Gloucestershire End of Life Care

Name:
Date of Birth: DD /MM /YY
ICS/MRN Number:
ICS/NHS/Hosp Number:
(or affix hospital label here)

Shared Care Plan

for the expected last days of life

Name.....

Likes to be known as .....

This care plan supports best possible clinical care when dying is anticipated. It is used in the expected last days of life and is designed to record all communication and care.

Staff guidance is available within staff resource folder and www.gloucestershireccg.nhs.uk/end-of-life

Details of symptom control and the specialist palliative care team can be found on page 7.
It is a multi-organisational document to be used by all care providers, the adult patient and those important to them, hereafter referred to as family/carers. The care plan can be introduced by medical or experienced professionals (in consultation with medical staff) within all care settings. The original stays with the patient and on transfer of care, it must be photocopied/scanned and filed into the medical notes.
If there is any content that you would like more information and explanation about, please speak to those who are currently providing care.

Blue stripe sections are for use by **MEDICAL STAFF and EXPERIENCED REGISTERED PROFESSIONALS who are recognised as being able to initiate this care plan.** Once this care plan has been commenced, there is no need to duplicate in medical notes. Offer family/carers the information sheet (pages 25/26) if deemed appropriate at this time.

Yellow stripe sections are for use by **NURSING TEAMS**. These may be registered or non-registered staff. This information is in addition to the blue stripe sections. Once this care plan has commenced there is no need to duplicate electronically. Please **use this care plan** so all care givers can contribute. Check that the information sheet (pages 25/26) has been offered.

No stripe sections are for use by all other staff that may include domiciliary care, hospice at home, spiritual care and other members of the multi-disciplinary team.
Patient/Family/Carers: Please feel free to contribute to the care record on pages 14-23 if you want to record what you have observed, want to mention or any care you have contributed to.

Care Team details (Complete where applicable)

Current Care setting: (e.g. hospital, home, care home)
Responsible Consultant/GP .....
Hospital Ward ..... Tel Nos: .....
Community Nurses in hours ..... Tel Nos: .....
Community Nurses out of hours ..... Tel Nos: .....
Specialist Palliative Care Team Contact ..... Tel Nos: .....
Hospice@Home Contact/s (if involved) .....
Transfer of Care – ensure direct communication with new care team including out of hours
Responsible Consultant/GP .....
Care setting:
Other contacts:
Does the patient have an IMCA (Independent Mental Capacity Advocate)? If yes, include
Name: and Tel Nos:

Next of Kin

Name 1 ..... Relationship ..... Tel Nos.....
Night call requested? Y / N details
Address.....
Name 2 ..... Relationship ..... Tel Nos.....
Night call requested? Y / N details
Is there a Lasting Power of Attorney for health and welfare in place? Y / N Has it been seen? Y / N
Has it been registered? Y / N Has a copy been taken and stored in medical notes? Y / N
Name of Person with LPA ..... Contact details .....
Identity confirmed (photographic evidence) ❑

Advance Care Plan has been completed Y / N

Summary of wishes and preferences including Advance Decisions have been discussed with the patient and/or the family or identified from an Advance Care Plan / Best Interests plan.
Does the patient appear to have Mental Capacity? Y / N
Have they expressed a preferred place to die? (please comment)

Other wishes

Is an Advance Decision to Refuse Treatment in place? Y / N
(please use in conjunction with page 4)
An Advance Decision – sometimes known as an Advance Decision to Refuse Treatment, an ADRT or a living will – is a decision that can be made to refuse a specific type of treatment at some time in the future). It is legally binding providing certain conditions are met.

Details:

The term 'recognition of dying' is used to define a time when someone is thought to be approaching the last days of their life and when care will focus on comfort and dignity. All possible reversible causes for the current condition have been considered and the patient is thought to be entering the terminal phase. This might include changes such as a decreased need for food and drink, changes in breathing and an increase in sleepiness.

Our goal is to provide individualised patient care that reflects their personal wishes and preferences with involvement of the family/carers if they so wish.

For use by Medical Staff/Experienced Professional – to be used in conjunction with page 4

A discussion has been held with the patient about Do Not Attempt Cardiopulmonary Resuscitation and ceiling of treatment/unwell patient status. Y / N

A discussion has been held with the family about Do Not Attempt Cardiopulmonary Resuscitation and ceiling of treatment/unwell patient status. Y / N

Ensure Mental Capacity has been considered and an assessment completed if there are any indications of lack of mental capacity (example form on page 4)

Brief summary of discussion:

Signature Print name Date / /

Yellow sticker to be completed and attached here
(this may need to be a duplicate yellow sticker)

OR
Yellow sticker can be found in:

South West Ambulance Service Foundation Trust Clinical Alert: This alert informs SWASFT that the patient is NOT for resuscitation. This should ensure the appropriate response to these patients. For information on how to send this information please follow https://www.swast.nhs.uk/What%20We%20Do/special-patient-information.htm Yes / No / N/A

For community patients and those transferring into the community:

Has the GP been alerted to update their clinical system with DNAR status which then updates the summary care record? Yes / No / NA

Clinician signature ..... (Consultant/GP/senior clinician)
Print name ..... on / /

Mental Capacity Assessment - use if required

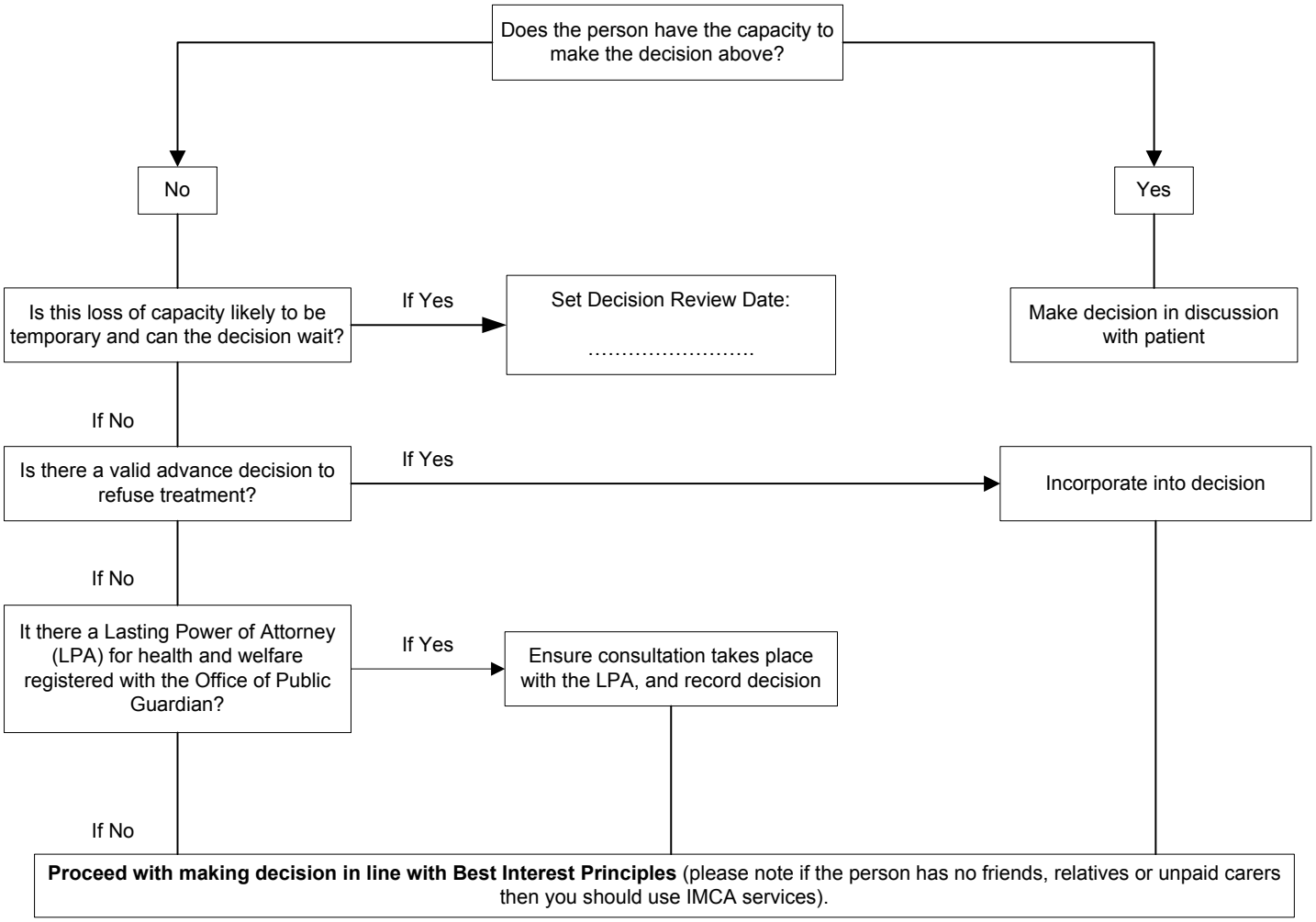
The Mental Capacity Act (2005) requires you to assume that individuals have capacity, unless you suspect the person has an impairment or disturbance of the mind or brain. It also requires any assessment to be time and decision specific. If you suspect someone lacks capacity you are required to complete a Mental Capacity Assessment. (Please follow local guidance)

Does the individual have an impairment or disturbance of the functioning of the mind of brain, which may impact on their ability to make the required decision?

Document Details: ……

What is the decision which needs to be understood and discussed?
Ceiling of care/resuscitation decision

4 Step Assessment – Can the patient...	**Yes**	**No**	Comment
1. Understand information about the decision to be made?			
2. Retain that information in their mind?			
3. Use or weigh that information as part of the decision making process?			
4. Communicate their decision (by talking, using sign language or any other means?)			



All people involved in delivering care, please sign below

Name (print)	Full Signature	Initials	Role	Telephone/Pager Number (if relevant)

Continuation Sheets available with Code: **GDH 3174 A**

Clinician Led Discussion with Patient and Family to agree the plan of care	Summary of discussion, understanding, concerns and actions
Whom did you talk to? Patients should be encouraged to be fully informed and involved in all decisions about their care. If mental capacity is compromised a mental capacity assessment must take place. If the patient does not have the mental capacity to make specific decisions, all decision making must be via their power of attorney or in their best interests.	
Recognising dying? Explain why the patient has been identified as dying and what to expect. Page 25/26 tear off information sheet has been provided to family/carers ☐	
Location of Care Refer to OT or Palliative Care Team if rapid discharge from hospital is required. See guidance on how to access Continuing Health Care Fast Track funding if required. Has CHC Fast Track form been completed? Yes / No / N/A	
Observations and investigations Review of the appropriateness of observations and investigations	
Current medication and intervention review Consider purpose of all medications and treatments **Symptom Control** Consider prescribing anticipatory medications and whether a syringe pump might be needed. Is there a Just In Case Box in the patient home? **Consider whether Implantable Cardioverter Defibrillator (ICD) deactivation is required.** Yes / No / NA	
Hydration and nutrition Explain what family/carers can expect with the dying process. Assess patient's ability to eat/drink together with symptoms of hunger/thirst. Discuss how these will be managed e.g. feed/drink at risk, regular mouth care, parenteral fluid trials	
Spiritual Care needs Offer support of own spiritual care lead or the chaplaincy team. Chaplaincy teams can provide support to those of all faiths and for those who have none	
Wishes about organ or tissue donation Discuss with the patient and family if the option of donation has been explored. For guidance refer to the flowchart in the Staff Guidance. To check the Organ Donor Register call 0117 975 7580. Refer to the national referral centre 0800 432 0559.	
Frequency of Review	

Experienced professional signature .....

Print name .....

Role ..... Date / /

GUIDANCE FOR SYMPTOM CONTROL IN END OF LIFE CARE

As health care professionals, acceptance of a diagnosis of dying can be difficult but it is one that must be considered and anticipated.

For any 'unwell patient', the MDT should be asking 'would we be surprised if this person dies during this admission/episode of illness?' If the answer is NO, ensure that this is recognised as part of the differential diagnosis, communicated to the family and patient where appropriate, and planned for.

The principles of good end of life care are:

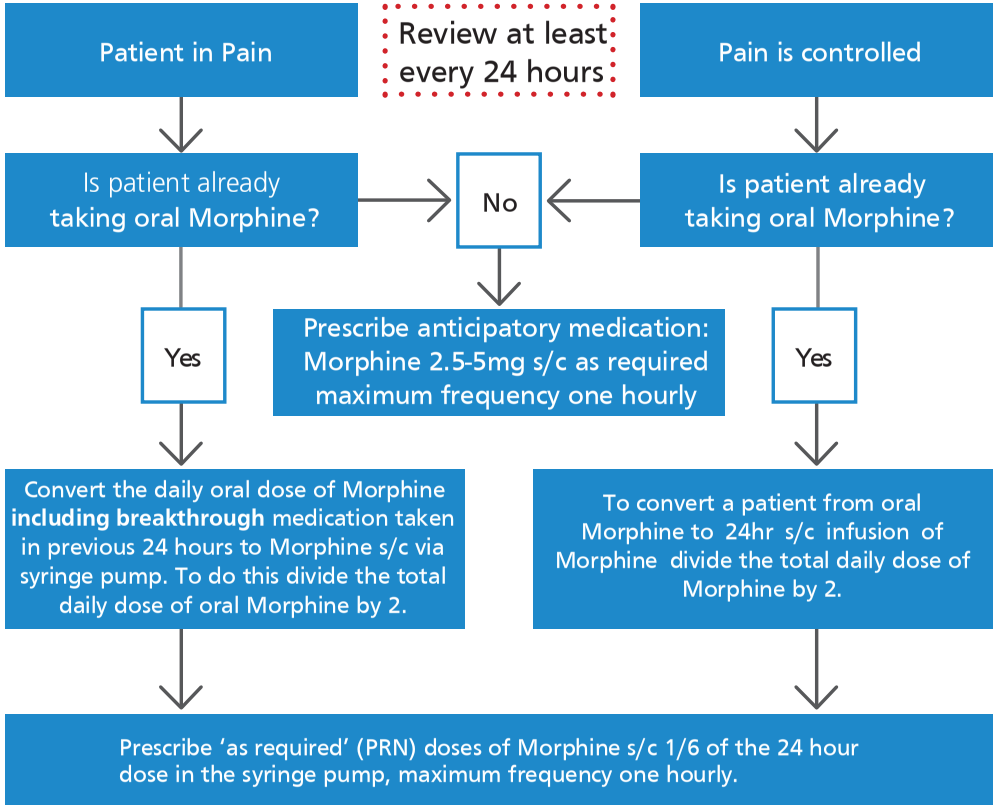
- → effective communication with patients and their families
- → regular assessment
- → management of symptom control
  e.g. ensure anticipatory medications prescribed (see below)
- → avoid unnecessary interventions e.g. ensuring DNACPR status, the need for ongoing observations/investigations/blood tests reviewed
- → provision of psychological, social and spiritual support
- → food/fluids as desired – may be appropriate for comfort even if unsafe swallow. Parenteral fluids may be continued/commenced if appropriate.

SYMPTOM	USUAL "AS REQUIRED" (PRN) STARTING DOSE	STARTING DOSE FOR SYRINGE PUMP IF NEEDED (Consider if 2 or more PRN doses needed in last 24hrs)
PAIN / TACHYPNOEA	Must be individualised see algorithm opposite	
NAUSEA	Levomepromazine 6.25mg s/c 6 hrly	Levomepromazine 6.25mg s/c over 24 hours * *Due to long half life drug single daily injection often adequate.
AGITATION / DISTRESS	Midazolam 2.5-5mg s/c every 30 mins until settled	Midazolam 5-10mg s/c over 24hrs
SECRETIONS (Review parenteral fluids)	Glycopyrronium 400mcg s/c 4hrly	Glycopyrronium 600-1200mcg s/c over 24 hrs

For palliative care advice

In hours: GRH 0300 422 5179, CGH 0300 422 3447,
Community single point of access: 0300 422 5370.
For out of hours please call the hospital switchboard on 0300 422 2222.

PRESCRIBING SUBCUTANEOUS MORPHINE IN THE DYING PATIENT WHO CAN NO LONGER TAKE ORAL MEDICATIONS



Approximate conversions of opioids	
	Oral Morphine 30mg = s/c Morphine 15mg
	Oral Morphine 30mg = s/c Diamorphine 10mg
	Oral Oxycodone 30mg = s/c Oxycodone 15mg
	Oral Morphine 30-45mg/24hrs = Fentanyl Patch 12mcg/hr

TRANSDERMAL PATCHES:
If already on a Buprenorphine or Fentanyl patch, leave on and add in additional analgesia via syringe pump as above. Remember to include patch strength when calculating PRN doses of Morphine.
NB: Transdermal analgesic patches should **not** be commenced in the dying phase as there is a long time lapse to reach peak plasma concentrations.

RENAL FAILURE:
Neither Morphine or Diamorphine are advised if eGFR<30mL/min.
Contact specialist palliative care/renal team for advice on appropriate opioid prescribing.

Initial nursing team assessment of the patient when care plan initiated – identifying care needs and action to be taken	
Physical assessment Aim: To assess how any relevant symptoms below are observed or expressed and managed. Consider pain, nausea, vomiting, respiratory secretions, breathlessness, mouth discomfort, skin and pressure areas, agitation, restlessness, problems with urinary or bowel actions Medication effectiveness? Syringe pump needed? Support patient with intake of food and fluid for as long as possible.	
Psychological assessment Aim: to assess psychological and emotional needs and document the plan of care. Consider the patient and family, fears, anxiety. Can we help them communicate this?	
Social Aim: to find out personal wishes and take action to meet these if possible. Consider choices about environment, where they want to be cared for, people around them, participation in care, understanding of the family, pets, equipment	
Spiritual - before and after death Aim: To assess and meet spiritual and cultural needs Ask what's important to them right now? How can we help them meet this? Consider religious and cultural beliefs and wishes, spiritual leaders, the need for prayer, music, fragrance, light/ darkness, therapies such as massage	
Nurse signature ..... Print name ..... Designation ..... Date / /	

Nursing team discussion: Communication with family/carers regarding their needs	Summary of discussion, needs identified and action taken
Understanding of patient's condition including symptoms, food and fluids – refer to clinicians' discussion notes to avoid repetition (page 6)	
Visiting wishes, problems & arrangements (e.g. driving, visiting times)	
Support at home	
Car parking	
If in hospital – carer's badge, overnight stay room and refreshments	
Given Tel Nos including emergency Tel Nos if at home (use Notes page on page 27)	
Offered spiritual care support	
Information leaflet – confirm that the tear out information on page 25/26 has been given. ☐	
Leaflets available for family/carers Support for carers looking after someone at the end of their lives GDH3216	
Local Leaflets (specify)	

Nurse signature ..... Print name .....

Designation ..... Date / /

Ongoing assessment and record of care needs

For adults, this chart supercedes the standard Early Warning Score observation chart.

To be completed every 4 hours or at each visit in line with local policy or if symptoms are moderate or severe please assess and review hourly. Ensure this symptom observation chart is used in conjunction with the multi-disciplinary care record.

Date																				
Time																				
Initials																				

1. PAIN

Severe																				
Moderate																				
Mild/None																				

2. NAUSEA and/or VOMITING

Severe																				
Moderate																				
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3. AGITATION

Severe																				
Moderate																				
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4. RESPIRATORY SECRETIONS (consider postural change)

Distressing																				
Not Distressing																				

5. SHORTNESS OF BREATH (e.g. in patients with respiratory rate over 20 breaths per minute)

Distressing																				
Not Distressing																				

6. THIRST AND HUNGER

Distressing																				
Not Distressing																				

7. DRY MOUTH – If Yes, Consider offering sips, drinks, mouth care if appropriate

Yes																				
No																				

8. MICTURITION / URINE OUTPUT / RETENTION

Distressing																				
Not Distressing																				

9. BOWEL MOVEMENT CONCERNS (report constipation or diarrhoea and care given)

Yes																				
No																				

10. SKIN AND PRESSURE AREAS INCLUDING WOUNDS (consider equipment, regular positioning and supplementary care plans if needed)

Not Satisfactory																				
Satisfactory																				

11. OTHER (e.g. hiccups, itch, nose bleed) describe:

Yes																				
No																				

Please report on the Care Record (from page 14)

12. MEDICATION:	Check its effectiveness, involve the patient and those important to them. -Report at least daily.
13. PSYCHOLOGICAL STATE:	What can be observed? Does the patient appear calm, anxious, distressed? -Report at least daily.
14. SPIRITUAL AND CULTURAL NEEDS ASSESSED AND MET?	How we can help address personal beliefs and wishes for care before and after death. "What's important to them right now?"
15. COMMUNICATION WITH THE FAMILY AND THOSE IMPORTANT TO THE PATIENT:	-Report at least daily.
16. OVERALL CONDITION	Is this care plan still appropriate? Is the patient still thought to be dying?

Severe Moderate	• Look for reversible causes. • Consider non-pharmacological treatment e.g. positioning • Give medication for symptom and review until Mild/None level is achieved. • Document Action/Use supplementary care plans if required	Mild/None	No intervention required.

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Continuation Sheets available with Code: **GDH 3174 B**

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Date/time	Care Needs Number	Record of change, action or observation Report daily on communication with the family/carers	Signature

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Care of patient and family/carers after death

(this document is to be scanned and filed according to local organisation)

Verification of death details

Name: Role:

Date of death: Time of death:

Did the patient die in their preferred place of death? Y / N If no, please comment

Follow local organisational policies

Religious and Cultural considerations of the patient and family – please describe

Preferred funeral director

Wishes to be buried/cremated/other?

Other wishes (e.g. choice of clothing)

Have the wishes of the deceased regarding organ and tissue donation been addressed?

1) Is a referral to the National Referral Centre required for Organ & Tissue Donation after death? Y/N

2) Referral to the National Referral Centre 0800 432 0559 completed post death? Y/N

Care of the family/carers – Refer to local bereavement policy or guidelines

Allow opportunity and time for further questions.

-Provide advice and discuss how to register a death. CCG Leaflet: After a Death - code GDH3216 ☐

-Provide information on Grief. CCG Leaflet: Grieving the Loss of Someone – code GDH1912 ☐

-Local leaflets

-Winston's Wish (bereavement support for children and young people) www.winstonswish.org ☐

-The plan to collect the belongings and jewellery has been discussed ☐

-The plan to collect the death certificate – follow local policy ☐

-Are there any further concerns about how the family/friends/carers might cope?

List the professionals involved in the care that have been informed of the death.
(e.g. GP, Continuing Health Care, DN, Hospice)

Questions you would like to ask or something you think we should know

Feedback on the care plan and this information leaflet is most welcome. Please address your comments or suggestions about this document and care you have received to PALS, NHS Gloucestershire Clinical Commissioning Group, Sanger House, 5220 Valiant Court, Gloucester Business Park, Gloucester GL3 4FE

Adapted information from Marie Curie and Saint Christopher's Hospice.

To discuss receiving this information in large print or Braille please ring **0800 0151 548.**

To discuss receiving this information in other formats please contact:

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PALS, NHS Gloucestershire Clinical Commissioning Group, Sanger House, 5220 Valiant Court, Gloucester Business Park Gloucester GL3 4FE

Additional Leaflets available with Code: GDH 3174 D

Gloucestershire End of Life Care

COPING WITH DYING

Information for the patient and those important to them

Responsible Doctor	
Hospital/hospice ward	Telephone
Community Nurses	Telephone
Other important contacts	

This is likely to be a difficult and challenging time. We want the person at the end of their life and those important to them to receive the best quality care, tailored to their wishes and preferences.

Some people choose not to be involved in detailed discussion or may wish someone who is important to them to help provide information to the clinical team. Your choices will be discussed with you.

Please discuss with the care team if you would like to be involved in helping with personal care.

If you have designated a Lasting Power of Attorney or have written an Advance Decision to Refuse Treatment or an Advance Care Plan, please inform the team looking after you.

Coping with dying – understanding the changes that might happen

The dying process is different for each person but there are common characteristics or changes that may indicate when a person is dying.

- needing less to eat and drink
- appear to be less interested in the people and place around them. Often referred to as 'withdrawing from the world'
- changes to breathing
- changes which occur before death

Needing less to eat and drink

There may come a time when people are no longer able or wish to eat and drink. Should this occur the care team will discuss if it's helpful for a drip to be considered. For example a drip may be helpful for people who are feeling thirsty. A dry mouth is often not a sign of dehydration and can be managed without a drip, by keeping it clean and moist. People in hospital and at home are offered food and drink and are helped to eat and drink as much as they choose.

It is understandable for someone to want to see their loved one eating well and often difficult to understand the person no longer wishes to eat or is unable to do so. Family/carers may wish to offer small amounts of favourite foods or sips of drinks. However, it's important not to force people if they are not wanting or are unable to eat and drink.

'Withdrawing from the world'

For most, the process of 'withdrawal from the world' is a gradual one. People spend more and more time asleep, and when they are awake they are often drowsy, and show less interest in what is going on around them. This natural process can be accompanied by feelings of calmness and tranquility. Even at this stage, we wonder whether a dying person may still be able to hear so talking to your loved one is important, as well as remembering not to say anything you wouldn't wish them to hear. There will be a time when the person slips into unconsciousness. This can last several days but can also be a much shorter time.

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 breathlessness are sometimes concerned that they may die fighting for breath, but in fact breathing often eases as they start to die.

Often breathing problems can be made worse by feelings of anxiety. The knowledge that someone is close at hand is not only reassuring; it can be a real help in preventing breathlessness caused by anxiety. So, just sitting quietly and holding their hand may make a 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 or saliva in the upper airways, which the person is no longer able to cough up. Medication may be used to reduce it and changes of position may also help. The noisy breathing can be upsetting to carers but we don't believe it distresses the dying person.

Changes which occur before death

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

If breathing appears laboured, remember that this is probably 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, then staff will talk to you about it and, having ensured that pain and other symptoms are controlled with appropriate medication, can administer some sedation.

The skin can become pale and moist and slightly cool prior to death. Most people do not rouse from sleep, but die peacefully, comfortably and quietly.

How we can help

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

Notes

Collaborative production between:

Gloucestershire Care Services NHS Trust
Gloucestershire Clinical Commissioning Group
Gloucestershire Hospitals NHS Foundation Trust
²gether NHS Foundation Trust
Great Oaks Hospice
Longfield
Sue Ryder

Ordering of Resources (FREE)

https://www.gloucestershireccg.nhs.uk/eolc

How to Order:

1. E-mail *Tessa@colourconnection.co.uk* or phone 01452 874999 giving delivery address
2. Please do not order more than you expect to use in a 6 month period.

Shared Care Plan for the Expected Last Days of Life	GDH 3174
Continuation Sheet - All involved in delivering care (list of names)	GDH 3174 A
Continuation Sheet - ongoing assessment and record of care needs	GDH 3174 B
Continuation Sheet Care Record	GDH 3174 C
Coping with Dying Leaflet	GDH 3174 D
Medication Prescription Chart - anticipatory medication	Y0666
Palliative Care - Guidance Concertina cards for Registered Staff	GDH 3524
Yellow Do Not Attempt Resuscitation Sticker - GPs and Community	H426
Yellow Do Not Attempt Resuscitation Sticker - Acute Hospitals	Y0331
Support for Carers Leaflet	GDH 3216
What to do after a Death in Gloucestershire - A practical guide	GDH 3611
After a Death - Grieving the Loss of Someone	GDH 1912
Preparing for End Stage Dementia - A Carers Leaflet	GDH 3221

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