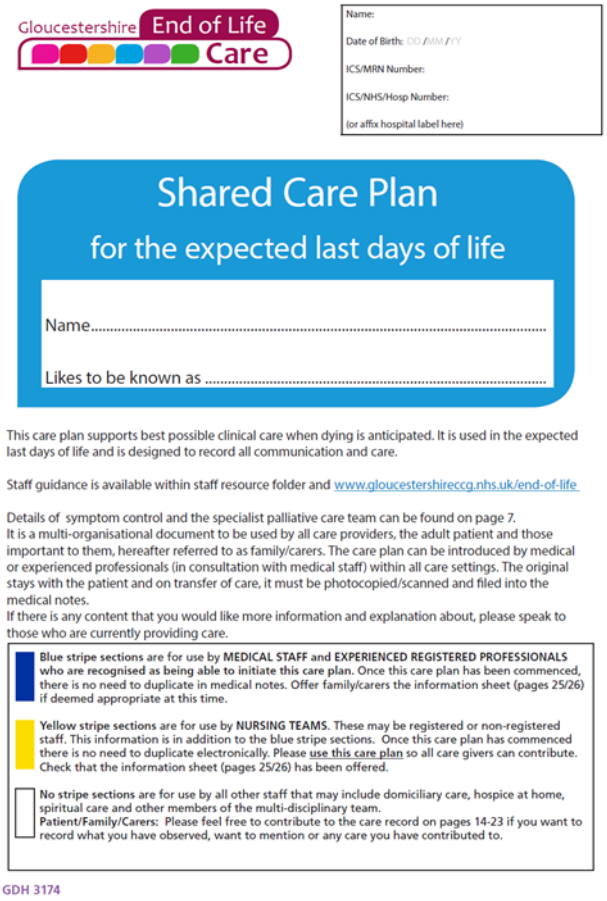
User Guidance

How to complete the Shared Care Plan for the expected last days of life



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.

GDH 3174

This guide is for health and social care colleagues who use the new Gloucestershire Shared Care Plan. The plan is introduced when it has been recognised that the adult person is dying and in the expected last days of life. It is designed to be used for adults in the last days of life in **ALL** care settings.

For professional palliative care advice

In hours: 9-5 Mon-Fri excluding bank holidays	Gloucestershire Royal Hospital:	0300 422 5179
	Cheltenham General Hospital:	0300 422 3447
Community Single Point of Access:		0300 422 5370
Out of Hours: Weekends & Bank holidays	Please call the hospital Switchboard:	0300 422 2222
Medicines Information Service:	Glos. Royal Hospital	0300 422 6108
	Cheltenham General Hospital	0300 422 3030

Contents

An overview of the Shared Care Plan

What is it?	This is a personalised and shared care plan that replaces the present shared care record. It should contain all relevant information needed to enable one plan to be used by all, including the patient and those important to them.
When should it be introduced?	When it has been recognised that the person is dying. This will be an expected death, the identification of which will have been informed by a multi-professional discussion. It is designed to be used for adults in the last few days of life.
How do we recognise when someone is dying?	The term 'recognition of dying' is used to define a time when someone is within the last few days of life and requires care focused on comfort and dignity. All possible reversible causes for their current condition have been considered. There may be some common characteristics: • The need for less food and drink • Reduced mobility and an increase in sleep • Changes in breathing • 'Withdrawing' from the world
Do I need to continue with writing medical notes and/or electronic end of life care templates?	No. This plan is designed to include all necessary sections needed by a wide range of carers, including the patient and family who don't have access to electronic systems. There is no need to duplicate written notes. SystmOne users: There is a tick box on the end of life template to complete when switching from electronic to this paper care plan. Resume electronic recording at, and after, verification of death (SWASFT staff will need to continue electronic records)
Why is it in paper format?	So everyone involved in the care can see it and contribute to the same record. There will be care givers such as hospice at home, domiciliary care, spiritual care as well as the family that do not have access to electronic records or medical notes.
Should the patient and family be informed of its use? The family have been the caregivers and would like to contribute to the care and care plan. Can they?	Yes, always keep the patient and family, or those important to the patient, informed. It's important that the family or significant others are involved in open and honest discussions. It should come as no surprise to learn that the patient is dying. There needs to be regular daily discussions. If the patient is happy they are involved, yes. Many families want to be involved in the care and want to write down what they have observed and have done for the patient, especially when at home. You can help by suggesting they might like to contribute to simple mouth care, talking to them, holding hands etc. But check frequently if they are happy to continue with care. There may come a point when they are not comfortable to be involved.
Can this care plan be used if the patient is transferred to another care setting?	Yes. It's intended to be used throughout Gloucestershire.The original stays with the patient and the copy is filed in the notes. Check with your local procedures.

Page by Page Guidance - for staff

Page 1 - Front page

Gloucestershire End of Life Care Logo is used throughout Gloucestershire health & social care organisations	There should always be a discussion with the patient, family and those important to the patient before introducing this care plan so this logo should not be a shock to anyone.
Space for address label	If available and used in your work area.
Name/Likes to be known as	Write official name as well as asking and documenting their preferred name.
Staff Guidance notes End of Life Care link workers/champions	This staff guidance is for staff only. It should be available in paper format as well as electronically on local intranets. Some work areas may have End of Life Care link worker or champions who can give you further advice and signpost you to further resources.
Instructions on use 1. Medical Staff/ Experienced professional 2. Nursing teams 3. Other staff 4. Patient/family	The care plan can be used by a wide range of organisations as well as the patient and those important to them. Some pages are highlighted by having yellow and blue stripes indicating who can contribute to each section. 1. Use the pages indicated by a blue stripe. A experienced professional may be a doctor, senior registered nurse or other experienced professional who has a responsibility in the planning of end of life care (e.g. clinical nurse specialist) 2. The yellow stripe sections can be completed by nursing teams. These may be registered or non-registered staff but recognised by the organisations as being able to complete these sections. 3. Other staff maybe from a wide range of staff such as occupational and physiotherapy, social work, psychology, hospice at home, domiciliary care, spiritual care and many more. They can contribute to the assessment and care record pages.(10-23). 4. Patients and those important to the patient (with consent) can also contribute on pages 10-23. It's important to remember that some prefer not to be involved.
Local policies and procedures	Please follow any related policies and procedures from within your organisations. E.g the syringe pump policy.

Page 2 - Care team details

Care team details	Complete this section with available and applicable information. It's important to remember that the family/carers often aren't aware of who the consultant in charge is. On transfer of care always make sure information has been completed.
What is an IMCA?	An Independent Mental Capacity Advocate is a person appointed to represent a patient who lacks capacity and who has no one else willing and able to take on this role. *https://www.gov.uk/government/publications/independent-mental-capacity-advocates*
Next of Kin	Complete fully. Always ask if they would like to be informed at night and take full contact details. Print clearly and check the details.
Lasting Power of Attorney (for health and welfare)	Some people choose to appoint a Lasting Power of Attorney who has legal power to represent the patient with respect to health and welfare related decisions should the patient lose capacity. *https://www.gov.uk/power-of-attorney* (Your organisations policies must be followed). There is a need to see a copy of the LPA and verify it has been registered with Office of Public Guardian as well checking the identity of the person by asking for photographic evidence.
Advance Care Plan	Patients may have expressed wishes, either verbally or in writing, about their preferences with respect to the care they would like to receive in circumstances when they lack capacity. It is important to be aware of this information, although not legally binding it can be very helpful in informing decision making. *www.gloucestershireccg.nhs.uk/end-of-life* *an advance care planning for those with learning difficulties is available from https://www.2gether.nhs.uk/wp-content/uploads/My-End-of-Life-Plan-January-2017.pdf*
Advance Decision	Also sometimes referred to as a living will. This provides information on interventions a patient wishes to refuse should they lose capacity. It is legally binding provided certain criteria are met. https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-decision-living-will/ (Your organisations policies must be followed)
Interpretation services Other formats	Please follow your organisations policies regarding interpretation and special format services. If an end of life care document is needed in another format such as easy read or braille please contact the end life care team or PALS at Sanger House 0800 0151 548

Page 3 - Recognising dying

Recognition of dying	When a patient's condition changes and they are thought to be dying they must be assessed by a clinician competent to judge whether their condition is potentially reversible or whether they are likely to die. The opinion of the multi-professional team must be sought. The assessment must occur in a timely manner and a timely response must occur. The assessment and any decision made must be recorded and communicated sensitively to the patient and those important to them. The patient must be regularly reviewed.
Discussion around deterioration of condition, DNAR Also known as DNACPR and AND (Allow a natural death)	Patients should be encouraged to be fully informed and involved in all decisions about their care. Please ensure that the patient and those important to them (unless the patient has indicated otherwise) are as informed as they wish to be about the clinical situation and that the patient is thought to be dying. Offer to explain what is happening and the likely prognosis. Ask about any goals or wishes they may have and offer to try to answer their questions.
What is a TEP form? (treatment escalation plan)	Treatment Escalation Plans (TEP) are also known as ceiling of care decisions. These are decisions which are made in advance to guide clinicians as to the appropriate interventions which should be offered to a patient should they deteriorate clinically. When a patient has been identified as dying it is usually most appropriate to focus on comfort care, rather than interventions with a goal of reversing what is happening. In circumstances where there is any uncertainty, senior guidance must be sought. In Gloucestershire Hospitals these decisions are recorded on purple 'Unwell Patient' (UP) forms. If working in Care Services NHST and 2gether NHSFT please use the form used in your area. Find out if you need to complete the pale blue Patient Treatment Option form, which is used in community hospitals.
What is a yellow sticker?	In Gloucestershire many organisations have adopted a large yellow sticker which indicates that, after a discussion with the patient and the family, it has been decided that an attempting cardiopulmonary resuscitation is not an appropriate intervention for the patient and to allow a natural death. Always ensure this sticker is available and visible on transfer of care. These stickers can be ordered free for use by medical or senior registered staff. Ordering details on back page. If you do not use a yellow sticker find out what procedure is in place.
For information: Electronic data recording systems	When this care plan is commenced there is no need to continue with electronic record keeping. This paper format can then be seen and used by a wide range of organisations. Resume electronic record keeping when recording the death. SystmOne users – tick the box on the end of life template to demonstrate you are now using this paper format. Resume after death. South west ambulance staff will continue with electronic system.

Clinical alert form for south west ambulance trust SWAST	This form alerts SWAST that the patient is NOT for resuscitation. This should prevent situations where patients are resuscitated against their wishes or when the intervention is considered to be futile. Different organisations use different documents or methods of communicating with SWAST. Find out your local procedure. SWAST have a form available for use via *swast.features@nhs.net*
GP alerted	For community patients or those transferring into the community, it is important that the GP is alerted to update their clinical electronic systems, this will include the DNAR status which will update the patients summary care record.
Clinician signature	This signature line MUST be completed. The clinician can be a doctor or an experienced registered practitioner recognised by their organisation.

Page 4 - Mental Capacity Assessment - to be used if required

The proforma is provided here to support the assessment of the patients mental capacity to make decisions around resuscitation and ceilings of care if there are indications that their mental capacity may be impaired.

Page 5 - People involved in delivering care

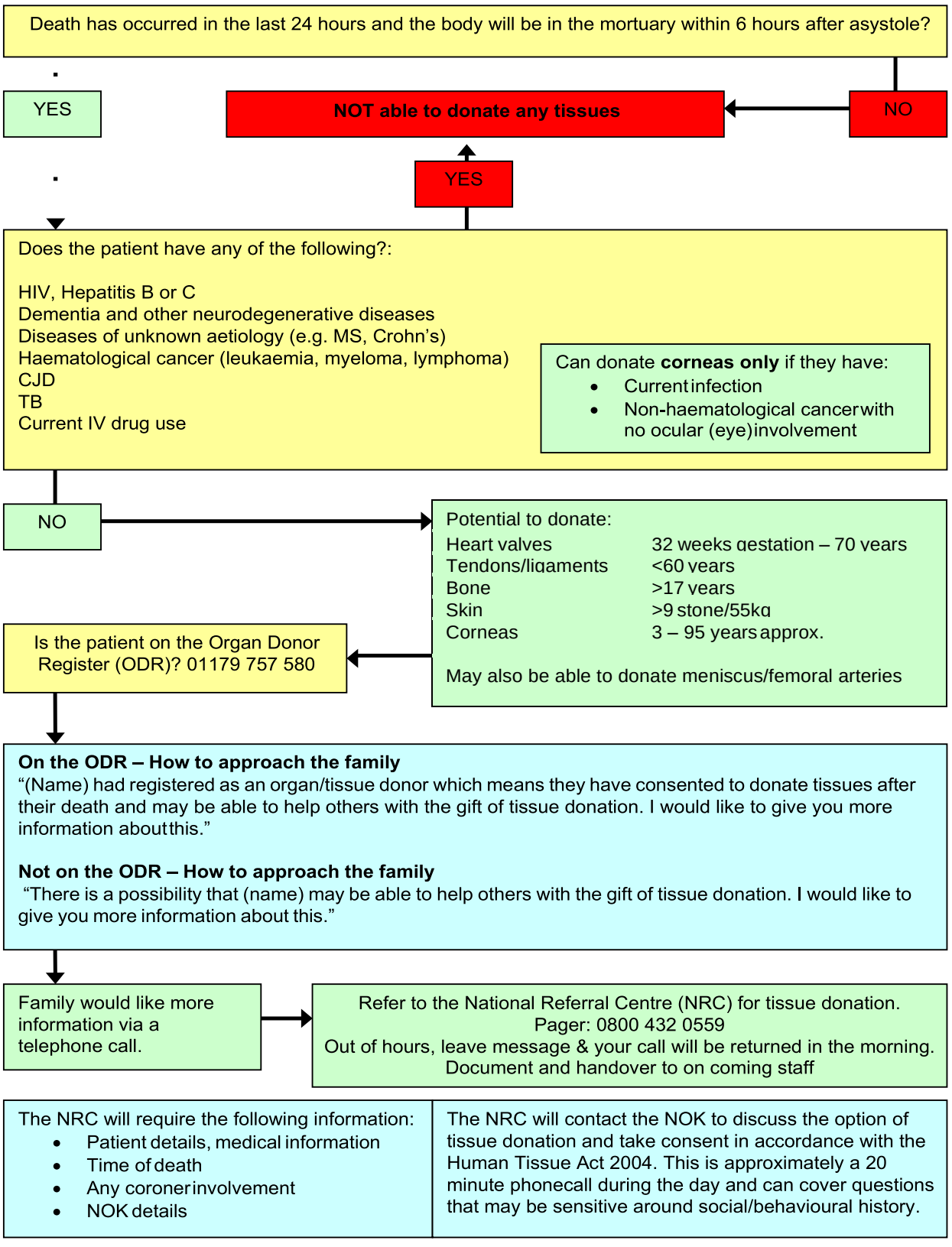
Who should complete this?	All main care team members and those who deliver care. This might be a member of the multi-disciplinary team, a family carer, hospice and agency staff etc. It's important, especially on transfer of care when the next care setting needs to liaise with previous staff. It's also useful for audit purposes. Continuation forms are available – see ordering details on the back page regarding GDH 3174 A

Page 6 - Clinician Led Discussion (medical or experienced professional to lead discussion)

Whom did you talk to?	Patients should be encouraged to be fully informed and involved in all decisions about their care. It is also important to inform and involve those important to the patient unless the patient has indicated otherwise. If mental capacity is compromised a mental capacity assessment must take place. If the patient does not have mental capacity to make specific decisions all decisions must be via their power of attorney or in their best interests.
Recognising dying	Recognising dying can be challenging. The patient must be assessed by a clinician competent to judge whether the patient's condition is potentially reversible and whether they are likely to die. The opinion of the multi-professional team must be sought. Additional guidance is available from NICE *https://www.nice.org.uk/guidance/qs144/chapter/Quality-statements*
Location of Care	Some people feel strongly about the place where they wish their care is provided and where they die. They may wish to be in the familiar surroundings of their usual residence such as their home or care home. However, some feel much safer in environments where there are clinical teams on hand. It is important to establish whether changing the care environment is a priority for the patient and, if so, to take action urgently. In the hospital setting, please contact ward discharge teams who will be familiar with services available to support the patient and local processes. Please contact therapy teams if equipment is required. The Specialist Palliative Care Team will also be able to assist if needed. For patients remaining in hospital please check whether they would prefer a side room. They will need to be made aware that these are not always available.
Observations and investigations	Please discuss with the patient, and those important to them, and document an agreed plan. This may include cessation of routine observations, commencement of symptom observations (as included in the Shared Care Plan document) and cessation of monitoring (such as blood glucose or blood tests). The plan should be individualised and no beneficial monitoring should be stopped. In circumstances of uncertainty please seek senior support.
Current medication and intervention review	Please review the management plan and drug chart and update, having given careful consideration to the purpose of all medications and treatments. There may be medication prescribed which is unlikely to provide benefit or for which the burden of the medication outweighs any benefit. This may include preventative medications for chronic conditions, antibiotics which have not resulted in an improvement and oral medications for a patient who is now struggling to swallow. No beneficial medication or treatment should be stopped.

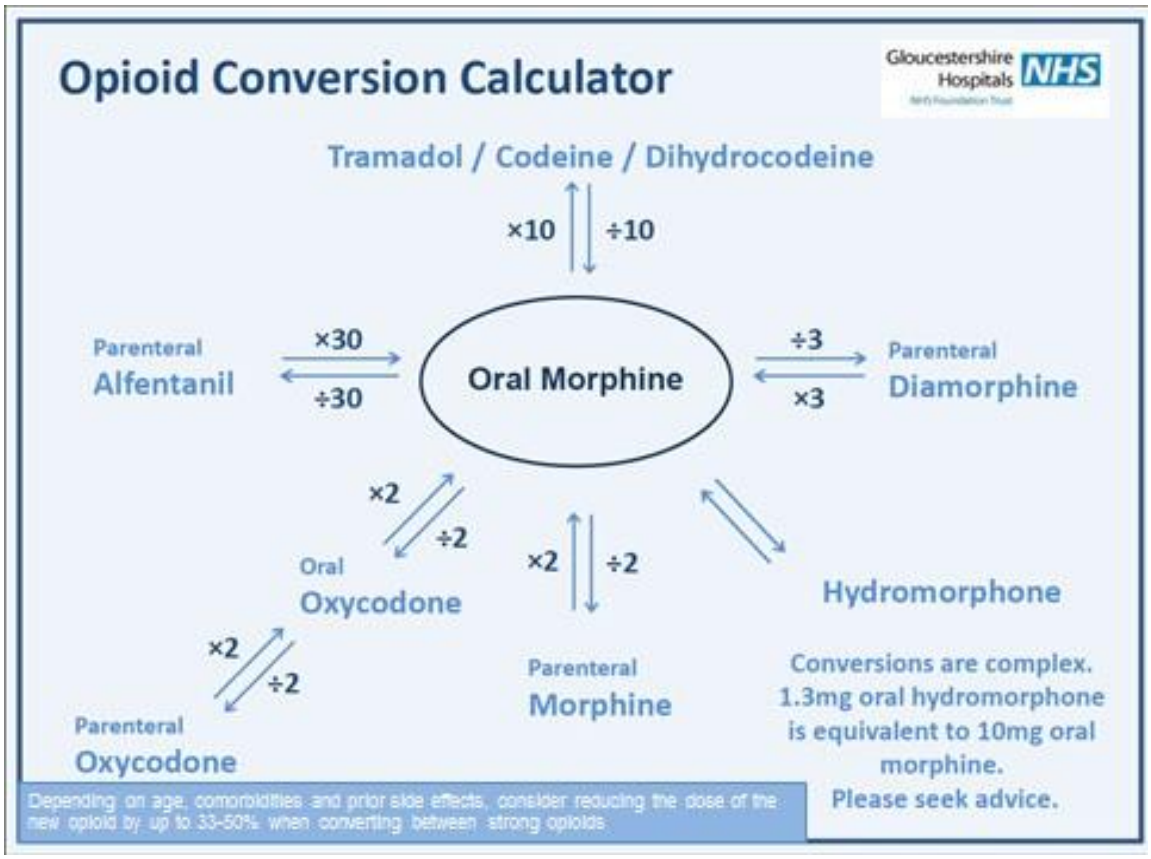
Symptom Control	Dying people do not necessarily experience pain or other symptoms. Patients and families often do not realise this and it can be helpful to let them know. When symptoms do occur it is important to consider the cause and simple non pharmacological measures to relieve them. It is often helpful to prescribe medications to be administered subcutaneously in anticipation of symptoms that may occur when people are dying. Guidance is available on page 7 of the care plan. Please make sure you discuss any medication prescribed, including the potential benefits and harms, with the patients and their family. Further information is available on the palliative care pages of the Gloucestershire Hospitals NHS Foundation Trust website https://www.gloshospitals.nhs.uk/our-services/services-we-offer/end-life-palliative-care/
ICD deactivation	It is not necessary to take any action if a patient only has a pacemaker implanted. However if they have an implantable cardioverter defibrillator (ICD) in place there is a risk that distressing shocks could be administered as the patient dies. Your organisations procedure document should be accessed and followed. Deactivation is undertaken by Cardiac Physiologists. In urgent situations a magnet may be placed over the device to deactivate it. Please follow your local policy or contact a hospital coronary care unit for advice. South west ambulances all carry a magnet for this purpose.
Hydration and nutrition	When people are dying they often eat and drink less. They must be offered food and drink and helped to eat and drink as much as they choose. Should they no longer be able to do so, it is helpful to have a plan agreed with the patient and family as to whether fluids should be administered through a drip. To make this decision it is important to consider the likely burdens and benefits of the intervention. For example, it may help if patients are symptomatic of dehydration such as those experiencing delirium or feeling thirsty. A dry mouth can usually be managed by keeping the patient mouth very clean and moist. Should a drip be prescribed it must be reviewed regularly. Family members can often worry that the patient will die of dehydration without a drip. It is uncertain whether a drip will prolong the life or improve the quality of life of someone who is dying.
Spiritual careneeds	This is often a neglected area for discussion. Spirituality isn't only about religion but about what's important to the person right now. There is an excellent link about many cultures that will inform you of beliefs, rituals and procedures around death and dying. https://www.glos-care.nhs.uk/CulturalAwareness/index.html

Organ and tissue donation	Does the patient wish to donate organs or tissues after their death? Please be aware that for patients with advanced underlying conditions only corneal donation may be possible and additional restrictions exist. Please contact the specialist nurse for organ donation through the Hospital Trust switchboard 0300 422 2222 or National Organ Donor Register 0117 975 7580. Please refer to the flowchart below.



Page 7 - Prescribing for symptom control

Prescribing medication and symptom control	Please refer to Gloucestershire's Palliative Care Guidelines and opioid conversion calculator below. https://www.gloshospitals.nhs.uk/our-services/services-we-offer/end-life-palliative-care/
Is there a special medication prescription chart?	Yes there is a medication prescription chart for anticipatory medicines. Code Y0666 Your organisation should keep a stock of these. See back page for ordering EoLC resources



Page 8 – Nursing team led discussion with patient (refer to page 6 to avoid repetition)

Overview	This is a summary of the discussion you will have with the patient and those close to them. This holistic assessment is essential to plan an INDIVIDUAL plan of care. Consider what's important to them at this time. (This information is in addition to the discussion indicated with blue stripes)
Physical assessment	The aim is to assess any relevant physical state or symptoms, prompts to consider are included within the care plan. There is further information on page 15 of this document.
Psychological assessment	This is often missed. What are the emotional needs of the patient? Use open ended questioning to explore their state of mind, their anxieties. E.g. what are your concerns at this present moment? What do you understand about your condition? How would you describe how you are feeling today?
Social	Depending on the circumstances at the time find out what their preferences are. Consider where would they like to be cared for ideally and if this is different to where they want to die. Is this realistic? Is there a second choice if the first choice isn't possible? Are they expressing a wish about who they would want close to them? Are there pets important to them? Can we help maintain any closeness with the pet or allay fears for the future? https://www.petscorner.co.uk/local-charities/the-cinnamon-trust
Spiritual	An often neglected area in assessment due to staff not approaching the subject. Remember religion is not the same as spiritual and cultural needs. Some may have beliefs, some not. Assessment- what are their beliefs and needs at this time? How do YOU feel addressing Spiritual needs? However uncomfortable it may be for us, remember it's the patient and the family at the centre and what's important to them. It can be helpful to ask 'What's important to you right now? If they have belief or culture that are unknown to you, find out about it and ensure any procedures needed are documented. An excellent link available… https://www.glos-care.nhs.uk/CulturalAwareness/index.html Refer to spiritual care (hospital) team or local clergy/leaders if desired and appropriate. Some may want to talk to family and make peace, say goodbye to loved ones. Some may want special music, candles, massage etc.
Nursing team signature	Remember to sign and print clearly in black ink.
Ongoing assessment and review	Once this initial assessment has been written, regular reviews will be recorded on pages 10-13. Complete your name and signature clearly.

Page 9 – Nursing team led discussion with family/carers

Overview	As you are having this conversation and completing this page, remember that it will not only provide an assessment on the present but can highlight any bereavement concerns.
Understanding of patients condition	Do you know what they have understood? Do they really understand the patient is dying? Has anyone told them? If you don't know, ask them. Ask someone to explain in simple language using no jargon.
Visiting wishes, problems and arrangements	Ask them if they have any problems visiting. Is there anything we can do to help? Do we have permits? Is there an overnight stay room and facilities? Can we help provide refreshments? You may have a leaflet to explain.
Support at home	Are they managing at home? Refer to the GP/other if there are concerns.
Car parking	Use this space to summarise what you have discussed and arranged for the family. It can be a distressing and expensive time if they need to find parking in a hurry or for long periods of time. Does your hospital have a permit available for them to use?
If in hospital – carers badge, overnight stay room and refreshments	What is available in your area? Document what has been discussed and offered.
Telephone numbers for the family/carer	Make sure they have all the numbers they will need. Write them down for them. Even better, have a list or card available for your own ward/home/work area. If in the community - consider district nurses number, hospice at home if being use, spiritual care team, GP, out of hours. There is space on page 27 that can be used for this purpose.
Offered Spiritual care support Spiritual care team	As a result of your assessment, you should be aware of any cultural needs and beliefs they may have. You need to learn about what's important to them and if there are any important things we need to know. For example some religions have requests about what happens after death. If in a hospital, the spiritual team will be able to help. If in the community find out who the best person would be. The patient and family will be able to help and may have it all in hand.

Leaflets available	Familiarise yourself with relevant leaflets that could be of use to the family and those important to them. Consider an end of life care leaflet supply in your own area. There are free county leaflets available such as carers leaflet, what to do after death and grief. Ordering details are on the last page of this guide.
Information Leaflet on page 25/6 "Coping with Dying"	On page 25/26 in this care plan is a tear out leaflet that explains what is happening when someone is dying. The doctor may have already given this to the family, but please check. If you need more copies, please order 'Coping with Dying' Leaflet, details on back page. please download a pdf version from www.gloucestershireccg.nhs.uk/end-of-life
Local leaflets	You may also need to consider other organisations resources such as local hospices (Great Oaks, Longfield and Sue Ryder in Cheltenham) Winston's Wish who support children and young people facing bereavement https://www.winstonswish.org Age UK https://www.ageuk.org.uk/ Carers Gloucestershire https://carersgloucestershire.org.uk Be prepared and have a folder of useful information ready. Consider having a link person to organise this.
Nursing team signature	Please sign and date here.

Pages 10-13 - Ongoing assessment and record of care needs

Who should use this assessment?	This is for use by all the multi-disciplinary team including the domiciliary care, hospice at home. If its appropriate the patient and carer might also want to contribute to it.
How often should it be completed?	This depends on your local area. For example, a ward may complete it every 4 hours, if in the community on each visit, or within any setting more frequently if symptoms indicate it.
How do I use it?	Number 1-11 indicates specific symptoms. Tick in the red, amber or green box indication how severe or dressing the symptom is. The key at the bottom of the page guides you to action which is then completed on page 14 onwards. Numbers 12- 16 are not symptoms but important areas to consider frequently. Report at least daily. Overall condition is expected to be reported on daily as suggested in NICE guidance.
I need more pages!	Continuation sheets are available. Ensure there is a stock in your area. Order code GDH 3174 B see back page for ordering details

1. Pain	Can be... Physical, Emotional, Spiritual. Verbalised or observed? Do you consider it to be severe, moderate or mild? Use the key at the bottom of page.
Possible actions	Using pages 14-23 provide description of where the pain is, the type of pain and any action taken. Review the medication with doctors. Is a syringe pump needed? Consider the use of a pain assessment tool eg. Abbey tool Consider repositioning of patient. Review hourly/4 hrly/each visit – according to your local guidance and policy
2. Nausea and/or vomiting	Assess whether this is severe, moderate or mild, using the key below.
Possible actions	Review medication with doctor. Consider other non-medical and therapeutic help.Are there heavy smells around that contribute? Eg, food, perfumes, scented flowers
3. Agitation	Do you consider the agitation severe, moderate or mild? How does it present? Cause?
Possible actions	Determine cause if possible Exclude urinary retention by clinical examination Exclude constipation. Try and note what/who helps the agitation. Does the patient have dementia? Does a dementia specialist need to be involved?
5. Respiratory secretions	Is this causing distress? Tick in red box if apparent. Respiratory Tract secretions -Is a "rattle" present?
Possible actions	Medication as soon as symptoms arise Consider repositioning Reassure the family and patient

6. Shortness of breath	Is the patient distressed? Indicate by ticking box.
Possible actions	Oxygen may be appropriate and the need should be assessed by a competent clinician. Consider a fan.Therapeutic, relaxing therapies (touch, massage, music, talking)
6. Thirst and Hunger	Is the patient distressed or not? Do they appear thirsty or hungry? Tick the appropriate box.
Possible actions	Continually assess needs of patient which may change as they deteriorate. Explain to the patient and family that patients often lose their appetite. Provide reassurance that changes in oral intake is a natural part of the dying process and there is no need to encourage a person to eat and drink. Give the family guidance on pages 25/26.
7. Dry Mouth	Is the mouth and are the lips dry? Look inside the mouth and tick the appropriate box.
Possible actions	Consider drinks or sips of water. Ask them if they would like an alternative. Consider Vaseline, lip salve, artificial saliva – these sprays and gels can often help. Some find sucking on certain fruit helps- e.g. fresh pineapple.
8. Micturition/ urine output/retention	Do they appear distressed? Assess output by observation. Observe the abdomen for signs of a distended bladder.
Possible actions	Ensure that the patient is not in retention of urine which can be extremely distressing. Are the use of pads or a catheter appropriate?
9. Bowel movements - concerns	Observe and record bowel movements. Report any concerns.
Possible actions	Report and treat any constipation. Report any loose stools. Follow infection control guidance. Maintain dignity and comfort. Observe and care for the skin as appropriate.
10. Skin and pressure areas – including wounds	Is skin intact, red, and broken? Is it causing distress? Is the skin in a satisfactory state?
Possible actions	Do you use an assessment tool? Consider Equipment, mattress, hygiene needs. Re positing of the patient if necessary- be aware that this can cause discomfort at the very end of life. Refer to local policy and introduce additional care bundles if required.
11. Other	Other problems may occur such as hiccups, itching. Use the heading space to describe the problem.
Possible actions	Refer to doctor and treat as prescribed.

12. **Medication**	Assess effectiveness by involving the patient and those important to them.
Possible actions Report at least daily using pages 14-23	Is breakthrough medication required and prescribed? Are just in case boxes ready in their home? (these are being piloted in parts of the county at present). Report effectiveness. Use local policies for medication procedures including syringe pumps. Ensure prescriptions are organised at home. Are plans in place for staff at home to review medication? https://www.gloshospitals.nhs.uk/our-services/services-we-offer/end-life-palliative-care/
13. **Psychological state**	Is the patient distressed? Are the patient and family/carers distressed? Listen to their concerns. Give them time. Regularly revisit these concerns and refer to others if you are not able to relieve the distress. E.g. Spiritual care teams, psychologists, hospices
Possible actions	Listen to their concerns. Give them time. Choose an appropriate environment. Obtain consent from the patient to speak to others where relevant. Regularly revisit these concerns and refer to others if you are not able to relieve the distress. E.g. Spiritual care teams, psychologists, hospices
14. **Spiritual and Cultural needs**	What are their beliefs and needs at this time? Are there cultural needs to be considered?

Pages 14-23 - Care Record: Multi-disciplinary

Who can write in this record?	It's a multi- professional care record which means anyone that contributes to the care can write in it. This can involve the patient and those important to them too. Medical, nursing staff, social care and spiritual care can all contribute to it.
What should I write?	Record any changes, important actions and observations but relate it to a care number (pages 10-13). If it asks for a daily report, then this should be recorded daily. An example : 1. Pain has now been relieved by increased Morphine administered via syringe pump? 12. Syringe pump started at 10 am. The pump has been explained to the patient and wife who both appear to be content with it. 13. Appears calm and less agitated since wife has visited 14. Own minister has visited and Fred took communion. 15. Care plan still appropriate. 16. Wife and daughter have been seen by the medical team who explained that his condition is deteriorating. There is no need to write on every care number at each visit.
Continuation sheets	Order Code GDH 3174 C – details on back page

Page 24 - Care of patient and family/carers after death

Verification of death (By medical staff and staff trained in the verification of death)	Find out how death is verified in your area and follow local policy Record the date and time at which the death occurred. Contact the appropriate practitioner to verify the death. A registered nurse can verify an expected death after receiving training and deemed competent check local policy. *https://www.nice.org.uk/guidance/qs13/chapter/quality-statement-13-care-after-death-verification-and-certification* *https://www.bma.org.uk/advice/employment/gp-practices/service-provision/confirmation-and-certification-of-death*
Care of the patient after death	• Follow the organisations/local care after death/last offices policy. • Support Advance Care Planning wishes e.g. organ or tissue donation. • Discuss with family/carers specific requests e.g. choice of clothing, undertaker, burial, cremation. Allow the opportunity and time for further questions.
Religious and cultural considerations of the patient and family Preferred Funeral director Buried or cremated Other wishes Tissue donation requests	Are there any specific wishes or requirements? (These should have been identified clearly in previous discussions). Be aware that some cultures may dictate that the body should only be touched by family, or that the body needs to leave your premises as soon as possible, or that the funeral needs to take place within a certain time frame. For more information regarding cultural and religious considerations visit: *https://www.glos-care.nhs.uk/CulturalAwareness/communities.html* Organ and Tissue Donation - see page 11 of this guidance. Follow local policy. If in doubt contact the organ donation specialist nurse through the hospital switchboard. This may have been specified on admission contact GHT 0300 422 2222 or National Organ Donation Register 0117 975 7580.

Care of the family/ carers	End of life care continues with caring for the bereaved. Consider the following: • Follow bereavement policy • Consider and respect information needs of the patient's family/friends/carers. • Do you have a private space where you can speak to the bereaved? Allow opportunity and time for further questions. • Refer to bereavement policy – trust or organisational and countywide bereavement guidelines • Provide information on registering a death e.g. CCG Leaflet 'What to do after a Death - a practical guide. Code: GDH3611 (see back page) *https://www.gloucestershireccg.nhs.uk/wp-content/uploads/2018/01/GDH3611_What-to-do-AfterADeath_2017-Dec-1st-reday-for-PRINT.pdf* • Provide information on Bereavement e.g. CCG leaflet 'Grieving the loss Code: GDH1912 (see back page) *https://www.gloucestershireccg.nhs.uk/wp-content/uploads/2018/01/GDH1912_Grieving-the-loss-of-someone-FINAL-OCT-17.pdf* / • Local leaflets e.g. Winston's Wish Is this name for the leaflet right? It has a different name in the PDF • Provide advice and local bereavement support available e.g. CRUSE, Hospices and other local group's referral to GP. • Are there any further concerns about how the family/friends/ carers might cope? Gloucestershire Hospitals NHS Foundation Trust has a bereavement office, it may be useful to pay a visit and find out what happens there. • How do you care for the bereaved? Do you see them again? Where can they get support?
Plan to collect belongings	Ensure the family are aware of when to come, and where to collect, the belongings. Think about how and where they will receive the property. Find a private area if you can. Make sure the property is well presented (not in a black bag). This will be an emotional and upsetting time for the person collecting. Plan a time when they will be given a private space and time to talk. Don't forget the jewellery and valuables which should be locked away.
Any concerns about how the bereaved might cope.	Have there been signs that the bereaved will have difficulty coping? Do they live alone? Do they have support? Do we need to make their GP aware of your concerns?
List the professionals involved in the care (if known)	It's important to contact those professionals who you know were involved. For example, the GP, community teams, hospice teams, Brokerage etc. This is important not only for recording keeping but for the emotional well- being of staff. It can help bring closure.

Pages 25/26 - 'Coping with Dying' information sheet

Who can this be offered to?	Usually family or those important to the patient. Be aware that some people do not want this information. It contains detailed information on the last few days or hours of life.
Can the patient see it?	Yes. If they indicate they would find it helpful. If patients want a different leaflet, please contact the palliative care team.
Who gives the leaflet and when?	This can be offered at the initial discussion by the doctor, nursing team or when family start asking questions about what might happen to the person as they die.
There is only one tear out leaflet "coping with dying". Can we order more?	Yes you can. Order details on the back page of this guidance. GDH 3174 D
What do we do with the care plan after death?	Once complete, photocopy or scan and file the original care plan into the patients notes. Record the death electronically if this is your policy.

Pages 27/28 - Notes and Back page

Notes page	Please use this for any other useful information.
Back page	This contains a list of resources to order that relate to this document. Please contact PALS at Sanger house 0300 421 1500 for any other formats required.

Additional Guidance for staff, the patient and family/ carers

CCG website https://www.gloucestershireccg.nhs.uk/about-us/contact-us/ Glos. Clinical Commissioning

Local NHS Trusts	
http://www.gloshospitals.nhs.uk/	Gloucester and Cheltenham hospitals – Acute
https://www.glos-care.nhs.uk/	Community NHS Trust
https://www.2gether.nhs.uk/	Mental Health and Learning Disability NHS Trust

Hospices	
http://www.great-oaks.org.uk/	Coleford, Forest of Dean Day hospice, hospice at home
https://www.longfield.org.uk/	Minchinhampton, Stroud Day hospice, hospice at home
http://www.sueryder.org/care-centres/hospices/leckhampton-court-hospice	Cheltenham: In-patient beds, day hospice and hospice at home

For professional palliative care advice

In hours: 9-5 Mon-Fri excluding bank holidays	Gloucestershire Royal Hospital: Cheltenham General Hospital:	0300 422 5179 0300 422 3447
Community Single Point of Access:		0300 422 5370
Out of Hours: Weekends & Bank holidays	Please call the hospital Switchboard:	0300 422 2222
Medicines Information Service:	Glos. Royal Hospital Cheltenham General Hospital	0300 422 6108 0300 422 3030

Ordering of FREE Resources

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

How to Order:

1. E-mail *Tessa@colourconnection.co.uk* or phone 01452 522411 giving delivery address
2. Please do not order more than you expect to use in a 6 month period.

Title	Code
Planning for your Future Care -Introductory Leaflet	GDH 1909 L
Planning for your Future Care – A4 Advance Care Planning Booklet	GDH 1909
Best Interest Decisions Booklet for EoLC - Booklet	GDH 3050
Preparing for End Stage Dementia – A Carers Leaflet	GDH 3221
Staff Guide Toolkit to Support Best Interests	GDH 3074
Shared Care Plan for the Expected Last Days of Life	GDH 3174
Continuation Sheet – All people 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

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