. Let the PCSE team know if you want to stop giving injections.



What you need to know

The PCSE nurses put in an injection line, which sits under the skin. The injection is given into this line, not directly into skin.

- You will be taught what the medication is for and when to give it and shown how to record each injection given, writing the date, time and reason, and whether the injection was effective in relieving the symptom. Ask your PCSE nurse for an injection chart
- The PCSE nurses will label the prescribed medication in individual doses and it is kept at room temperature (for up to 48 hours) with a sterile cap covering until required
- You will be taught how to safely dispose of any used needles and syringes
- There will be an additional injection available for any uncontrolled pain. You can repeat in 30 minutes if the person is still in pain
- The PCSE nurse will review the person's medication dosage regularly and adjust it if necessary, in consultation with the GP

If pain is still there 30 minutes after the second extra injection, call the PCSE team for further advice.



Step-by-step guide

Check the injection site for redness, tenderness or leakage. If there is none present:

- 1 Collect required medication from the ready-to-go supply
- 2 Wash hands
- 3 Uncap line
- 4 Uncap syringe and give injection via line
- 5 Flush line with 0.3ml of flush solution
- 6 Recap line
- 7 Safely dispose of any needles/syringe
- 8 Re-check site for redness or leakage (call PCSE if this occurs)
- 9 Record the injection given on the document provided

Important

If the person you are caring for is dying, an injection may relieve their discomfort and pain at this point. This is quite common and does not hasten their death.

*You **WILL** feel better*

2.4 Planning for emergency care

In palliative care, an emergency is usually a sudden change in circumstances that impacts on quality of life in new ways.

It is important to plan and prepare for emergency care. Having an understanding of possible events and how to respond will build your confidence in case of one of these events. Some events can be expected and planned for, and some even prevented.

Our general approach to planning for emergency care includes:

- 1 — Plan to prevent any emergency event before it occurs
- 2 — Establish the reason for the event
- 3 — Determine course of action (arrange for a nurse to visit or call an ambulance)

Be familiar with any Advance Care Directives to guide your response in case of emergency.

If an ambulance needs to be called, please be mindful of any directives or certificates arranged by the client. Keep the documents on hand to show the ambulance staff on arrival.

Contact the PCSE team if you are unsure of how to proceed.

The following sections describe common palliative emergency scenarios and the steps you can take. The PCSE team will talk to you about these so that you can be prepared.

Emergency care scenarios:

-  Fall
-  High temperature
-  Nausea and vomiting
-  Restlessness / agitation
-  Seizures / fitting
-  Severe bleeding
-  Shortness of breath
-  Spinal cord compression
-  Sudden change in breathing
-  Sudden decrease in mobility / movement
-  Sudden unexpected change in consciousness
-  Sudden unexpected increase in pain

What to do if the person you are caring for experiences...

Fall

- Use pillow and/or blanket to make the person comfortable
- Do not assist them off the floor
- CALL 000 if you need urgent assistance or call PCSE for advice/support

A medical review in hospital might be considered.

- If physical improvements seen, review position of comfort with emergency staff and assist to bed/chair

High temperature

- Is the person receiving chemotherapy? When was the last dose of chemotherapy? You may need to contact the hospital where the treatment was given for further advice
- Has there been any signs of infection e.g. cough, increased need to urinate?
- CALL PCSE for advice if:
 - temperature is above 38 degrees for 2 hours OR
 - the person has dizziness, sweats, diarrhoea, pain on passing urine, a moist cough, shakes or feels unwell

A nursing visit or medical review in hospital may be required. Do not delay in seeking medical help.

Nausea and vomiting

- Give the regular anti-nausea medication early, rather than let the nausea become more severe
- Keep a record of medication (what/when)
- Determine if nausea/vomiting is new or existing
- Give breakthrough medication if available
- CALL PCSE for advice if not improved or is worse

A nurse will visit if required and can provide additional medications. The nurse will check for possible causes.

Restlessness/agitation

- Is it new or existing restlessness/agitation?
 - if new, CALL PCSE
 - if existing give breakthrough medication as advised. CALL PCSE for advice if not improved or worse

Nurse visit may be required, nurse may have additional medications

- You can also try:
 - checking that the person is not too hot
 - checking the bedclothes for any irritation
 - sitting with the person, take their hand & talk to them
 - if it's night time try a night light, radio or music
 - repositioning for comfort

Seizures/fitting

- Make the person safe and position them on their side to keep airway free
- If the person has a history of seizures they may have medications that you can give, e.g. clonazepam drops under the tongue
- CALL PCSE for advice and support

A nurse will visit if required; can administer calming medications.

- CALL 000 if prolonged seizure and not responding to medications

Severe bleeding

- If you need help immediately call 000
- Give breakthrough medication if available
- Apply positive pressure to an open wound
- Use dark towels to clean up and cover the area of the bleed
- CALL PCSE for advice if not improved or worse

There are medications that could be given by the visiting nurse or ambulance officer to sedate and relax in case of a major bleeding event.



Shortness of breath

- If shortness of breath is sudden or severe, CALL 000
- Determine if shortness of breath is new or existing:
 - if new, CALL PCSE
 - if existing, give breakthrough medication if available and repeat in 30 minutes if not improving. CALL PCSE if breathing not improved or worse

A nurse visit or medical review in hospital may be required.

- You can also try:
 - sitting person upright
 - setting up a fan for gentle air near the face
 - opening a window or door



Spinal cord compression

- Is it new back pain or an increase in existing back pain?
- Is there:
 - pain spreading/radiating down the leg?
 - numbness/pins and needles of the feet and legs?
 - leg weakness?
 - changes in bowel/bladder habits?
 - ‘banding pain’ around body or abdomen?
- If YES to any of these questions this can be a serious medical emergency, CALL PCSE for advice

A nursing visit or medical review in hospital may be required.

Sudden change in breathing

- Change position for comfort; use a fan if it helps
- Give breakthrough medications
- Repeat in 30 minutes if not effective
- CALL PCSE if breathing not improving or getting worse

Sudden decrease in mobility/movement

- CALL PCSE for advice

A nurse may visit if required to check for possible causes.

Sudden unexpected change in consciousness

- If sudden loss of consciousness, CALL PCSE for advice and support

Sudden unexpected increase in pain

- Give breakthrough pain medication if available – give early rather than waiting
- Keep a record of medication (what/when)
- Repeat in 30 minutes if not improving
- CALL PCSE for advice if the pain is not improving or worse

A nurse may visit and administer additional medication.

2.5 After hours contacts

When to call 000?

If the person you are caring for has any of these symptoms:

- Central or crushing chest pain
- Unexpected unconsciousness or suffering seizure or fit
- Difficulty breathing or turning blue
- Severe bleeding
- Victim of severe accident
- Or on instruction from PCSE nursing helpline

Lifeline crisis support

13 11 44

GriefLine counselling support

(03) 9935 7400

Your local after hours GP clinic
(if applicable)

After hours GP helpline health direct
1800 022 222

Home visit GP Services:

National Home Doctor Service

13 74 25

Doctor Doctor

13 26 60

Websites:

National Health Service Directory:

about.healthdirect.gov.au/nhsd

After hours pharmacy locator:

www.healthdirect.gov.au/after-hours-gp-helpline

Symptom Checker:

www.healthdirect.gov.au/symptom-checker

2.6 Accessing our nursing services after hours

Caring at home after hours, especially at night, can feel isolating. PCSE offers an after hours nursing phone service to support you.







After Hours Palliative Nursing Phone Support Service

03 5991 1300





Sometimes there is a wait for this service but your call will be answered.

The after hours nursing service:

-  has access to client information
-  is qualified to provide high quality palliative care and carer support
-  will assess your situation by telephone and organise a nurse to visit (if applicable) or will arrange for a home visit by Ambulance Victoria or a Locum Doctor
-  updates the PCSE team in the morning

When should I call?

The after-hours service can assist you in situations which require an immediate response, such as

-  symptom management
-  significant changes in condition
-  you are having difficulty caring
-  medication or equipment problems

A simple call can provide relief and reassurance overnight, and calling the nursing staff before contacting 000 could save you the inconvenience of lengthy waits and hospital admissions.

If the call is not urgent, please do not call the after hours service.



Calls about minor illness, management of routine paperwork and prescriptions, organising appointments, questions regarding equipment or service can wait until morning.

What happens when you call after hours?





Your call will be answered by a call service for you to leave a message. Identify that you want to speak to a nurse and leave your details. This message will be sent to the nurse on call who will ring you back.

Depending on severity, the after hours nursing service will:

- discuss symptoms and give reassurance
- give you advice on the telephone and ask you to monitor the person
- refer to locum or an after hours GP
- refer to GP in the morning
- refer to other service
- organise a nurse to visit (if available)
- advise you to visit an Emergency Department
- arrange or advise you to contact Ambulance Victoria by calling 000

If you are worried or unsure at any time, call for reassurance rather than worrying through the night.



The after hours nursing service can		The after hours nursing service cannot	
	Give advice, e.g. on how to improve symptoms		Make a medical diagnosis or prognosis
	Guide you through administering medications		Provide medical (doctor) assistance
	Arrange for a nurse to visit if available		Provide an emergency service
	Advise what to do if a person collapses, falls or is injured		Arrange medicines or prescribe scripts
	Advise you what to do in an emergency or where death is close		Advise to use medication or doses not prescribed by your doctor
	Advise what to do if death has occurred		Arrange a nurse to visit if the situation is not urgent, or where medications are not available in the home to use
	Arrange for hospice or hospital if necessary		
	Arrange for a visit by Ambulance Victoria or a Locum Doctor		

Note: Our nursing service is NOT an emergency service, however we are always contactable by phone and will respond to your call in a timely manner.



Hints for using our after hours nursing service



Use your regular medications, including 'break-through' and 'as required' medications to treat symptoms before calling. Refer to the pain and symptom management guide in this kit



Repeat the plan back to the nurse to ensure understanding. Having the medications and Home Folder at your side during the call can help



If there is no response from a nurse within 10 minutes of your call, call back. Try to remain calm and patient during the call

3. Preparing for death

We're all in this together

3.1 Preparing for death

Some questions you might use as conversation starters with your PCSE team.

	What can we expect in the last days of life?
	What should I say if the person I care for asks, 'Am I dying?'
	Will you be able to tell me when it is getting close to the time that the person I care for will die?
	When should I call the rest of the family? What should I say to them? Could you speak to them?
	How will I know when the person I care for has died?
	What happens after they die? (What happens to the body? How do we arrange a funeral?)
	What support is available to the family after the person dies?

Why is it important to prepare?

The last few days of a person's life are very different – being prepared will help you get through this difficult time. Our service is available to provide support, help and understanding during this time. We can help you prepare a simple plan which deals with immediate practical issues.

Organise a local GP in advance to prepare the death certificate, especially if you have specific personal or spiritual rituals (for example, burial is required within 24 hours of death), and in case the death occurs over the weekend

If you have any particular traditions or cultural needs, please tell the PCSE team

If you are usually alone with your loved one, you may prefer to have a close friend or relative available at short notice to be with you at this time. The deceased person may remain at home for several hours. You may like other close friends and relatives to be able to say goodbye, in addition to spending some time alone with them before they are picked up by the funeral director.

Plan to have someone available for you.

The funeral director will make an appointment to discuss arrangements and costs with you, when you are ready to do so and normally within a day or two after death has occurred. You can involve friends and family as much as you wish.

Select a funeral director

Preparing for death checklist

Is a quick burial required?	<input type="checkbox"/> YES <input type="checkbox"/> NO
If yes, have I discussed with my PCSE team?	<input type="checkbox"/> YES <input type="checkbox"/> NO
Who is available to support me at short notice? Record name & phone number here:	1.
	2.
	3.
	4.
Has a GP been arranged for a death certificate?	<input type="checkbox"/> YES <input type="checkbox"/> NO
Has a Funeral Director been selected?	<input type="checkbox"/> YES <input type="checkbox"/> NO
Has a religious / spiritual guide been notified?	<input type="checkbox"/> YES <input type="checkbox"/> NO

Signs that someone is dying

- The time before death is generally peaceful
- Please ask the PCSE team for help at anytime
- We usually have increased contact with you during the last stages of life
- Simply sitting with a person, holding their hand and speaking in a calm and reassuring manner brings enormous benefits, even if there is no response

‘Being with’ can be more important than ‘doing for’

The following is an overview of common physical and emotional changes prior to end of life. Not all of the changes will occur, nor will they occur in any particular order. These changes indicate that the body is preparing itself for the final stages of life. During this stage, the systems which sustain life begin to shut down, with physical, mental, emotional and spiritual changes happening over weeks or days, or may begin only hours before death.

Physical changes



Sleeping

The person will gradually spend more time sleeping and may stop communicating and be difficult to wake up. Don't shake the person or speak loudly; speak softly and naturally. Never assume someone cannot hear – hearing is one of the last senses to go.

Spend time with your loved one when they seem most alert.



Fluid & food

As death approaches, there will be less need for food and drink as the person will naturally conserve energy. This is a natural process. Trying to feed someone who is unable to swallow may cause distress.

Food requirements reduce as the body shuts down:

solids → soft food → liquids
water ← ice chips ←

Moist mouth swabs (sponge on a stick) or tiny amounts of crushed ice will help relieve feelings of thirst. Do not force food or drink at this stage. Let your loved one know it is OK not to eat at this time.

Respect and acceptance helps your loved one and you.

Your PCSE nurse can help you with mouth care.

Restlessness

Restlessness, agitation and repetitive actions can occur in the last days or hours of life. This may be caused by low circulation, toxins or spiritual or psychological issues.

Do not try to restrain motions.
Make the environment safe.
Speak calmly and quietly.

Find ways to help your loved one relieve tension or fear. Things which may be helpful include:

- Massaging hands or forehead lightly
- Recalling a favourite place
- Recalling a favourite experience
- Reading something comforting
- Playing soft and familiar music
- Giving assurance that it is OK to let go

Call PCSE if you are concerned.
Medications are available.

Confusion & disorientation

The person may become increasingly confused about time and place and people they know. Levels of awareness may change frequently and unexpectedly. The use of a night light may help. Do not disagree with what they say. Hold their hand and reassure them.

Identify yourself by name and talk calmly and confidently to be reassuring.



Call PCSE if you are concerned about your loved one.



Incontinence

Loss of control of urine or bowel movements can occur very close to death.

Maintain dignity and respect. Use incontinence pads and sheets to protect the person and bedding. This will help maintain comfort & cleanliness. It is a good idea to keep track of bowel movements and tell the PCSE team when they call.

It is important to keep the skin clean and dry.



Urine output

Urine output decreases and can become dark in colour. This can be caused by lower fluid intake.

Secretions

Saliva and mucous may increase and collect in the back of the throat, as cough or swallowing decreases. This sometimes causes a gurgling or bubbling noise known as the 'death rattle'. This can be distressing for carers, but usually causes no harm for the person. The sound does not indicate new or severe pain.

Lift head off the bed with pillows. Turning body from side to side may help.



Call PCSE if you are concerned. Some medications can dry secretions.



Temperature

Changes in body temperature are common, and your loved one may feel hot and clammy sometimes and cool other times. The colour of the skin on the arms, legs and underside may change as circulation slows down.

Create warmth if they appear cold and remove covers or use a light sheet when hot.



Too much heat can cause restlessness. Provide good ventilation and cool towels if necessary. Be guided by your loved one's wishes – even if they seem odd.

Breathing

Breathing patterns can become irregular: sometimes faster, sometimes slower. It is normal to have intervals from ten seconds to several minutes where no breathing occurs. Providing oxygen at this stage is not necessary.

Continue to support and reassure your loved one – hold their hand and speak gently. This is the time to just be with them.



Call PCSE if you are concerned.



Emotional changes

As death approaches, people may become less interested in the outside world and details of daily life. They may become less interested with other people, wanting only a very few close. This process is part of letting go and saying goodbye.

A person may reflect on different memories or have conversations with others who have already died. They may also become delirious, which might involve agitation, hallucinations or out of character gestures or requests.

Call PCSE if you have any concerns during this time. We are available to provide support, help and understanding.



Withdrawal

The person you are caring for may seem unresponsive, withdrawn or in an unconscious state. This might mean they are preparing for death - withdrawing from surroundings and close relationships - and might signal that they are ready to go. Hearing is thought to be the last sense that remains.

Speak to your loved one in a normal voice. Identify yourself by your name and hold their hand and say what you wish to say.



Vision-like experiences

A person who is dying may speak or claim to have spoken to people who have already died. This does not necessarily mean that they are hallucinating, but withdrawing from this life.

Do not contradict or argue about what is said or seen. Affirm the experience - they are normal and common.



Giving permission

Giving permission to your loved one to let go, without making them feel guilty for leaving or trying to keep them with you to meet your own needs, can be difficult. A dying person will normally try to hold on, even though it may bring discomfort, to make sure those who are going to be left behind will be alright.

Giving your loved one reassurance that it is alright to let go whenever they are ready is one of the most important things you can do for them at this time.



Saying goodbye

A family's ability to reassure and give the person 'permission to die' can help them to let go. Saying goodbye is personal and can be said and done in many different ways. It may include lying in bed with them, holding their hand or saying whatever you wish to say.

Tears are a natural part of the grieving process and you should not feel they need to be hidden or apologised for.



What happens when someone dies?

How will I know that death has occurred?

Signs that death has occurred:



Not breathing



No heartbeat



No pulse



Release of bowel and bladder



No response



Eyelids slightly open



Pupils are enlarged



Eyes fixed on a certain spot,
does not blink



Jaw relaxed and mouth slightly open



What do I do next?

A death is not considered to be an emergency. Nothing must be done immediately

Take a deep breath. Do everything in your own time – there is no need to hurry

There is no need to contact the police or call an ambulance

There is no need to contact anyone immediately

Spend as much time as you want with your loved one

Your loved one can stay at home as long as you need (hours or days), so that family and friends can come to say goodbye

When you are ready

- You can call your PCSE team if you would like some support. We can attend the home
- Call for a PCSE nurse or your GP to complete a verification of death
- The funeral director will take this verification of death when they come to your home

If death happens at night, you can wait until the morning to arrange verification of death.



- There is no need to bathe the person, but you may sponge away bodily fluids or perspiration
- Remove sources of heat from the room such as heaters, electric blankets or hot water bottles
- Straighten your loved one's body to prevent stiffness. Replace dentures

When you are ready to have your loved one attended to and transferred

- Contact the Funeral Director
- They will liaise with the GP/doctor to obtain a death certificate (A funeral will not be able to take place if the death certificate is not available)
- They will take your loved one and support you through the funeral arrangements

Call PCSE if you need help or advice.



3.2 Grief

People often experience grief before bereavement. As a carer you may see changes in your sleeping, eating, concentration and management of feelings. Understanding that this is a normal response to your situation can assist and support self compassion.

We all feel grief in our own way – there is no right or wrong way to feel. It is important that you let yourself grieve as much and as long as you need to.

Sometimes it may be difficult to make sense of how we are feeling. Grief may present as anger, regret, sadness, panic, fear, isolation, resentment, guilt, relief or other feelings and thoughts, physical symptoms such as changes to sleep or eating habits, spiritual questioning and social changes.

The grief response comes and goes and at times may feel overwhelming or somewhat manageable. At other times, we may feel there is no end to our inner pain and it's difficult to see a way forward.

We are here to support you during this time of change.



Be kind to yourself

3.3 Bereavement support

Bereavement Support Program

Bereavement refers to the period of mourning and grief following the death of a loved one. This period of time can be one of the most significant life experiences and sometimes the most challenging. It can bring a tremendous sense of change and loss of control, and within this experience may be the opportunity for self-awareness and personal growth.

PCSE has staff trained in grief, loss and bereavement to support this journey.

Our Bereavement Support Program provides individual and group support for 13 months. Support includes counselling, music therapy, spiritual care and volunteer support to partners, children, family members and close friends.

“It’s great to meet up with others that have been through/are going through a similar experience who understand your circumstances”

Speaking with our trained staff may assist you to

- ✓ Manage and understand your grief
- ✓ Reflect on thoughts or beliefs that are causing distress or concern
- ✓ Develop strategies to cope with life changes
- ✓ Find methods to reduce stress
- ✓ Discuss issues resulting in anxiety and depression
- ✓ Provide you with the opportunity to be heard with compassion, care and non judgement
- ✓ Find clarity and meaning within difficult circumstances
- ✓ Work towards acceptance of life changes
- ✓ Receive education about what you may experience during bereavement

The Bereavement Support Program is free of charge to you and your family.



Remembrance Service

A remembrance service is held twice a year and is facilitated by PCSE staff to reflect and share the memories of your loved one.

Bereavement Social Support Group

PCSE holds a monthly social group for those who have lost a loved one. The group provides the opportunity for you to connect with others who have experienced loss and who are learning to rebuild their lives. The group is facilitated by our trained staff and volunteers and is an opportunity for you to engage socially with others in a supportive environment.

We are here for you



4. Resources and links

We're all in this together

Organisation	Phone	Website	Description
Carer Information			
Alfred Health Carer Services	1800 052 222	carersouth.org.au	Advisory and support for carers in Melbourne's south. List of carers support groups.
CareSearch	08 7221 8233	www.caresearch.com.au	Palliative care knowledge website with information on: Living with illness, how to care, at the end, bereavement, grief & loss, groups with specific needs.
Carers Victoria	1800 514 845	www.carersvictoria.org.au	Statewide voice for family carers, representing and providing support to carers in Victoria.
Carer Gateway	1800 422 737	www.carergateway.gov.au	National online and phone service that provides practical information and resources to support carers. Interactive service finder helps carers connect to local support services.
Palliative Care Australia		www.palliativecare.org.au	National peak body for palliative care. Provides links to services in your area & resources
Palliative Care Victoria	03 9662 9644	www.pallcarevic.asn.au	Information, support and advocacy for quality palliative care. PCV offers two important booklets: 1. About Palliative Care 2. Supporting a person who needs palliative care – A guide for families and friends
LGBTI Carers	1800 242 636	www.carersvictoria.org.au/how-we-help/LGBTI-carers	Support for LGBTI carers
Young Carers Respite and Information Services Program	1800 242 636	www.youngcarers.net.au	Carer stories, tips, resources, bursary program, advocacy. You can also call 1800 052 222 to find out about respite, practical help and social activities for carers under 25
LifeCircle		www.lifecircle.org.au	Information and tools for improving understanding of dying

Organisation	Phone	Website	Description
Carer Services			
Advocacy			
The Office of Public Advocate	1300 309 337	www.publicadvocate.vic.gov.au	Level 5, 436 Lonsdale Street, Melbourne, VIC 3000
State Trustees	03 9667 6084 1300 138 672	www.statetrustees.com.au	Provides a broad range of legal and financial services (legal wills, estate planning, probate, power of attorney and trustee services)
Elders Rights Advocacy	1800 700 600	www.era.asn.au	An independent agency funded by the Australian Government to provide advocacy services for people receiving Australian Government funded aged care services in Victoria.
Seniors Rights Victoria	1300 368 821	www.seniorsrights.org.au	Information, support, advice and education to help prevent elder abuse and safeguard the rights, dignity and independence.
Aged Care Complaints Commissioner	1800 951 822	www.agedcarequality.gov.au	Free service to raise their concerns about the quality of care or services being delivered to people receiving aged care services subsidised by the Australian Government.
Veterans' Affairs Network (VAN)	1300 551 918	www.dva.gov.au/contact/van-state-office-locations#vic	Assistance for Veterans, widow(er)s and their families
Australian Charter of Healthcare Rights		www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights	The key rights of patients and consumers when seeking or receiving healthcare services.

Organisation	Phone	Website	Description
Carer Services			
Counselling			
beyondblue	1300 22 4636	www.beyondblue.org.au	24-hour telephone counselling service. Online and email counselling 7 days a week.
Lifeline	13 11 14	www.lifeline.org.au	24-hour telephone crisis support and suicide prevention.
National Carer Counselling Program	1800 422 737	www.carersaustralia.com.au	Carers Australia program: Provides short-term counselling. The Carers Associations in each state and territory also run local support groups
Australian Centre for Grief & Bereavement	1800 642 066	www.grief.org.au	Grief education and a range of consultancy services to develop and enhance the capacity of individuals, organisations and communities to deal effectively with loss.
GriefLine	1300 845 745 03 9935 7444	www.griefline.org.au/online-counselling	Griefline Community and Family Services listens, cares and supports people experiencing loss and grief at any stage in life. Includes online counselling service.
Equipment and aids			
Coastcare Medical Equipment	03 9707 4955	www.coastcaremed.com.au	Rehabilitation and medical products for hire and sale. Accredited for DVA and SWEP. Equipment that can be provided quickly overnight: Shower chairs, Commode, Recliner chairs, Hospital beds.
Independent Living Centres Australia	1300 885 886	ilcaustralia.org.au	Offers advice on a range of products and services to help with aspects of day-to-day living, including mobility, sleeping, eating and transport
Endeavour Life & Care	9703 2900	endeavourlifecare.com.au	Provider of home health care equipment.
City of Casey		www.casey.vic.gov.au/ community-services/disability- services/disability-services- directory/equipment-and-aids	City of Casey's guide to programs and services for equipment and aids for people with disabilities.

Organisation	Phone	Website	Description
Carer Services			
Financial support / government agencies			
Financial Counselling Australia	1800 007 007	www.financialcounsellingaustralia.org.au	Information about financial counselling and help to find a qualified counsellor.
Centrelink	13 27 17	www.humanservices.gov.au/individuals/centrelink	
Department of Veterans Affairs	13 32 54	www.dva.gov.au	
Home help			
Your local council	PCSE can help you organise some Council community and in-home services		
Home modifications			
Peninsula Health Domiciliary Care Referral	1300 665 781	www.peninsulahealth.org.au/services/services-a-e/agedcare/domiciliary-care	Home based assessment and maintenance program for frail, older and younger disabled people and their carers who live at home
mecwacare	1800 163 292	www.mecwacare.org.au	Provides in-home nursing and care throughout Melbourne's southern & eastern suburbs.
Home nursing			
PCSE	Home nursing can be organised as part of your palliative care. Private services are also available		
Bolton Clarke at Home Support	1300 33 44 55	www.boltonclarke.com.au	Provides a range of practical, flexible home care services covering nursing, home assistance, allied health & mental health.
Issue resolution			

Organisation	Phone	Website	Description
Health Complaints Commissioner	1300 582 113	hcc.vic.gov.au	If you are not satisfied with your health service provider, you can raise your concerns with the Health Complaints Commissioner.
Carer Services			
Living at home assessments			
Council services		Your local council website	Cardinia, Casey, Greater Dandenong, Kingston Councils. Living at home assessments assist people to explore a range of ways to live independently and remain active members of their community
Personal care			
Council carers Alfred Care Baptcare MECWA Bolton Clarke at Home Support	13 22 78 1800 163 292 1300 33 44 55	Your local council website www.alfredhealth.org.au www.baptcare.org.au www.mecwacare.org.au www.boltonclarke.com.au	Cardinia, Casey, Greater Dandenong, Kingston Councils.
Respite / short breaks			
Commonwealth Respite and Carelink Centre Southern Region	1800 052 222 (BH) 1800 059 059 (Outside BH)	www.dss.gov.au/disability-and-carers/programmes-services/for-carers/commonwealth-respite-and-carelink-centres	Respite, practical and emotional support for carers in southern Melbourne.
Support groups			
PCSE Carers Support Group	03 5991 1300	www.palliativecaresoutheast.org.au	Call PCSE for further information
Alfred Health Carer Services	1800 052 222	carersouth.org.au	Links to carer groups located in Melbourne's south
Transport			

Organisation	Phone	Website	Description
Red Cross	1800 733 276	vic@redcross.org.au	Has disease specific volunteer transportation
Carer Services			
Illness-specific organisations			
Cancer Council of Victoria	13 11 20	www.cancervic.org.au	<p>Communities of people affected by cancer that you can connect with online, by phone or in person</p> <p>Lines are open Monday to Friday, 9am to 5pm and staffed by experienced cancer nurses with oncology qualifications. Although staff are unable to give individual medical advice, they can talk about the effects of specific types of cancer and explain what will happen during processes like chemotherapy, radiotherapy or other cancer treatments</p>
Dementia Australia	1800 100 500	www.dementia.org.au Helpline email: helpline.nat@dementiaalzheimers.org.au Webchat: www.dementia.org.au/helpline/webchat	<p>Dementia Australia advocates for the needs of people living with all types of dementia and their families and carers and provides support services, education and information.</p> <p>The helpline operates nationally from 9am – 5pm Monday to Friday excluding public holidays. A message service is available outside of office hours. Leave a message and your call will be returned next working day.</p>
MND Victoria	1800 806 632	www.mnd.asn.au	Promotes the best possible care and support for people living with Motor Neurone Disease.

Organisation	Phone	Description
Palliative Care Units		
McCulloch House, Monash Medical Centre Clayton	03 9594 5320	A purpose built inpatient palliative care/hospice unit located at Monash Medical Centre.
Wantirna Health Palliative Care Inpatient Unit	03 9955 1341	A 32 bed specialist palliative care unit offering symptom control, end of life care, respite & assessment.
Peninsula Health Palliative Care Unit, Frankston	03 9784 8600	A purpose built facility that accommodates the inpatient Palliative Care Unit.
South Eastern Private Hospital	03 9549 6555	11 bed palliative care unit (Abelia) is supported by experienced nurses. Pastoral care also provided.
Peninsula Private Hospital	03 9788 3466	23 bed Acacia Cancer and Haematology ward - mixed ward of oncology, haematology, palliative.
St John of God, Berwick Hospital	03 9709 1414	Specialist palliative care unit comprising of 6 ensuited single rooms.
Ward D, Casey Hospital, Berwick	03 8768 1550	An acute medical and palliative ward
District Nursing		
Bolton Clarke	1300 33 44 55	Formally known as the Royal District Nursing Service (RDNS).
Kooweerup Regional Health Service	03 5997 9679	
Local Hospitals		
Casey Hospital	03 8768 1200	
Dandenong Hospital	03 9554 1000	
Frankston Hospital	03 9784 7777	
Moorabbin Hospital	03 9928 8111	
Monash Medical Centre (Clayton)	03 9594 6666	
Peter MacCullum Cancer Centre	03 9656 1111	
South Eastern Private Hospital	03 9549 6555	
St John of God, Berwick Hospital	03 9709 1414	
Wantirna Hospital	03 9955 7341	



After Hours Emergency Care Plan

PERSON REQUIRING CARE		CARER NAME	
Name		Name	
Age		Relationship to person requiring care	
Address		Address	
Telephone		Telephone	
Languages Spoken		Languages Spoken	

EMERGENCY CONTACTS		
Name	Relationship	Telephone

HEALTH INFORMATION - DETAILS ABOUT THE PERSON BEING CARED FOR

Person's illness:

Doctor's name, address,
telephone (GP and/or
Specialist):

Medicare number:

Centrelink number:

Health Insurance fund &
number:

Ambulance fund/
registration number:

Medic-Alert number:

Description of care needs:

EMERGENCY PLAN: In an emergency, my contacts will have (tick the applicable box):

☐ NFR orders

☐ Advance Care Plan directive

☐ Refusal of Treatment Certificate

Enduring Power of Attorney
(Medical Treatment) details:

Preferred location of death:

☐ Instructional Directive

☐ Values Directive

☐ Medical Treatment Decision Maker details:



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Palliative Care South East acknowledges the Bunurong and Wurundjeri people as the traditional custodians of the land and we pay our respects to the Bunurong and Wurundjeri Elders, past, present and emerging.