Personalised Care Record Policy for Dying Adults in the Expected Last Days of Life

January 2020

DOCUMENT PROFILE

Document Registration	HSS-PP-CG-0561-01 PPPG-CE-00073-20191113-v1
Document Type	Policy
Short Title	Care of dying adults in the last days of life
Author	Nicola Bailhache, Gail Edwards
Publication Date	13 November 2019
Target Audience	HCS, JHC, FNHC, PCB, Jersey Care Federation
Circulation List	HCS, JHC - Clinical Effectiveness, PCB, FNHC, Jersey Care Federation
Description	To provide guidance and documentation to all health care professionals caring for dying adults in their expected last days of life
Linked Policies	The Capacity and Self-Determination (Jersey) Law 2016 Code of Practice , Rapid Discharge, Care of the Deceased (Adult) Guideline in HSS, Ambulatory Syringe Pump Policy, Anticipatory Prescribing Policy, DNACPR policy and other organisations policies on Care of the Deceased
Approval Forum	Policy and Procedure Ratifying Group End of Life Care Implementation Steering Group
Review Date	3 years from approval
Contact Details	01534 876555

HSS-PP-CG-0561-01

CONTENTS LIST:

1. INTRODUCTION

1.1 Rationale

People approaching their last days of life have rapidly changing needs that require a different focus for their care concentrating on comfort, dignity and excellent communication.
Following the withdrawal of the Liverpool Care Pathway (LCP) a national coalition of organisations called the Leadership Alliance for the Care of Dying People (LACDP) published guidance in the "One Chance to get it Right" document (LACDP, 2014) and the National Institute for Health and Clinical Excellence (NICE) in their guideline "Care of dying adults in the last days of life" (NICE, 2015). The coalition recommend that the five priorities for care of the dying person be implemented when it is thought that a person may die within the next few days or hours. These are:

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person and those identified as important to them.
3. The dying person, and those identified as important to them are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support is agreed, co-ordinated and delivered with compassion.

In Jersey, the Gold Standards Framework (GSF) is used and HCPs are encouraged to identify the needs of a patient alongside their prognosis (this coding system is described in the glossary). Patients in the last days of life are coded as GSF Red.

Over the last two years a Personalised Care Record for the Expected Last Days of Life (PCR) was piloted across the Hospice, the Community and the Hospital (Appendix 1). This closely follows the five priorities for the care of the dying person. It was developed by a local Task and Finish Group with representation from Jersey General Hospital, Jersey Hospice Care, Family Nursing and Home Care, Primary Care Body and the Care Federation.

An audit of the pilot projects in all three care settings compared care of the dying person using the PCR or the organisation's standard documentation. Those patients whose care was planned using the PCR had improved documentation of:

- Communication with the patient and family about prognosis
- Discussion with the family around hydration and nutrition
- Spiritual care
- Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) discussions
- The likelihood of a holistic assessment
- Symptom control

1.2 Scope

This policy is intended to be used by registered clinical professionals who manage adult (aged over 18) patients in the last days of life within Jersey Health and Social Services Department (HSSD), Family Nursing & Home Care (FNHC), Primary Care Body (PCB), Jersey Hospice Care (JHC) and Nursing and Residential Care Homes.

The above organisations are encouraged to develop their own Standard Operating Procedures addressing the following areas:

- The seniority and competency of the health care professionals involved in the Multi-Disciplinary Team (MDT) recognition of the last days of life
- The seniority and competency of the nurses and doctors involved in regular medical or senior nurse review
- Ensuring ongoing staff training and compliance with this policy (with support from JHC)
- Ensuring care of patients in the last days of life is audited and fed back to the authors of this policy, clinical managers and care providers.

1.3 Principles

The LACDP organisations, which Jersey Health Care Professionals (HCPs) are members of, committed to ensuring that all care given to people in the last days and hours of life:

- is compassionate
- is based on and tailored to the needs, wishes and preferences of the dying person and, as appropriate, their family and those identified as important to them
- includes regular and effective communication between the dying person and their family and health and care staff and between health and care staff themselves
- involves assessment of the person's condition whenever that condition changes and timely and appropriate responses to those changes
- is led by a senior responsible doctor and a lead responsible nurse, who can access support from specialist palliative care services when needed
- is delivered by doctors, nurses, carers and others who have high professional standards and the skills, knowledge and experience needed to care for dying people and their families properly.

2. POLICY / GUIDELINE PURPOSE

All adult patients aged over 18 years who have been recognised to be in the last days of life (GSF red) should have their care guided by the five priorities for the care of the dying patient. The PCR has demonstrated improvement in the application of the five priorities and it is expected that it will be used in all patients who are thought to be in the last 2-3 days of life and in whom there is no reversible cause for their deterioration.

3. PROCEDURE

3.1 Roles and Responsibilities

Divisional / departmental managers, ward managers, care home managers, team leaders, clinical consultants and any others identified within each organisation as involved with staff management are responsible for the implementation and compliance with this policy within their clinical teams. Individual healthcare professionals are also accountable for their own practice.

3.2 Recognition

The recognition that a person is in the expected last days of life and that there is no reversible cause must be a MDT decision involving at least; a senior doctor (General Practitioner, Consultant or Specialist doctor) and nurse involved in the patient's care. The dying person and those identified as important to them, should be involved in recognition to the extent that the dying person wants. See page 5 of the PCR for further information.

3.3 Communication

Sensitive communication with the patient, if they have capacity to take part in the conversation and those identified as being important to them should include:

- the reason why the patient is expected to die and any concerns they may have about the diagnosis and care plan
- discussing changes such as treatment and monitoring focusing on comfort and dignity, medications and interventions, or stopping the National Early Warning Score (NEWS2)
- discussing the wishes of the patient, including their preferred place of death and prior organ and tissue donation decisions
- plans for hydration and nutrition as per GMC guidance in "Treatment and care towards the end of life" (General Medical Council, 2010)
- the plan for symptom control including anticipatory prescribing and the possible use of an ambulatory syringe pump

The PCR will help guide the HCP through this discussion. NEWS2 will be replaced by the Symptom and Care Chart (SCC) (Appendix 2) which is part of the PCR documentation.

3.4 Capacity and decision making

Some patients will lack capacity to make some decisions. However, they may have already taken steps to ensure their preferences are known:

- in written form using an Advance Decision to Refuse Treatment (ADRT) which will advise on treatments they would not want
- with a person who has been legally appointed as a Lasting Power of Attorney for Health and Welfare (LPA) for the patient and who will make decisions on their behalf

You should ask if your patient has any of the above in place and you must respect them.

Sometimes a patient who lacks capacity may not have made any legal arrangements regarding decision making. In such circumstances, decisions are made using best interests. The Capacity and Self-Determination (Jersey) Law 2016 Code of Practice explains how to make best interest decisions on behalf of people who lack capacity. This includes consulting with family and carers who can give written or verbal information to the multi-disciplinary team or decision-maker.

3.5 Documentation

The PCR is divided into three sections:

- Part 1: This section includes the MDT recognition of the dying phase, communication of this with the patient and family, a clinical management plan, a section if the PCR is suspended because the patient has improved and a section for after death.

- Part 2: includes 10 care plans and the MDT communication sheets for documentation of care.

- Symptom and Care Chart (SCC): that will be used to record symptom control and care and comfort measures.

Not all the care plans will be needed; healthcare professionals are expected to use those they assess as relevant to their patient's needs.

All documentation of care and clinical decision making should be in the PCR. This is for all members of the MDT to use and share.

The documentation must be kept in the patient's care setting and those identified as close to the patient should be allowed to read it and explanations should be offered. If the patient transfers to another care setting with a different organisation e.g. from JGH to JHC, the PCR and SCC should accompany the patient and JGH should take photocopies for their records. The patient should also transfer with their DNACPR form, copy of their drug charts and a transfer letter with relevant clinical details and other requirements according to the discharge policy of the transferring organisation.

If the documentation is not available the HCPs will still be expected to care for the patient and their family along the principles outlined in the PCR and this policy.

3.5.1 Documentation in the community setting

Patients who are identified as GSF amber, that is with a prognosis of weeks, and whose preferred place of death is home will be encouraged to keep the PCR in a yellow folder in their home in case it is needed in the future, this will be alongside other documentation such as the DNACPR order and anticipatory medication charts.

If a GP visiting his/her patient recognises that the patient is now in the last days of life with no reversible cause, the GP should inform the senior nurse from the team leading the patient's end of life care by telephone and fill in the doctor section of the PCR.

3.5.2 Documentation after death

If the patient dies on the In-Patient Unit (IPU), the original copy of the PCR document must be retained for filing in the patient's medical records and scanned onto EMIS.

If the patient dies within a care home setting the original copy of the PCR document must be retained for filing in the patient's records and scanned onto EMIS by FNHC, JHC or GP depending on which organisation is leading the patient's end of life care.

If the patient dies in a private home, the original copy must be removed from the house and retained for filing and scanned onto EMIS by FNHC or JHC depending on which organisation is leading the patient's end of life care. If neither FNHC nor JHC are involved in the patient's care the GP will be responsible for removing the record, retaining it and scanning it onto EMIS.

If the patient dies in JGH, the original copy will be filed in the patient's notes.

Responsibility for obtaining a copy of the PCR, if required in accordance with individual organisational polices, lies with the HCPs involved from those organisations.

3.6 Review

Regular review of the patient's condition should be undertaken by a doctor or senior nurse as per the organisation's SOP. The review should identify symptom and communication issues and involve and support those closest to the patient.

In some cases the patient's condition may improve and if the MDT assess that the patient is no longer in the last days of life and now has a longer prognosis, the PCR should be revoked and the patient's care should be documented as per the organisation's normal practice.

The SCC should be completed four-hourly in an inpatient setting and on each nurse's visit in the community setting. If the patient scores 2 or more on this chart, symptom control measures e.g. medication or mouth care should be offered and review should be continued more frequently until symptoms are controlled, after which the nurse should return to the previous frequency of observation.

3.7 Patient / Carer Information

A leaflet called "Coping with Dying" (Appendix 4) should be given to those identified as close to the patient when the PCR is commenced. This is available on HCSnet and the JHC website: http://www.jerseyhospicecare.com/wp-content/uploads/2016/08/04.08.16-Coping-with-Dying-leaflet-V4-Ratified.pdf

3.8 Care of patient and family / carers after death

Each organisation's own policy should be followed for care of the deceased. Please remember to support those important to the patient with information and bereavement leaflets available on HSSnet and JHC website: https://www.jerseyhospicecare.com/our-services/community-bereavement-service/

4. DEVELOPMENT AND CONSULTATION PROCESS

The PCR was developed by a Task and Finish Group whose regular members are listed in the schedule below:

4.1 Consultation Schedule

Name and Title of Individual	Date Last Consulted
Dr Tim Harrison, Consultant in Palliative Medicine, JGH & JHC	11-10-2019
Dr Nicky Bailhache Associate Specialist in Palliative Medicine, JGH & JHC	11-10-2019
Dr Jon Bevan, Consultant Physician, JGH	11-10-2019
Gail Edwards, Nurse Champion, Education Team, JHC	11-10-2019
Sandra Keogh–Bootland, Senior Clinical Audit and Effectiveness Officer, JGH	11-10-2019
Imelda Noonan, CNS, JHC	
Dr Jenny Du Feu, Staff Grade JHC	20-09-2019
Tim Hill, Practice Development Nurse, JGH	11-10-2019
Ann Appleton, Care Federation	
Jessica Clark, District Nurse FNHC	
Tia Hall, Operational Lead Adult Services FNHC	
Sharon Pentony, Nurse Team Leader, Mental Health, HCS	
Dr Kirsi Jaakola, GP EOLC Champion	11-10-2019
Dr Ben Rogers, GP EOLC Champion	11-10-2019
Dr Steve Perchard, GP EOLC Champion	11-10-2019

Name of Committee/Group	Date of Committee / Group meeting
Chief Nurse Group	25-10-2019
Associate Medical Director Group	6-11-2019
Clinical Effectiveness, JHC	16-10-2019

5. REFERENCE DOCUMENTS

LACDP, 2014. *One Chance to get it Right.*
National Institute for Health and Care Excellence, 2015. *Care of dying adults in the last days of life ,* London: NICE.
General Medical Council, 2010. *Treatment and care towards the end of life: good practice in decision making* , paragraphs 112-127.

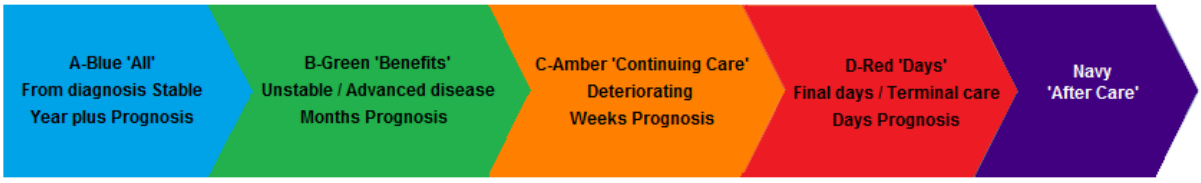
6. BIBLIOGRAPHY

National Palliative and End of Life Care Partnership, 2015. *Ambitions for palliative and end of life care: A national framework for local action 2015-2020,* s.l.: s.n.
National Institute for Health and Care Excellence, 2017. *Care of the dying adult in the last days of life, quality standard 144,* s.l.: NICE.
Neuberger, J., 2013. *More Care Less Pathway,*
Royal College of Physicians, 2016. *End of Life Care Audit – Dying in Hospital.,* London

7. GLOSSARY OF TERMS / KEYWORDS AND PHRASES

Capacity is the concept which refers to an individual having the ability to make a specific decision at the time it needs to be made. This assumption can only be overridden if the person concerned is assessed as lacking the capacity to make a particular decision for him or herself at the relevant time.

The Gold Standards Framework (GSF) is a systematic, evidence based approach to optimising care for all patients approaching the end of life, it uses the following prognostic indicator guideline:



- Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)
- General Medical Council (GMC)
- Leadership Alliance for the Care of Dying People (LACDP)
- Liverpool Care Pathway (LCP)
- Multi-Disciplinary Team (MDT)
- National Early Warning Score (NEWS)
- National Institute for Health and Care Excellence (NICE)
- Personalised Care Record for the Expected Last Days of Life (PCR)
- Symptom and Care Chart (SCC)

8. IMPLEMENTATION PLAN

Managers of each organisation should ensure that all staff are made aware of this policy.

Education will be required prior to the use of the PCR and the SCC. Each organisation will be responsible for the education and competency of their staff involved in caring for the dying person.

A brief educational package will be developed to cover the following components:

- Context: framing within the five priorities of care with an emphasis on the benefits to the individual, family and staff
- Use of the PCR and Symptom and Care Chart (SCC)
- Questions and discussion

This package will be delivered to staff with an educational role within targeted organisations to allow them to cascade the training to their staff.

Action	Responsible Person	Timeframe
Develop brief educational package with guidance notes	Gail Edwards & Dr Nicky Bailhache	
Convene core group of educational staff to identify informal and formal opportunities and deliver package to identified areas as below: • JHC • HCS • FNHC • Primary Care • Care Federation	Dr Julie Luscombe Gail Edwards, Judy Le Marquand & SPCT Wendy Baugh TBC Dr Nicky Bailhache Gail Edwards	
Delivery of educational package • Maintain training log	All delivery team as above	

9. APPENDICIES

Appendix 1 Personalised Care Record for the Expected Last Days of Life (PCR) Part 1

URN:

Name:

Date of Birth:

Address:

ADDRESSOGRAPH

CONSULTANT/ GP			
CARE SETTING			
DATE			

Personalised Care Record for the expected last days of life Part 1 – Recognition and Communication

This care record is designed to support best possible clinical care at the end of life in accordance with the person's needs and wishes.

It is a multi-organisational document to be used by all professionals and is to be shared with the person, their family and carers. Each organisation should comply with their own policies and procedures.

If there is any content that you would like more information on, please contact the professionals that are currently providing care.

Name		DOB		URN	

Guidelines for staff

This replaces all other nursing and medical documentation excluding medication charts.

1. This care record is designed to record the communication and collaboration between the multi-professional team, individual adult patients and their family / carers.
2. If you require any additional support and advice please contact the Specialist Palliative Care Team Jersey Hospice Care (JHC) on 01534 876555.
3. For guidance on symptom management at the end of life please refer to local guidelines for symptom management. Available on JHC website and HCS intranet.
4. In the community this document should stay with the patient and be adapted to their needs and wishes.
5. In hospital the document is held in the notes and replaces existing nursing and medical documentation and should be adapted to the patient's needs and wishes.
6. On discharge from hospital the document must be photocopied, the original is to be transferred with the patient and the copy filed in the patient's medical notes.

Health Care Professional Record

All people involved in decision making and delivery of care, please complete and sign below

Full Name (Print)	Signature	Initials	Designation	Date

1

Name		DOB		URN	

Priorities of Care of the Dying Person

1. Recognise

The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly. Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.

2. Communicate

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. Involve

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

4. Support

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

5. Plan & Do

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Leadership Alliance for the Care of Dying People (2014) One Chance to Get it Right. Improving people's experience of care in the last few days and hours of life.

2

Name _____ DOB _____ URN _____

Person's Details

Name: _____

Preferred Name: _____

Address: _____

_____

Post Code: _____

Home Telephone: _____

Mobile Telephone: _____

Religion / Faith: _____

GP: _____

Address: _____

_____

_____ Post Code: _____

Telephone No: _____

_____

Communication Barrier:
(please state) _____

Language Service Assistant required: Yes / No

Family/Carer Assistance used: Yes / No

Name: _____

Telephone No: _____

Language: _____

Big Word required: _____ Yes / No

Big Word access code: _____

BOOKING a Language Service Assistant / Interpreter:

During office hours (09:00-17:00) contact 01534 442460 or email hss.interpreter@health.gov.je
Out of hours – refer to theBigword if appropriate (access codes are available for the service).

Contact hospital switchboard 01534 442000 for advice if the person is audibly impaired.

Next of Kin's Details

Name: _____

Relationship to patient: _____

Address: _____

_____

Post Code: _____

Telephone No. day: _____

Telephone No. night: _____

Mobile Telephone: _____

Able to contact anytime (please state):

_____

Communication Barrier:
(please state) _____

Language Service Assistant required: Yes / No

Family / Carer Assistance used: Yes / No

Name: _____

Telephone No: _____

Language: _____

Big Word required: _____ Yes / No

Big Word access code: _____

Name _____ DOB _____ URN _____

Designated Clinical Team

Consultant / GP (please circle) Telephone No: _____

Print Name: _____ Date: _____

Transfer of Care to another Clinical Team or Care Setting

Ensure direct communication with new clinical team via telephone / fax / email. (Please circle method used)
Please contact JDoc (Tel: 01534 444341) to confirm transfer of care.

Name of new Consultant / GP: (please circle)

_____ Date: _____

Care Setting:

_____ Date: _____

Name of new Consultant / GP: (please circle)

_____ Date: _____

Care Setting:

_____ Date: _____

Capacity and Decision Making

If your patient is able and wishes to, it is important to discuss the multi-disciplinary team's recognition that they are now in the last days of life, recording what their preferences are and looking at how their care plan will change.

Some patients will lack capacity to make some decisions. However, they may have already taken steps to ensure their preferences are known:

- in written form using an Advance Decision to Refuse Treatment (ADRT) which will advise on treatments they would not want
- with a person who has been legally appointed as a Lasting Power of Attorney for Health and Welfare (LPA) for the patient and who will make decisions on their behalf

You should ask if your patient has any of the above in place and you must respect them.

Sometimes a patient who lacks capacity may not have made any legal arrangements regarding decision making. In such circumstances, decisions are made using best interests. The Capacity and Self-Determination (Jersey) Law 2016 Code of Practice explains how to make best interest decisions on behalf of people who lack capacity. This includes consulting with family and carers who can give written or verbal information to the multi-disciplinary team or decision-maker.

Name _____ DOB _____ URN _____

DOCTORS

Recognition of Dying

The term 'recognition of dying' is used to define a time when someone is now thought to be approaching the last days of their life.

All possible reversible causes for current condition have been considered and the person is now thought to be entering the last hours or days of life for the following reasons:

Diagnosis: _____

Symptoms of dying phase: _____

Who did you discuss this with?

Patient Yes ☐ No ☐ If no, why? (e.g. lack of capacity, patient declines discussion) _____

Family Name: _____ Relationship to patient: _____

LPA Name: _____ MUST BE CONTACTED

Other Name: _____ Relationship to patient: _____

What did you say?

Any concerns voiced, by whom and action taken?

Agreed frequency of medical or senior nurse review (e.g. Daily):

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Form completed to allow a natural death	Yes ☐	No ☐	If no, why?
Implantable Cardioverter Defibrillator (ICD) deactivated?	Yes ☐	N/A ☐	
Is there an existing Advance Decision to Refuse Treatment (ADRT) to refer to?	Yes ☐	No ☐	
Does the patient have a LPA for Health and Welfare?	Yes ☐	No ☐	
If there is an Advance Care Plan (which may include tissue and organ donation), have the patient's wishes been respected?	Yes ☐	No ☐	N/A ☐

Where are these documents? _____

Name		DOB		URN	

DOCTORS

Recognition of Dying

Document which medical / nursing interventions you have reviewed and discontinued. These may include blood tests i.e. blood glucose monitoring, x-rays / scans, National Early Warning Score (NEWS2) observations chart and reviewing regular medications:

NEWS2 discontinued by:	Signature:		Designation:	
	Date:		Time:	

Anticipatory medications for pain, dyspnoea, agitation, nausea and respiratory secretions discussed and prescribed:	**Yes** ☐ **If no** ☐ **Why?** .....
Possible use of syringe pump discussed:	**Yes** ☐ **If no** ☐ **Why?** .....

Communication with patient / family / carers regarding Nutrition and Hydration

Document discussions you have had with the patient / family /carers around what to expect during the dying process with regards to **food and fluids** (which may include oral, enteral feed / parenteral fluids):

Gold Standards Framework register updated in GP Surgery:		**Yes**	☐	**No**	☐
(Please initial once completed)	☐	Date:			

Preferred Place of Death (PPD):	**1st Choice**	**2nd Choice**

If person wants to return home to die please support Rapid Discharge procedures.

Responsible Doctor's Signature:		**Designation:**	
Print Name:		**Date:**	
***Responsible Doctor should be a Consultant / GP or Specialist Doctor**		**Time:**	

Name _____ DOB _____ URN _____

Spiritual Care

- Enquire about and respect any religious / faith or cultural specific requirements that are considered important to the patient, family or carer e.g. Last Rites.
- Support timely involvement of chaplaincy / spiritual leaders where this is required:

Document identified needs and action taken: _____

_____

_____

_____

Name and role of spiritual advisor: _____

Telephone Number: _____

Suspension of the PCR

The PCR should be suspended if the patient's condition improves and the MDT no longer believes the patient to be in the last days of life. The documentation should then revert to the organisation's normal records.

Suspended by: _____ Signature: _____ Designation: _____

Date: _____ Time: _____

How was the suspension of the PCR communicated with the patient / family / carers?

If the patient's condition deteriorates and the MDT again recognises that they are likely to be in the last hours or days of life please document below (or consider starting a new PCR, if the patient has been stable for weeks).

How was the recommencement of the PCR communicated with the patient / family / carers?

Name _____ DOB _____ URN _____

Support of Family and Carers

- Be aware and address any concerns or information needs expressed by the family / significant others whilst observing the patient's confidentiality and consent
- Consider early referral for emotional support by contacting the Community Bereavement Service on 285144
- Explore if the patient has any worries or fears which may need discussion
- Carer leaflet (Coping with Dying) given: Yes ☐ No ☐

  Who to: _____

Please document concerns raised / discussion

Date:	Time:		Signature:

8

Care of patient and family / significant others after death

Confirmation of death. (Follow own organisation's policy)

Date of death:	**Time of death:**	Actual place of death:	
		PPD:	

Reason if preferred place of death not achieved:

Persons present at time of death and relationship to the deceased (including professionals)

If not present, has the patient's family / significant others been informed?	Yes	☐	No	☐	No family / significant others	☐	
If no state reason:							
Name of person informed:		Relationship:					
Telephone number:							

Name of HCP verifying death:	**Date:**	**Time:**
Name of Doctor confirming death:	**Date:**	**Time:**
Name of Doctor certifying death:	**Date:**	**Time:**

Please record death confirmation in the HCPs own organisation's records as well as the PCR

If death occurs in hospital please complete PS47 form	**Signature:**

Referred to Deputy Viscount	☐	**Burial**	☐	**Cremation**	☐	**Funeral Director**	

Relative and Carer Support and Guidance

- Offer family and significant others present, the opportunity to participate in preparing the deceased person for transfer to the mortuary or funeral directors premises
- Allow opportunity and time for further questions
- Provide Jersey General Hospital Bereavement leaflet if appropriate
- Provide information on Jersey Hospice Care Community Bereavement Services
- Provide information on Jersey Hospice Care Community Bereavement Services

Please fax this page to the patient's GP

9

9. APPENDICIES Appendix 2: Personalised Care Record for the Expected Last Days of Life: Part 2 (PCR)

After death contact check list				
Date	Professionals to be informed as relevant	Name of professional	Tel No	Completed by
	G.P.			
	Specialist Palliative Care Team			
	Family Nursing & Home Care			
	Home Care Providers			
	Medical Records/TRAK			
	Jersey Care Commission			
	Oncology			
	Wards/Care Home			
	Consultants involved in patient's care			
	Physiotherapist			
	Occupational Therapist			
	Social Worker			
	Clinical Nurse Specialist involved in patient's care			
	Spiritual Advisor			
	Cancer Relief			
	Equipment Providers			
	Volunteers			
	Others			
Community Action Required				
	Advise family re safe disposal of medication			
	Complete Anticipatory Prescribing outcome form			
	Remove Just in Case Box			
	Remove Syringe Pump			
	Remove Wendylett sheets			
	Remove Sharps box			
	Organise equipment return			

URN:

Name:

Date of Birth:

Address:

ADDRESSOGRAPH

CONSULTANT/ GP			
CARE SETTING			
DATE			

Personalised Care Record for the expected last days of life Part 2 - Care

This care record is designed to support best possible clinical care at the end of life in accordance with the person's needs and wishes.

It is a multi-organisational document to be used by all professionals and is to be shared with the person, their family and carers. Each organisation should comply with their own policies and procedures.

If there is any content that you would like more information on, please contact the professionals that are currently providing care.

Name		DOB		URN	

Guidelines for staff

This replaces all other nursing and medical documentation excluding medication charts.

1. This care record is designed to record the communication and collaboration between the multi-professional team, individual adult patients and their family / carers.
2. If you require any additional support and advice please contact the Specialist Palliative Care Team Jersey Hospice Care (JHC) on 01534 876555.
3. For guidance on symptom management at the end of life please refer to local guidelines for symptom management. Available on JHC website and HCS intranet.
4. In the community this document should stay with the patient and be adapted to their needs and wishes.
5. In hospital the document is held in the nursing notes and replaces existing nursing documentation and should be adapted to the patient's needs and wishes.
6. On discharge from hospital the document must be photocopied, the original is to be transferred with the patient and the copy filed in the patient's medical notes.

Health Care Professional Record

All people involved in decision making and delivery of care, please complete and sign below

Full Name (Print)	Signature	Initials	Designation	Date

1

Name		DOB		URN	

Health Care Professional Record

All people involved in decision making and delivery of care, please complete and sign below

Full Name (Print)	Signature	Initials	Designation	Date

Name _____ DOB _____ URN _____

Personalised Care Plan for last days of life

_____ is now thought to be approaching the last days of his / her life and requires individual holistic care focused on comfort and dignity. Use only the following symptom control care plans that your patient needs.

Agreed Goals:

- Ensure compassionate, person centred communication with the person (when possible), and with family and / or significant others
- Ensure the person is included when possible. If the person lacks capacity for a decision ensure this is documented and how this conclusion was reached. Please note capacity is decision and time specific
- Ensure frequent updates are given to the family and / or significant others concerning the person's condition
- To provide care for these last days that reflects his / her individual and specific needs
- To promote care that ensures his / her safety, wellbeing and dignity
- To promote his / her involvement and that of the family / significant others, if they so wish, in the planning of care
- Ensure effective handover of the person's condition, including any changes in planned care to all relevant staff

Guidance for the use of the Symptom and Care Chart

- For adults, this chart supersedes the National Early Warning Score Observation chart when it is no longer deemed appropriate by the medical team
- For use by the multi-professional team
- Observations to be recorded at each contact in a community setting or at least **4 hourly** in an in-patient setting
- To be completed **hourly** or earlier if any symptom is **severe / distressing or moderate**
- All symptoms should be scored 0-3 and appropriate action taken in line with the guidance
- Please ensure this Symptom and Care Chart is used in conjunction with the Personalised Care Record
- Ensure inappropriate interventions have been discontinued

Key for Care/Goal Codes

1. Mouth Care
2. Skin Integrity
3. Bowel and Bladder Care
4. Eating and Drinking
5. Pain
6. Nausea and Vomiting
7. Agitation and Anxiety
8. Respiratory Secretions
9. Breathlessness
10. Other Symptoms

Name _____ DOB _____ URN _____

1. Mouth Care

- Offer and support the patient to eat and drink for as long as they want / or are able to
- Maintain good, regular mouth care to promote the patient's comfort; consider use of soft toothbrush
- Ensure anticipatory prescribing of oral care preparations (e.g. BioXtra gel®)
- Consider using ice cubes / pops to relieve dry mouth where appropriate
- Ensure the family / significant others are aware of the importance of mouth care and how they can support this
- Explain the symptoms of dry mouth or cracked lips do not necessarily mean the patient is thirsty, and this may be related to mouth breathing
- Record on Symptom and Care Chart

Date	Personalised Care Plan	
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:

Name _____ DOB _____ URN _____

2. Skin Integrity

- Observe skin integrity by implementing appropriate support and positioning schedules according to comfort
- Record position on Symptom and Care Chart i.e. Left, Right, Back
- Support the hygiene needs of the patient based upon their comfort
- Consider the use of aids e.g. slide sheets, pressure relieving mattress and ensure correct set up for weight / size of patient
- Discuss importance of comfort positioning with patient, family and significant others
- Consider issues of privacy and dignity e.g. side room, noise levels

Date	Personalised Care Plan	
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:

Name		DOB		URN	

3. Bowel and Bladder Care

- Ensure privacy and dignity is maintained at all times
- Acknowledge patient preferences utilising appropriate continence aids for e.g. conveen
- Consider urinary catheter for retention and / or comfort
- Provide pads if weakness causes incontinence
- If available utilise a catheter care bundle for patients requiring catheterisation
- Monitor and support skin integrity
- If distressed by constipation consider bowel intervention
- Communicate with patient, family or significant others
- Record on Symptom and Care Chart

Date	Personalised Care Plan	
	Goal:	**Completed by:**
	Action Plan:	
	Anticipated outcome:	**Review date:**
	Goal:	**Completed by:**
	Action Plan:	
	Anticipated outcome:	**Review date:**
	Goal:	**Completed by:**
	Action Plan:	
	Anticipated outcome:	**Review date:**

Name		DOB		URN	

4. Eating and Drinking

- The desire for food and drink may naturally decrease towards the end of life
- Offer and support the patient to eat and drink for as long as they want / or are able to
- Assess patient's swallowing ability and continue to support oral fluids if appropriate / tolerated
- Monitor for signs of distress or aspiration
- Communicate with the family and the significant others in order to recognise their understanding about potential risks associated with eating and drinking
- Continually review the appropriateness of any artificial hydration and nutrition
- Offer to discuss the benefits and burdens of artificial hydration and nutrition with patient and or family
- Liaise with the multi-professional team

Date	Personalised Care Plan	
	Goal:	**Completed by:**
	Action Plan:	
	Anticipated outcome:	**Review date:**
	Goal:	**Completed by:**
	Action Plan:	
	Anticipated outcome:	**Review date:**
	Goal:	**Completed by:**
	Action Plan:	
	Anticipated outcome:	**Review date:**

Name _____ DOB _____ URN _____

5. Pain

- Ensure anticipatory prescribing is in place at a dose appropriate to the person's regular analgesia
- Consider other underlying causes e.g. constipation, retention of urine, pressure damage
- Address psychological / spiritual causes if appropriate
- If a patient is already receiving regular analgesia ensure administration by an appropriate route
- If pain is reported or observed, assess intensity and severity of pain (use pain scale 0-10 if appropriate)
- Record on Symptom and Care Chart
- If a syringe pump is in place ensure regular checks are made in line with the Ambulatory Syringe Pump Policy
- Communicate with patient, family or significant others
- Obtain palliative care advice where needed

	Personalised Care Plan	
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:

Name _____ DOB _____ URN _____

6. Nausea and Vomiting

- Ensure anticipatory prescribing in place
- Ensure regular anti-emetic is prescribed by an appropriate route
- Consider bowel related causes
- Consider positioning of person
- Ensure access to vomit bowls, tissues if appropriate
- Offer regular mouth care (see care plan 1)
- Record on Symptom and Care Chart
- Provide explanations and information to patient, family or significant others as appropriate
- Obtain palliative care advice where needed

	Personalised Care Plan	
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:

Name _____ DOB _____ URN _____

7. Agitation and Anxiety

- Ensure anticipatory prescribing in place
- Exclude reversible causes if appropriate e.g. bladder retention, bowel pain
- Discuss with patient / family / significant others to try to ascertain likely cause
- Consider non-pharmacological options to manage symptoms and explain these options to patient, family or significant others as appropriate
- Discuss spiritual needs
- Ensure regular anxiolytic and / or antipsychotic is prescribed by an appropriate route
- Record on Symptom and Care Chart
- Obtain palliative care advice where needed

Date	Personalised Care Plan	
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:

Name		DOB		URN	

8. Respiratory Secretions

- Ensure anticipatory prescribing is considered and in place early
- Provide understandable explanations of possible secretions and likely effectiveness of medication to family
- Re-position patient if necessary
- Give subcutaneous anti-cholinergic either as required or via a syringe pump
- Review with medical team
- Record on Symptom and Care Chart
- Obtain palliative care advice where needed

Date	Personalised Care Plan	
	Goal:	Completed by:
	Action Plan:	
	Anticipated outcome:	Review date:
	Goal:	Completed by:
	Action Plan:	
	Anticipated outcome:	Review date:
	Goal:	Completed by:
	Action Plan:	
	Anticipated outcome:	Review date:

Name		DOB		URN	

9. Breathlessness

- Ensure anticipatory prescribing in place
- Consider use of a fan and open windows
- Consider re-positioning
- Consider relaxation techniques
- Consider use of pharmacological interventions if appropriate
- Address anxieties if appropriate
- Acknowledge changes with breathing patterns and discuss any concerns with the patient and family
- Record on Symptom and Care Chart
- Obtain palliative care advice where needed

Date	Personalised Care Plan	
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:

Name _____ DOB _____ URN _____

10. Other Symptoms

- For example: dry eyes, hiccups, itch
- Record on Symptom and Care Chart

Date	Personalised Care Plan	
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:
	Goal: Action Plan: Anticipated outcome:	Completed by: Review date:

Name		DOB		URN	

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg.3)	Record of Action and Outcome	Signature

Name _____ DOB _____ URN _____

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg. 3)	Record of Action and Outcome	Signature

Name		DOB		URN	

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg. 3)	Record of Action and Outcome	Signature

16

Name _____ DOB _____ URN _____

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg.3)	Record of Action and Outcome	Signature

Name _____ DOB _____ URN _____

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg.3)	Record of Action and Outcome	Signature

Name		DOB		URN	

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg.3)	Record of Action and Outcome	Signature

Name _____ DOB _____ URN _____

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg.3)	Record of Action and Outcome	Signature

Name _____ DOB _____ URN _____

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg.3)	Record of Action and Outcome	Signature

Name		DOB		URN	

If the patient dies or the PCR is suspended please also document in part 1.

Ongoing Assessment / Multi-professional Care Record

Date	Time	Care/Goal Code (Pg.3)	Record of Action and Outcome	Signature

Appendix 3: Symptom and Care Chart

Name:

Date of Birth:

URN:

SSD No:

ADDRESSOGRAPH

For adults, this chart supersedes the standard National Early Warning Score 2 (NEWS 2) observation chart when this is no longer appropriate, as decided by the medical team.

Symptom and Care Chart

Record observations at each contact or at least 4 hourly in an inpatient setting

Date													
Time													
Initials													
Pain	3												
Reported/observed	2												
	1												
	0												
Nausea and Vomiting	3												
	2												
	1												
	0												
Agitation and Anxiety	3												
	2												
	1												
	0												
Respiratory Secretions	3												
	2												
	1												
	0												
Breathlessness	3												
	2												
	1												
	0												
Other Symptoms	3												
	2												
	1												
	0												
Other Symptoms	3												
	2												
	1												
	0												

3
Severe/Distressing symptom present, requires medication
*Look for reversible causes
*Consider non-pharmacological treatment e.g. positioning
*Give medication for symptom
*Regular review until absent
*Document action

2
Moderate symptom present, requires medication
*Look for reversible causes
*Consider non-pharmacological treatment
*Give medication for symptom
*Regular review until absent
*Document action

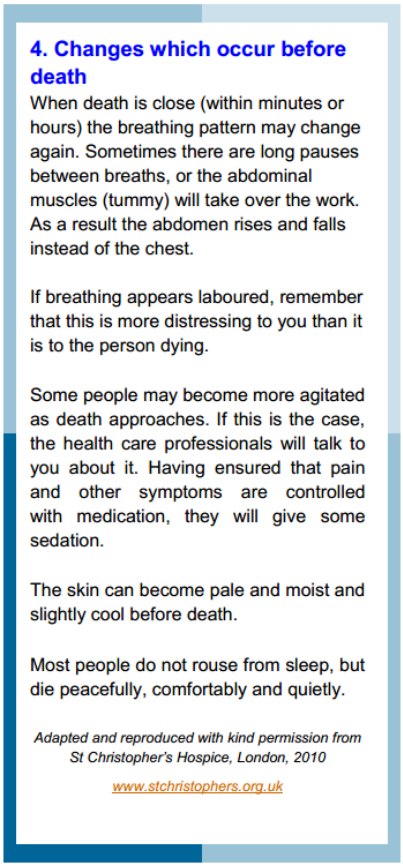
1
Mild symptom present, resolves spontaneously
No intervention required

0
Symptom absent
No intervention required

^ Enter D if care declined by patient or family

SYMPTOM AND CARE CHART																									
DATE COMMENCED:									**FREQUENCY:**																
KEY	**Y:** Yes			**N:** No					**N/A:** Not Applicable				**D:** Declined					**C:** Catheter							
Alert	Confused			Voice					Pain				Unconscious					Sleeping							
	DATE																								
	TIME																								
PERSONAL CARE																									
Level of consciousness **A C V P U S**																									
Mouth care																									
Eye care																									
Passed urine																									
Bowels open																									
Personal hygiene																									
Taking diet																									
Taking fluids																									
SKIN																									
Is pressure prevention equipment functioning correctly?																									
Are sheets/bedding smooth?																									
Check positioning of invasive devices **(Tick)**																									
SKIN INSPECTION **Is there any evidence of pressure damage?**																									
Buttocks																									
Elbows																									
Sacrum																									
Trochanters (hips)																									
Spine and shoulders																									
Heels																									
Occipital area (back of head)																									
Toes																									
Other (describe):																									
Repositioning: From and To	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**	**F**	**T**
L: Left, **R:** Right, **B:** Back, **P:** Prone, **SU:** Sitting Up, **C:** Chair, **M:** Mobilising																									
Initial																									
Role/Designation																									

Appendix 4: Coping with dying - Information leaflet



4. Changes which occur before death

When death is close (within minutes or hours) the breathing pattern may change again. Sometimes there are long pauses between breaths, or the abdominal muscles (tummy) will take over the work. As a result the abdomen rises and falls instead of the chest.

If breathing appears laboured, remember that this is more distressing to you than it is to the person dying.

Some people may become more agitated as death approaches. If this is the case, the health care professionals will talk to you about it. Having ensured that pain and other symptoms are controlled with medication, they will give some sedation.

The skin can become pale and moist and slightly cool before death.

Most people do not rouse from sleep, but die peacefully, comfortably and quietly.

Adapted and reproduced with kind permission from St Christopher's Hospice, London, 2010

www.stchristophers.org.uk

5. How we can help

This is likely to be a difficult and painful time for you, as you lose someone you love or have cared for. It can be hard to know what to say, how to help or what to do.

Nurses, doctors and other staff are there to help you work through your worries and concerns and to offer you care and support.

We hope that you will come and talk to us if there is anything on your mind. We will write a care plan with you, based on your loved one's individual needs.

Useful Contacts

Jersey Hospice Care

Specialist Palliative Care Team

Tel: 01534 876555 (24 hours a day)

or via **Jersey General Hospital**

Tel: 01534 442722 (Mon-Thurs 08.30-16.30 Fri 08.30-15.30)

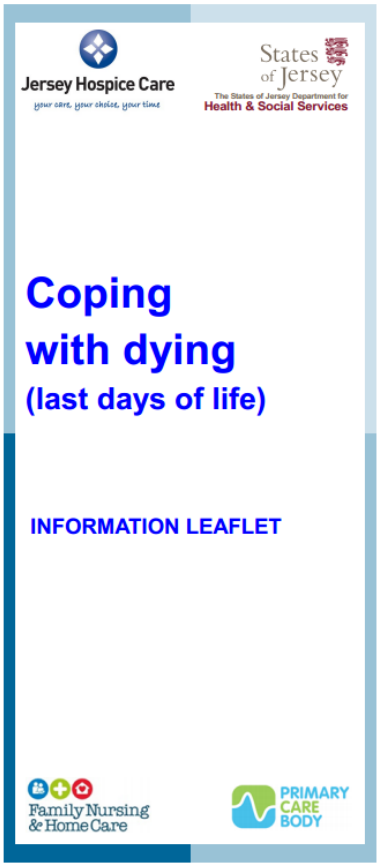
Family Nursing & Home Care

Tel: 01534 443600 (Mon-Fri 08.30-16.30)

Tel: 01534 442000 (JGH switchboard) 16.30-23.00 and weekends

Or please contact your own **General Practitioner**

EOLC-MISC-00001-20160804-v1



Jersey Hospice Care

your care, your choice, your time

States of Jersey

The States of Jersey Department for Health & Social Services

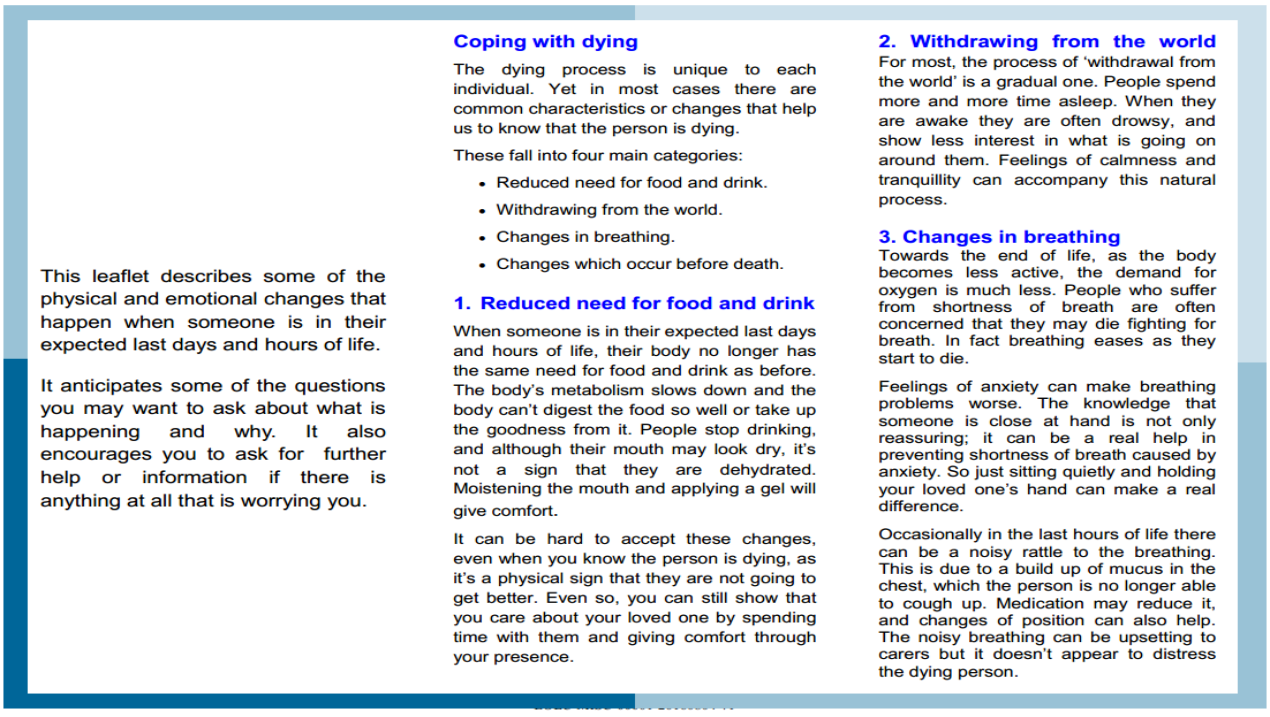
Coping with dying

(last days of life)

INFORMATION LEAFLET

Family Nursing & Home Care

PRIMARY CARE BODY



This leaflet describes some of the physical and emotional changes that happen when someone is in their expected last days and hours of life.

It anticipates some of the questions you may want to ask about what is happening and why. It also encourages you to ask for further help or information if there is anything at all that is worrying you.

Coping with dying

The dying process is unique to each individual. Yet in most cases there are common characteristics or changes that help us to know that the person is dying.

These fall into four main categories:

- Reduced need for food and drink.
- Withdrawing from the world.
- Changes in breathing.
- Changes which occur before death.

1. Reduced need for food and drink

When someone is in their expected last days and hours of life, their body no longer has the same need for food and drink as before. The body's metabolism slows down and the body can't digest the food so well or take up the goodness from it. People stop drinking, and although their mouth may look dry, it's not a sign that they are dehydrated. Moistening the mouth and applying a gel will give comfort.

It can be hard to accept these changes, even when you know the person is dying, as it's a physical sign that they are not going to get better. Even so, you can still show that you care about your loved one by spending time with them and giving comfort through your presence.

2. Withdrawing from the world

For most, the process of 'withdrawal from the world' is a gradual one. People spend more and more time asleep. When they are awake they are often drowsy, and show less interest in what is going on around them. Feelings of calmness and tranquillity can accompany this natural process.

3. Changes in breathing

Towards the end of life, as the body becomes less active, the demand for oxygen is much less. People who suffer from shortness of breath are often concerned that they may die fighting for breath. In fact breathing eases as they start to die.

Feelings of anxiety can make breathing problems worse. The knowledge that someone is close at hand is not only reassuring; it can be a real help in preventing shortness of breath caused by anxiety. So just sitting quietly and holding your loved one's hand can make a real difference.

Occasionally in the last hours of life there can be a noisy rattle to the breathing. This is due to a build up of mucus in the chest, which the person is no longer able to cough up. Medication may reduce it, and changes of position can also help. The noisy breathing can be upsetting to carers but it doesn't appear to distress the dying person.