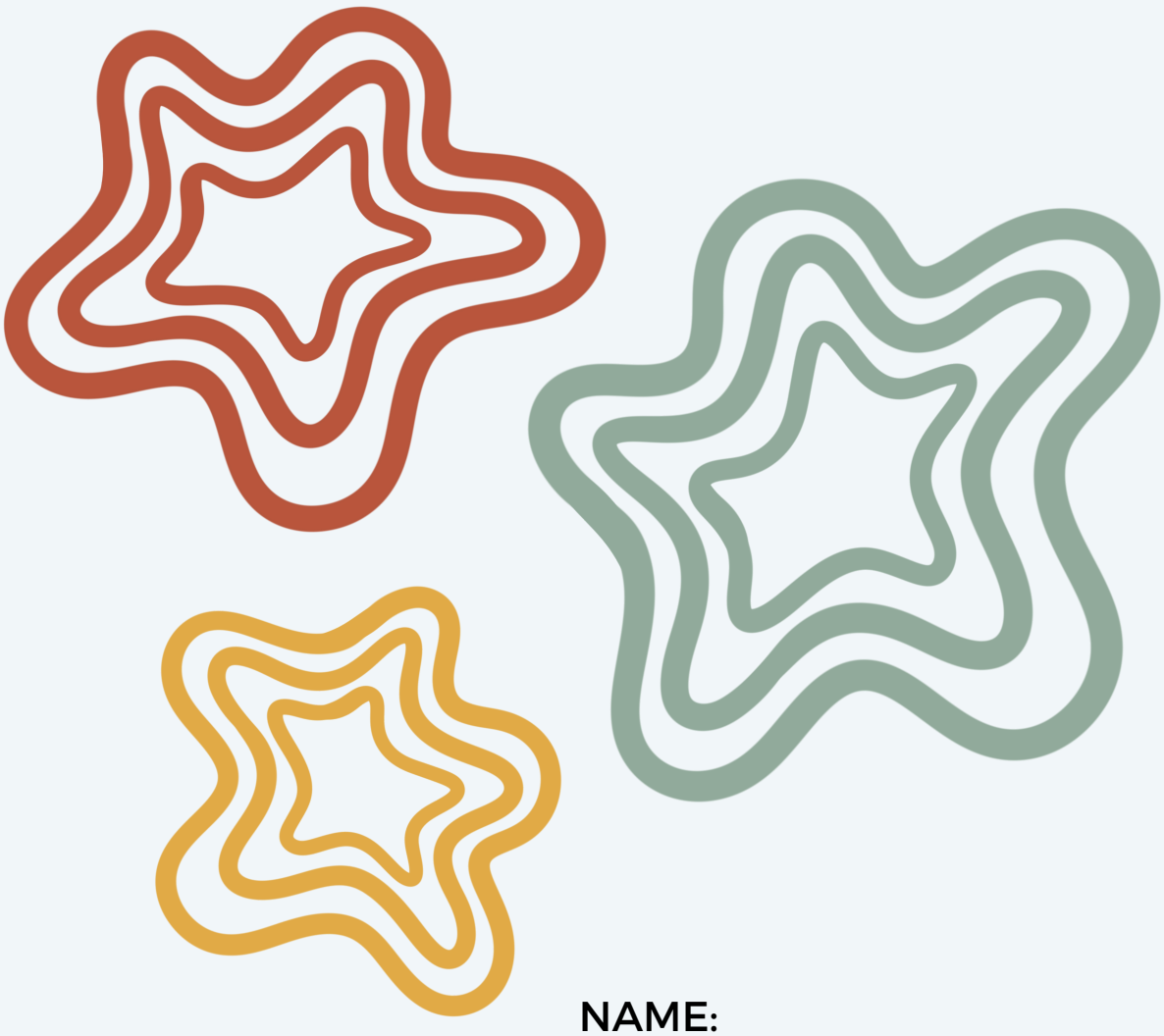
HUME REGION
Palliative Care
Consortium

https://humepalliativecare.org.au/

Version 4 June 2024

GUIDE FOR DISABILITY SUPPORT WORKERS - PALLIATIVE CARE AT END OF LIFE



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OVERVIEW

This booklet is designed to support disability support workers (DSWs) in the event that a resident/client may be approaching end of life.
It is a guide only - to support you to advocate for your client and gain an understanding of the resources that may be available to you as their carer.
Please use this document in line with your own policies and scope of practice.
More resources and links to supporting services are found at the end of this document.
It is hoped that this guide will empower you and your team to provide care with confidence, and to seek education and support as necessary, to achieve the goal of better dying for those in your care, and a better experience for you.
For further clarification or questions, please contact us below.

East Hume Aged & Disability Palliative Resource Nurse
Rose Sexton Ph: (03) 5722 5184
email: rose.sexton@nhw.org.au
West Hume Aged & Disability Palliative Resource Nurse
Samantha Moorhouse Ph: (03) 5735 8070
email: sam.moorhouse@seymourhealth.org.au

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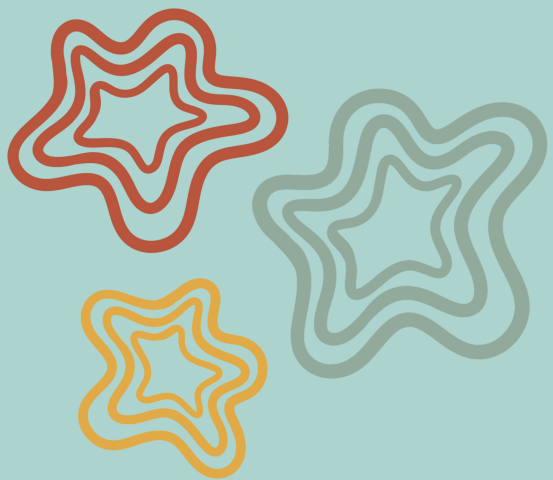

What is Palliative Care?

Palliative care is an approach that improves the quality of life of individuals and their families facing problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, physical, psychological and spiritual."

World Health Organisation, 2003

What can Specialist Palliative Care teams help you with?

- Specialist assessment and care coordination
- Symptom Management ie pain , nausea
- Emotional and practical support
- Information provision
- Grief and bereavement support
- Education and assistance to health and community care workers and the general community
- Work along side local district nursing teams in order to provide in-home care if needed

https://humepalliativecare.org.au/

What is Terminal Care?

What is the "Terminal Phase' ?

The terms 'end-of-life' (EoL) and 'terminal' are used variably. In different settings and circumstances, both have been used to describe the period of the last few days/weeks when a person is irreversibly dying.

Good end-of-life care focuses on providing a good and dignified death.

Signs and symptoms associated with the terminal phase

- Experiencing rapid day to day deterioration that is not reversible
- Requiring more frequent interventions
- Becoming semi-conscious, with lapses into unconsciousness
- Increasing loss of ability to swallow
- Refusing or unable to take food, fluids or oral medications
- Irreversible weight loss
- An acute event has occurred, requiring revision of treatment goals
- Profound weakness
- Changes in breathing patterns

https://www.carerhelp.com.au/tabid/5614/Default.aspx

Overview of the Hume Region

Please phone the palliative care service prior to sending a referral

Referring to Palliative Care

- Referrals are accepted from medical, nursing, allied health, and other health professionals as well as carers.
- Client consent is required.
- Preferred method of referral is online via the PalCare referral links attached to the website below.
- Self-referral is also welcome by calling a Community Palliative Care Service to make an enquiry.

https://humepalliativecare.org.au/health-professionals/referral-to-palliative-care/

Getting Help navigating Palliative Care and Resources

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Rose Sexton Ph: (03) 5722 5184
email: rose.sexton@nhw.org.au

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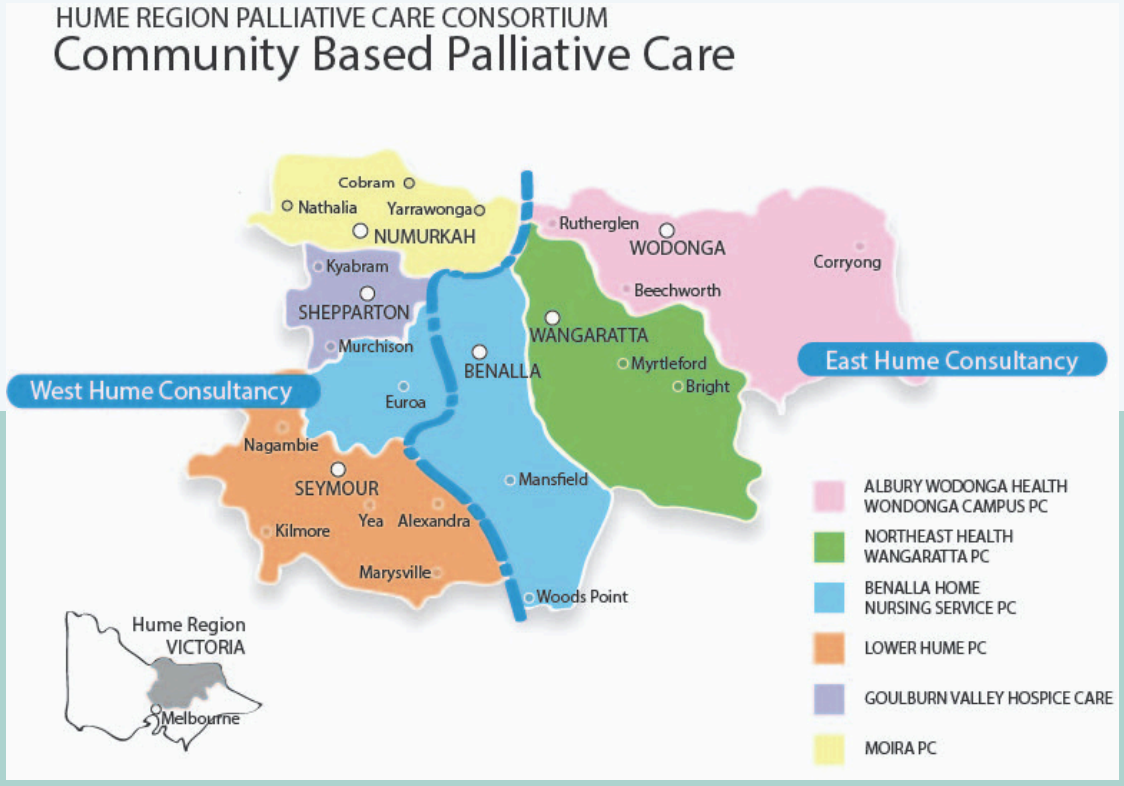
email: sam.moorhouse@seymourhealth.org.au

Our Area



FORWARD PLANNING

We can all plan, discuss and prepare for the end of life at any time.
This may help make the experience more comfortable and provide a greater sense of control when it happens

What you can do to help as a carer:

- Start talking with the person and their family about what is important, this could include:

- **Advance Care Planning** with health professionals, family and friends to discuss their wishes, values, beliefs and preferences for future medical treatment. Appoint an Attorney for personal, and/or financial matters using an Enduring Power of Attorney form and appoint a Medical Treatment Decision Maker.

  www.advancecareplanning.org.au/create-your-plan/create-your-plan-vic

- **Write a Will** and ensure it is up-to-date and easy to find - Some people have a will and others die without one. A Will needs to be written before a person's death.

- Start **funeral planning** if possible, and talk about who will be the point of contact for organising the funeral . Most people in Victoria use a funeral director to help organise a funeral or memorial service. Funeral directors are not compulsory, but they make things easier.

- Consider who will care for children, other dependents and pets

- You can offer to write letters, record videos, create photo albums or put together keepsakes for loved ones. Some people may wish to write cards or arrange gifts for future birthdays or significant life Events

- Talk about organ and tissue donation, understand what's involved, and let their family know their wishes —for more information visit donatelife.gov.au

- Make a list of their personal details and passwords and store them in a safe place and add a 'legacy contact' to Facebook (Social Media sites) to allow someone they trust to manage their account after death.

- Make a record of the care plan and share it with people who need to see it

Discussion Points at End of Life

Medical Intervention	Date/Time
Should Non-essential medications be discontinued?	
Inappropriate interventions and observations discontinued (e.g. blood pressure monitoring)	
Medications ordered for any symptoms by GP	
Advance Care Planning	
Future care plan discussed with resident / resident's representative (e.g. transfer to hospital, use of antibiotics). And Advance Care Plan and/or Medical Treatment Decision Maker forms updated if needed. www.advancecareplanning.org.au	
'Acute Resuscitation Plan' / 'Not for Resuscitation' order discussed and agreed to by resident / resident's representative (as per your policy)	
Issues surrounding PEG feeding have been discussed with the resident / resident's representative (if appropriate)	
Spiritual / Religious / Cultural Needs	
Have the spiritual / religious / cultural needs of the resident been addressed?	
Has the resident / resident's representative expressed a preferred Funeral Director? Name of Company:	
Communication with resident / resident's representative	
Have contact details of resident's representative been updated? Name and Contact:	
Have attempts been made to inform the resident's representative that the resident is dying? Contact Date: Message left:	
Comfort Planning	
Need for special mattress assessed?	

ACTION	DATE TIME A	DATE TIME B	DATE TIME C	DATE TIME D	DATE TIME E
Check the client is comfortable					
Are they in a good position?					
Mouth Care – is mouth clean and moist?					
Eye Care – Are eyes clean and moist?					
Is skin intact, clean and no rashes or redness from pressure?					
Is continence pad (if applicable) clean?					
Has the client urinated or opened their bowels today?					
Have family/carers been informed of any changes?					
Does GP need to be contacted for update?					
Any new concerns responded to?					
Spiritual, religious, cultural needs / rituals identified and facilitated					

After Death Action	Date/Time
***Resident's representative informed of death**	
***Manager informed**	
***GP informed of death**	
***Staff / residents informed of death as appropriate**	
***Removal of deceased resident from DAS according to policy**	
***Pharmacy informed of death**	

Tool 1: Symptom Assessment Chart for carer to use with client

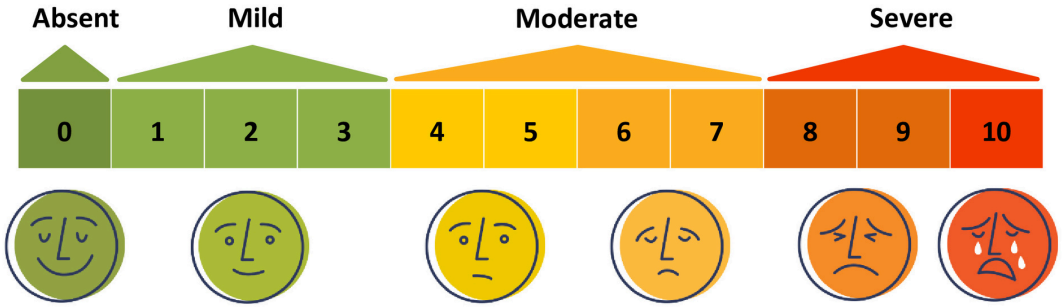
PCOC
palliative care outcomes collaboration

(Please complete or affix Label here)

UPI:
Surname
First name:
DOB:

Symptom Assessment Scale

Please use this form to tell us about the symptoms that bother, worry or distress you. This information will help us to meet your needs.



1. Write the day or date in the first row.
2. Use the scale above to choose a number between 0 and 10 that shows how bothered, worried or distressed you are.
3. You can add other symptoms in the blank space at the bottom of the list.

Day or date									
Difficulty sleeping									
Appetite problems									
Nausea									
Bowel problems									
Breathing problems									
Fatigue									
Pain									
Other									

Tool 2: How to Use Tool 1

Talking about your symptoms

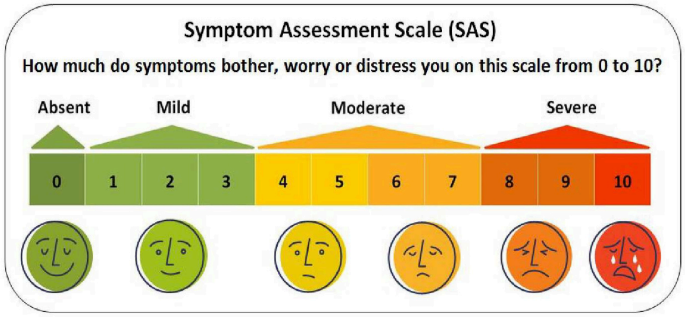
Talking about your symptoms is important

Symptoms are feelings or sensations in your body or mind that are causing you discomfort, pain or suffering. We want to know about the distress (concern or worry) caused by your symptoms. We need to understand this, so we can manage it well.

What will you be asked to do?

We will ask you to score each symptom between **0 and 10.** You will be asked to look at the scale below and pick the number that matches how you feel. Use the face, colour or word to help with this.

Before you answer, please think about your experience of each symptom on that day.



What do the scores mean?

0 means that you have no distress or worry from that symptom.

1 means that you are experiencing slight distress or worry from that symptom.

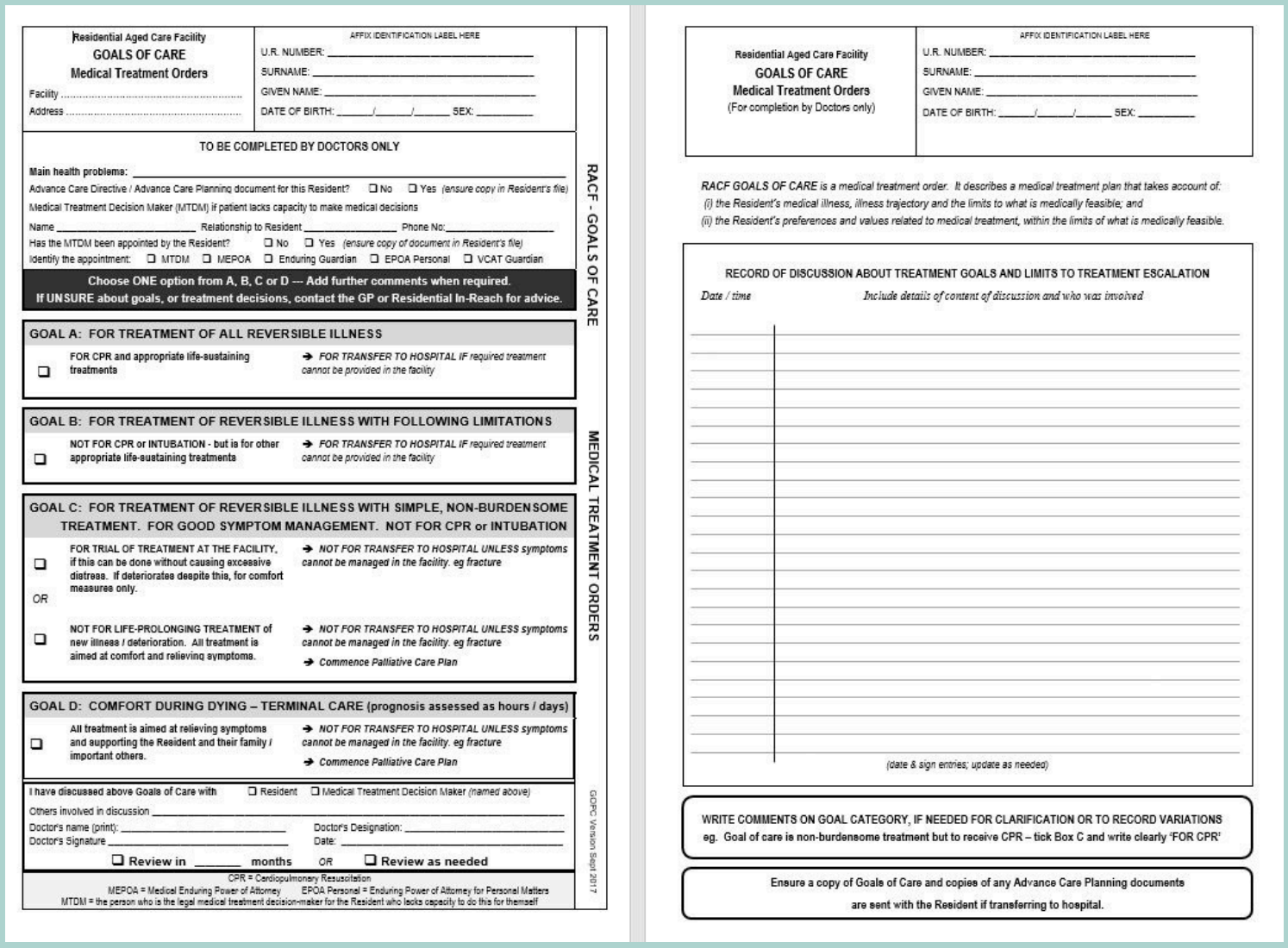
10 means that you are experiencing the worst possible distress or worry from that symptom.

The symptoms we will ask you about are:

- Difficulty sleeping
- Appetite problems
- Nausea
- Bowel problems
- Breathing problems
- Fatigue
- Pain
- *Any others for you?*

Please score your symptoms yourself. If needed, a member of your family or one of the clinical staff can help.

Tool 3: Example of a Goals of Care Form



Residential Aged Care Facility
GOALS OF CARE
Medical Treatment Orders
Facility .....
Address .....

AFFIX IDENTIFICATION LABEL HERE
U.R. NUMBER: _____
SURNAME: _____
GIVEN NAME: _____
DATE OF BIRTH: _____/_____/_____ SEX: _____

TO BE COMPLETED BY DOCTORS ONLY

Main health problems: _____

Advance Care Directive / Advance Care Planning document for this Resident? ❑ No ❑ Yes *(ensure copy in Resident's file)*

Medical Treatment Decision Maker (MTDM) if patient lacks capacity to make medical decisions

Name _____ Relationship to Resident _____ Phone No: _____

Has the MTDM been appointed by the Resident? ❑ No ❑ Yes *(ensure copy of document in Resident's file)*

Identify the appointment: ❑ MTDM ❑ MEPOA ❑ Enduring Guardian ❑ EPOA Personal ❑ VCAT Guardian

Choose ONE option from A, B, C or D — Add further comments when required.
If UNSURE about goals, or treatment decisions, contact the GP or Residential In-Reach for advice.

RACF - GOALS OF CARE

MEDICAL TREATMENT ORDERS

GOAL A: FOR TREATMENT OF ALL REVERSIBLE ILLNESS

❑ FOR CPR and appropriate life-sustaining treatments → *FOR TRANSFER TO HOSPITAL IF required treatment cannot be provided in the facility*

GOAL B: FOR TREATMENT OF REVERSIBLE ILLNESS WITH FOLLOWING LIMITATIONS

❑ NOT FOR CPR or INTUBATION - but is for other appropriate life-sustaining treatments → *FOR TRANSFER TO HOSPITAL IF required treatment cannot be provided in the facility*

GOAL C: FOR TREATMENT OF REVERSIBLE ILLNESS WITH SIMPLE, NON-BURDENSOME TREATMENT. FOR GOOD SYMPTOM MANAGEMENT. NOT FOR CPR or INTUBATION

❑ FOR TRIAL OF TREATMENT AT THE FACILITY, if this can be done without causing excessive distress. If deteriorates despite this, for comfort measures only. → *NOT FOR TRANSFER TO HOSPITAL UNLESS symptoms cannot be managed in the facility. eg fracture*

OR

❑ NOT FOR LIFE-PROLONGING TREATMENT of new illness / deterioration. All treatment is aimed at comfort and relieving symptoms. → *NOT FOR TRANSFER TO HOSPITAL UNLESS symptoms cannot be managed in the facility. eg fracture*
→ *Commence Palliative Care Plan*

GOAL D: COMFORT DURING DYING – TERMINAL CARE (prognosis assessed as hours / days)

❑ All treatment is aimed at relieving symptoms and supporting the Resident and their family / important others. → *NOT FOR TRANSFER TO HOSPITAL UNLESS symptoms cannot be managed in the facility. eg fracture*
→ *Commence Palliative Care Plan*

I have discussed above Goals of Care with ❑ Resident ❑ Medical Treatment Decision Maker *(named above)*

Others involved in discussion _____

Doctor's name (print): _____ Doctor's Designation: _____

Doctor's Signature _____ Date: _____

❑ Review in _____ months *OR* ❑ Review as needed

CPR = Cardiopulmonary Resuscitation
MEPOA = Medical Enduring Power of Attorney EPOA Personal = Enduring Power of Attorney for Personal Matters
MTDM = the person who is the legal medical treatment decision-maker for the Resident who lacks capacity to do this for themself

GCPC Version Sept 2017

Residential Aged Care Facility
GOALS OF CARE
Medical Treatment Orders
(For completion by Doctors only)

AFFIX IDENTIFICATION LABEL HERE
U.R. NUMBER: _____
SURNAME: _____
GIVEN NAME: _____
DATE OF BIRTH: _____/_____/_____ SEX: _____

RACF GOALS OF CARE is a medical treatment order. It describes a medical treatment plan that takes account of:
(i) the Resident's medical illness, illness trajectory and the limits to what is medically feasible; and
(ii) the Resident's preferences and values related to medical treatment, within the limits of what is medically feasible.

RECORD OF DISCUSSION ABOUT TREATMENT GOALS AND LIMITS TO TREATMENT ESCALATION

Date / time *Include details of content of discussion and who was involved*

(date & sign entries; update as needed)

WRITE COMMENTS ON GOAL CATEGORY, IF NEEDED FOR CLARIFICATION OR TO RECORD VARIATIONS
eg. Goal of care is non-burdensome treatment but to receive CPR – tick Box C and write clearly 'FOR CPR'

Ensure a copy of Goals of Care and copies of any Advance Care Planning documents are sent with the Resident if transferring to hospital.

NB this is an example of a Goals of Care form typically used in Aged Care. It is for your reference.

CARING FOR YOURSELF AND OTHERS: UNDERSTANDING GRIEF

Grief affects our thoughts and feelings, how we do things and our relationships with others. It can also have a physical impact. It's important to know that grief is normal, and it affects people in different ways including:

- crying and sadness (or a reluctance to cry)
- anger and irritability
- regret
- feeling numb
- difficulty sleeping and having nightmares
- changes to appetite
- difficulty concentrating and making decisions
- feeling tense, sick and difficulty breathing
- losing interest in family, friends and hobbies
- disorientation and confusion
- nausea and headaches.

There are lots of other reactions to grief. If the person has been in extreme suffering it is common and natural to even feel a sense of relief that their pain has ended. You might not experience all of these feelings, but if you do, they will not necessarily come in any particular order.
Your grief is like your fingerprint. It is unique and personal to you.

Resources

End of life and palliative care for people living with a disability
www.valid.org.au
Easy English resources Developed by Palliative Care Victoria (PCV) and the Victorian Advocacy League for Individuals with Disability (VALID)

The Talking End of Life ...with people with intellectual disability (TEL)
www.caresearch.com.au/tel/

Fact sheets for staff in disability group homes
The Southern Metropolitan Region Palliative Care Consortium have developed a number of fac t sheets for staff in disability group homes who are caring for a resident with a terminal illness.
https://smrpcc.org.au/disability/

Palliative Care Advice Service
1800 360 000 7am-10pm seven days a week
Free Advice for anyone in Victoria

PEPA
Learning guide for disability support workers
www.pepaeducation.com

NOTES PAGE