Department of **Health Western Australia**
**WA Cancer and Palliative Care Network**

# Caring in the last days of life

## Patient and family/carer(s) information

Your needs and wishes are very important at this time. As you know your health is changing. Your health team believes that you are dying and wants to make sure your care needs are met according to your wishes. Please tell us if you need anything, no matter how big or small. We will do our very best to meet your needs now and in the time ahead. You may also want to involve your family and close friends.

We care about what is right for you, so please let us know. We are here to listen, explain, support and comfort you.

### Changes which may occur before death

It is difficult to predict how long the dying process will take. It may be a matter of hours or days or even longer.

You may spend more time sleeping and will often be drowsy when awake. Most people will lapse into unconsciousness. When death is close there may be changes to breathing, skin colour and temperature.

### Comfort

Our staff will support you whether you are awake or asleep. Your comfort, be it physical, emotional and/or spiritual, is our priority.

Your family and close friends may want to assist with your comfort. Our staff will involve them if you and they feel comfortable to do so, for example with mouth or skin care.

### Medication

Medicines that are not helpful may be stopped and new medicines for symptom control will be given, as needed, to help relieve any symptoms and keep you at ease.

### Reduced need for food and drink

A person lying quietly in bed uses very little energy. A decreased energy need is also part of the dying process. Most people will experience a loss of appetite, difficulty swallowing and/or loss of interest in drinking and may not want to eat or drink at this time. However, we will support you to eat and drink for as long as possible and we will be guided by you.

Introducing intravenous drips and feeding tubes may reduce your comfort. Fluids given through a drip will only be administered when it will improve your comfort and not be harmful.

You may experience a dry mouth but this does not mean you are dehydrated. It is very important to keep your mouth clean and moist. If your family and close friends feel comfortable, the nurse will explain how they can provide you with this care.

Caring for you, your family and close friends is important to us. We will continually talk with you and those near to you, according to your wishes, to ensure all know what is happening for you.

**We are here to look after you, so please let us know if we can assist you in any way.**

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**Not to be filed in patient's medical record – please remove this page.**

# Care Plan for the Dying Person

## Guidance for Health Professionals

Dying is both an individual and universal human experience. The dying person must be provided with complete care which responds to their individual needs, wishes and preferences. This includes providing meticulous physical, psychosocial, emotional and spiritual care. Family/carer(s) and others identified as important to the patient are integral and should be involved as part of their care. Excellence in care affirms the dignity and worth of each individual.

The Care Plan for the Dying Person:

- prompts health professionals in holistic care of the dying
- aims to support individualised care and complement clinical judgement
- supports completeness of care and does not preclude any treatment or therapy
- is person-centred; all decisions must be made in the patient's best interests
- must be aligned to the wishes and individual needs of the patient and family/carer(s)
- prioritises goals of care that have been discussed with the patient and family/carer(s)
- is agreed, coordinated and delivered with compassion
- relies on frequent assessment, critical thinking, individualised care planning, decision-making and continuous review
- will be discontinued in the event that the patient's condition improves.

Health professionals must be trained or mentored in use of the Care Plan for the Dying Person. Critical decisions regarding care should always be made in consultation with a senior doctor. A second opinion or specialist palliative care advice can be obtained, as needed.

Good communication is a priority for care especially when it is thought that a person may die in the next few days or hours. All members of the Multidisciplinary Team (MDT) must take time to talk together with the dying person and their family/carer(s) and advise them of any significant change in condition. Good communication within the team and clear documentation is an essential part of care. Priorities for communication include:

- use simple, comprehensive and sensitive communication with both the patient and family/carer(s)
- involve the patient and family/carer(s) in any decisions leading to a change in care
- provide the patient and family/carer(s) with relevant written information as needed.

It is important to be aware that uncertainty is part of caring for the dying person and this should be communicated sensitively to all concerned. A patient who is expected to die may live less or longer than predicted.



DISCLAIMER: This resource was produced by the WA Cancer and Palliative Care Network (WACPCN) in consultation with clinicians. The Care Plan is intended for use by health professionals who have been trained in its use. It is designed as an aid to be used alongside the user's own professional judgement in the care provided to patients. All reasonable efforts have been made to ensure that the information contained in the Care Plan is correct. The WACPCN will not be held responsible for any erroneous care provided using the Care Plan document.

**Not to be filed in patients' medical record – please remove this page.**

This documentation has been developed based on the work of the: International Collaborative for Best Care for the Dying Person

SMHS Version No: 1, Nov 2015 Review date: Nov 2016

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# Care Plan for the Dying Person

## Multidisciplinary Team (MDT) review and decision-making

Seek Specialist Palliative care advice as needed

Patient, family/carers opinions and concerns are responded to and respected

Deterioration in the patient's condition suggests it is likely that the patient will die within the next few days or hours:
- they have a life-limiting illness, and
- reversible causes of deterioration have been excluded

↓

The most senior treating doctor agrees that death is likely and that the Care Plan for the Dying Person (Care Plan) should commence

↓

There is consensus of opinion between the patient and family/carer(s) and MDT that the patient is likely to be dying

↓

The Care Plan commences

↓

Communication with patient*

Communication with family/carer(s)

↓

Review of individual care needs

↓

Ongoing assessment:
- **daily MDT review considers the appropriateness of Care Plan**
- minimum two (2) hourly review of continuing goals of care

→ **Care Plan is ceased**

If patient improves:
- MDT reviews options with patient, family/carer(s)
- consider second opinion and/or referral to specialist palliative care service

↓

Care after death

↓

Communication with family/carer(s)

Care of deceased and other Health Service requirements



Specialist palliative care services are available for advice and support regarding any aspect of care especially if symptom control is difficult and/or there are other communication issues.

* Also refer to the patient's Advance Health Directive and/or Advance Care Plan.

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# CARE PLAN FOR THE DYING PERSON – COMMUNITY

Hospital: .....

Doctor: .....

| Family Name | | UMRN | |
|---|---|---|---|
| First Name | | DOB | Gender |
| Address | | | Postcode |

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## Section 1: Communication with patient

### Record of discussion with patient

**Has the most senior treating doctor agreed that the Care Plan should commence?**
**Yes ☐ No ☐ (If no, do not commence the Care Plan).**

| Doctor's name (print): | Nurse's name (print): |
|---|---|
| Doctor's signature: | Nurse's signature: |
| Date: ___ /___ /_____ at _____ hours | Date: ___ /___ /_____ at _____ hours |

**Names of family/carer(s) present:** _____

**Names of any other professionals present:** _____



### Baseline information

1.1 Describe primary life-limiting illness: _____

1.2 List co-morbidities: _____

1.3 Does the patient have?

- Advance Health Directive (AHD) Yes ☐ No ☐
- Advance Care Plan (ACP) Yes ☐ No ☐
- Enduring Power of Guardianship (EPG) Yes ☐ No ☐
  EPG contact name: _____ Phone: _____
- Instructions to donate tissue/organs Yes ☐ No ☐
- Other (please specify): _____

1.4 The coroner is <u>likely</u> to be involved. Yes ☐ No ☐

1.5 Does the patient require?

- Interpreter Yes ☐ No ☐
- Spiritual/religious advisor Yes ☐ No ☐
- Cultural advisor Yes ☐ No ☐
- Social work referral Yes ☐ No ☐

**If 'YES' is recorded for any of the above questions (1.3 to 1.5), a further action is required and must be recorded on the Action report, Section 7.**

MR723.1 – CARE PLAN FOR THE DYING PERSON

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

1.6 Is the patient able to fully participate in this discussion? Yes ☐ No ☐

If no, describe why the patient is unable to participate e.g. the patient is confused but conscious/semi-conscious/unconscious/other: _____

_____

*If the patient is **unable** to participate in the following discussion, go to Section 2: Communication with family/carer(s).*

1.7 Does the patient understand that they are dying? Yes ☐ No ☐

**If 'NO' is recorded for question 1.7, a further action is required and must be recorded on the Action report, Section 7.**

1.8 It is now important to ask the patient the following questions:

a. What is important for your care now? _____

_____

b. What is important for you at the time of death? _____

_____

c. What is important for you after death? _____

_____

d. In the absence of family/carer(s), who else do you want us to share this information with? _____

_____

e. Is there anything else you need to tell us or ask us? Yes ☐ No ☐

If yes, describe: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

## Section 2: Communication with patient and family/carer(s)

**Record of discussion with patient and family/carer(s)** *Document any details on page 6*

| Doctor's name (print): | Nurse's name (print): |
|---|---|
| Doctor's signature: | Nurse's signature: |
| Date: ____/____/_____ at _____ hours | Date: ____/____/_____ at _____ hours |

**Names of family/carer(s) present:** _____

**Names of any other professionals present:** _____



2.1 Does the patient have a family/carer(s)? Yes ☐ No ☐
In the event there is **no identified family/carer(s),** go to Section 3: Review of care needs.

2.2 Is the family/carer(s) able to fully participate in this discussion? Yes ☐ No ☐
Describe: _____

2.3 Does the family/carer(s) understand the patient is dying? Yes ☐ No ☐

**If 'NO' is recorded for any of the above questions (2.1 to 2.3), a further action is required and must be recorded on the Action report, Section 7.**

2.4 Does the family/carer(s) require?

- Interpreter Yes ☐ No ☐
- Spiritual/religious advisor Yes ☐ No ☐
- Cultural advisor Yes ☐ No ☐
- Social work referral Yes ☐ No ☐

**If 'YES' is recorded for question 2.4, a further action is required and must be recorded on the Action report, Section 7.**

2.5 It is important to ask the family/carer the following questions:

a. What is important for you now? _____

b. What is important for you at the time of the patient's death? _____

c. What is important for you after the patient's death? _____

_____

d. Is there anything else you need to tell us or ask us? Yes ☐ No ☐

If yes, describe: _____

_____

_____

_____

_____

_____

_____

_____

_____



2.6 Who should be contacted in the event of the patient's death?

Name of first contact: _____ Relationship to patient: _____

Phone: _____ At any time ☐ Not overnight ☐

Name of second contact: _____ Relationship to patient: _____

Phone: _____ At any time ☐ Not overnight ☐

## Additional information from family meeting.

| Date | |
|---|---|
| | |
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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

## Section 3: Review of individual care needs

| **Record of discussion with patient and family/carer(s)** | |
|---|---|
| Doctor's name (print): | Nurse's name (print): |
| Doctor's signature: | Nurse's signature: |
| Date: ____ /____ /_____ at _____ hours | Date: ____ /____ /_____ at _____ hours |
| **Names of family/carer(s) present:** _____ | |
| **Names of any other professionals present:** _____ | |



3.1 Will the patient have MET/MER calls in response to current/further deterioration? Yes ☐ No ☐

**If 'YES' is recorded for question 3.1, a further action is required and must be recorded on the Action report, Section 7.**

3.2 Does the patient have a "Do Not Attempt Cardiopulmonary Resuscitation Order" in place? Yes ☐ No ☐

3.3 Implantable Cardioverter Defibrillator (ICD) is deactivated? N/A ☐ Yes ☐ No ☐

3.4 Has the team discussed ongoing Permanent Pacemaker (PPM) management with the patient and family/carer(s)? N/A ☐ Yes ☐ No ☐

3.5 Is the patient's skin being assessed? Yes ☐ No ☐

Risk assessment tool e.g. Braden: _____ Score: _____

If additional equipment is required please describe: e.g. pressure relieving mattress.

_____

**If 'NO' is recorded for question 3.2 to 3.5, a further action is required and must be recorded on the Action report, Section 7.**

3.6 Is the patient experiencing urinary and/or bowel problems? Yes ☐ No ☐

**If 'Yes' is recorded for question 3.6, a further action is required and must be recorded on the Action report, Section 7.**

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

3.7 At the time of the assessment: ( ☑ tick all applicable)

| Is the patient currently? | Yes | No | Is medication prescribed and available for? | Yes | No |
|---|---|---|---|---|---|
| Free of dyspnoea | ☐ | ☐ | Dyspnoea | ☐ | ☐ |
| Free of nausea and vomiting | ☐ | ☐ | Nausea and vomiting | ☐ | ☐ |
| Pain free | ☐ | ☐ | Pain | ☐ | ☐ |
| Not troubled by respiratory tract secretions | ☐ | ☐ | Respiratory tract secretions | ☐ | ☐ |
| Free of agitation | ☐ | ☐ | Agitation | ☐ | ☐ |
| Describe other symptoms: _____ | | | | | |

**Considerations:**
- Current medication assessed and non-essentials discontinued
- Medications are prescribed and available for any of the above symptoms on a prn basis
  This will ensure that there is no delay in response if a symptom occurs
- Refer to "Evidence based clinical guidelines for adults in the terminal phase" (EBCG flipbook).

**If 'No' is recorded for question 3.7, a further action is required and must be recorded on the Action report, Section 7.**



3.8 Have current interventions been assessed and non-essentials discontinued?
( ☑ tick all applicable)

| | Not applicable | Commenced | Continued | Discontinued |
|---|---|---|---|---|
| Routine blood tests | ☐ | ☐ | ☐ | ☐ |
| Clinically assisted hydration<br>IV☐ Port☐ Subcut☐ PEG/PEJ☐ NG/NJ☐ | ☐ | ☐ | ☐ | ☐ |
| Clinically assisted nutrition<br>PEG/PEJ☐ NG/NJ☐ TPN☐ | ☐ | ☐ | ☐ | ☐ |
| Intravenous antibiotics | ☐ | ☐ | ☐ | ☐ |
| Anticoagulant therapy | ☐ | ☐ | ☐ | ☐ |
| Blood glucose monitoring | ☐ | ☐ | ☐ | ☐ |
| Routine vital signs | ☐ | ☐ | ☐ | ☐ |
| Oxygen therapy | ☐ | ☐ | ☐ | ☐ |
| Other(s), describe: _____ | ☐ | ☐ | ☐ | ☐ |

**Consideration:**
The patient should be supported to take fluids and nutrition by mouth for as long as tolerated.

3.9 Is the patient experiencing any other issues? Yes ☐ No ☐

**If 'Yes' is recorded for the above question 3.9, a further action is required and must be recorded on the Action report, Section 7.**

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

## Section 4: Continuing goals of care

| | **Care Plan Day:** | | **Care Plan Day:** | | **Care Plan Day:** | |
|---|---|---|---|---|---|---|
| | **Visit date:** | | **Visit date:** | | **Visit date:** | |
| Code a Y or N at each timed assessment | **Time** | **Y/N** | **Time** | **Y/N** | **Time** | **Y/N** |
| **Symptom management** | | | | | | |
| Is the patient: **Y = Yes N = No** | | | | | | |
| Free of dyspnoea | | | | | | |
| Free of nausea and vomiting | | | | | | |
| Free of pain | | | | | | |
| Not troubled by respiratory tract secretions | | | | | | |
| Free of restlessness/agitation | | | | | | |
| Free of other symptoms _____ | | | | | | |
| Free of urinary problems | | | | | | |
| Free of bowel problems | | | | | | |
| **Personal comfort care** | | | | | | |
| Have actions been taken to ensure the patient/patient's: **Y = Yes N = No** | | | | | | |
| Receives fluids to support needs | | | | | | |
| Mouth is clean and moist | | | | | | |
| Personal hygiene needs are met | | | | | | |
| Skin care needs are met | | | | | | |
| Eyes are clean and moist | | | | | | |
| Physical environment is adjusted to support needs | | | | | | |
| Emotional needs are met | | | | | | |
| Is comfortably positioned | | | | | | |
| **Patient/family care** | | | | | | |
| Have actions been taken to ensure that: **Y = Yes N = No** | | | | | | |
| Procedures/care plan are explained | | | | | | |
| Information regarding change is provided | | | | | | |
| Family/carer is supported | | | | | | |
| **If 'NO' is recorded for any of the above, a further action is required and must be recorded on the Action report, Section 7.** | | | | | | |
| **Nurse's name** | | | | | | |
| **Nurse's signature** | | | | | | |

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

## Section 4: Continuing goals of care

| | **Care Plan Day:** | | **Care Plan Day:** | | **Care Plan Day:** | |
|---|---|---|---|---|---|---|
| | **Visit date:** | | **Visit date:** | | **Visit date:** | |
| Code a Y or N at each timed assessment | **Time** | **Y/N** | **Time** | **Y/N** | **Time** | **Y/N** |
| **Symptom management** | | | | | | |
| Is the patient: **Y = Yes N = No** | | | | | | |
| Free of dyspnoea | | | | | | |
| Free of nausea and vomiting | | | | | | |
| Free of pain | | | | | | |
| Not troubled by respiratory tract secretions | | | | | | |
| Free of restlessness/agitation | | | | | | |
| Free of other symptoms _____ | | | | | | |
| Free of urinary problems | | | | | | |
| Free of bowel problems | | | | | | |
| **Personal comfort care** | | | | | | |
| Have actions been taken to ensure the patient/patient's: **Y = Yes N = No** | | | | | | |
| Receives fluids to support needs | | | | | | |
| Mouth is clean and moist | | | | | | |
| Personal hygiene needs are met | | | | | | |
| Skin care needs are met | | | | | | |
| Eyes are clean and moist | | | | | | |
| Physical environment is adjusted to support needs | | | | | | |
| Emotional needs are met | | | | | | |
| Is comfortably positioned | | | | | | |
| **Patient/family care** | | | | | | |
| Have actions been taken to ensure that: **Y = Yes N = No** | | | | | | |
| Procedures/care plan are explained | | | | | | |
| Information regarding change is provided | | | | | | |
| Family/carer is supported | | | | | | |
| **If 'NO' is recorded for any of the above, a further action is required and must be recorded on the Action report, Section 7.** | | | | | | |
| **Nurse's name** | | | | | | |
| **Nurse's signature** | | | | | | |

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

## Section 5: Care Plan for the Dying Person (Care Plan ceased)

**Record of discussion with patient and family/carer(s)**

**Has the MDT agreed that the Care Plan should be ceased?** Yes ☐ No ☐

| Doctor's name (print): | Nurse's name (print): |
|---|---|
| Doctor's signature: | Nurse's signature: |
| Date: ____/____/_____ at _____ hours | Date: ____/____/_____ at _____ hours |

**Names of family/carer(s) present:** _____

**Names of any other professionals present:** _____

5.1 Reason(s) why the Care Plan was ceased: _____

5.2 Outline of discussion with patient and family/carer(s) including revised plan of care: _____

5.3 Does the patient require referral to a specialist palliative care service? Yes ☐ No ☐

Describe reason for referral: _____

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

## Section 6: Care after death

| Doctor's name (print):<br>Doctor's signature:<br>Date: ____/____/_____ at _____ hours | Nurse's name (print):<br>Nurse's signature:<br>Date: ____/____/_____ at _____ hours |
|---|---|
| **Names of family/carer(s) present:** _____ | |
| **Names of any other professionals present:** _____ | |

Date of death: _____ Time of death: _____

Persons present at the time of death: _____

If family/carer(s) not present, have they been notified? Yes ☐ No ☐

Name of person informed: _____

Relationship to patient: _____ Phone: _____



| | | | | |
|---|---|---|---|---|
| **Patient care** | 6.1 | Care of the body has been undertaken according to health service policy/procedure. | Yes ☐ | No ☐ |
| **Family/ carer(s)** | 6.2 | The family/carer(s) has been provided with information regarding next steps. | Yes ☐ | No ☐ |
| **Health service** | 6.3 | Other documentation has been completed according to health service policy/procedure: | | |
| | | • life extinct form N/A ☐ | Yes ☐ | No ☐ |
| | | • death certificate | Yes ☐ | No ☐ |
| | | • cremation certificate N/A ☐ | Yes ☐ | No ☐ |
| | | • discharge letter | Yes ☐ | No ☐ |
| | 6.4 | The death is communicated according to health service policy/procedure: | | |
| | | • primary health care team/GP | Yes ☐ | No ☐ |
| | | • hospital census/data base | Yes ☐ | No ☐ |

**If 'No' is recorded for any of the above questions (6.1 to 6.4), a further action is required and must be recorded on the Action report page.**

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

## Section 7: Action Report

**Important:** Report any issue arising from previous sections. Describe further action item, MDT actions and outcomes for care.

| Item for further action | Action taken | Outcome |
|---|---|---|
| Date/time: _____ | | Name: _____<br>Designation: _____<br>Signature: _____<br>Date/time: _____ |
| Date/time: _____ | | Name: _____<br>Designation: _____<br>Signature: _____<br>Date/time: _____ |
| Date/time: _____ | | Name: _____<br>Designation: _____<br>Signature: _____<br>Date/time: _____ |
| Date/time: _____ | | Name: _____<br>Designation: _____<br>Signature: _____<br>Date/time: _____ |
| Date/time: _____ | | Name: _____<br>Designation: _____<br>Signature: _____<br>Date/time: _____ |

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|---|---|---|---|
| | First Name | DOB | Gender |
| | Address | | Postcode |

## Section 8: Integrated progress notes

**Important:** Report the following: changes in condition, **minimum daily MDT review** including appropriateness of Care Plan, and ongoing care, significant events/conversations/visits, or other.

| Date | Time | Notes |
|---|---|---|
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