

Patient details

NHS No..... Forename..... Surname..... D.O.B.....

Shropshire and Telford & Wrekin End of Life Care Group

End of Life Plan



Shropshire Community Health **NHS**
NHS Trust

The Shrewsbury and Telford Hospital **NHS**
NHS Trust

NHS
Telford and Wrekin
Clinical Commissioning Group

NHS
The Robert Jones and Agnes Hunt
Orthopaedic and District Hospital
NHS Foundation Trust

NHS
Shropshire County
Clinical Commissioning Group

Caring for adults in the last few hours and days of life



Patient Name: _____ DOB: _____

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Shropshire and Telford & Wrekin End of Life Plan

Caring for adults in the last few hours and days of life

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Appendix 1:

Guidance for Dying Patients Severn Hospice

Pain Flow Chart

Nausea and Vomiting Flow Chart

Restlessness/Agitation Flow Chart

Respiratory Secretions Flow Chart

Breathlessness Flow Chart

Appendix 2:

Information Sheet for Relatives/Friends

Appendix 3:

Community prescription/syringe pump sheets and Nursing Continuation Sheets to be added by community teams as needed

Written by Shropshire Clinical Commissioning Group, Telford and Wrekin Clinical Commissioning Group, Shrewsbury and Telford Hospital NHS Trust, Shropshire Community Health NHS Trust, Severn Hospice and Shropshire Partners in Care.

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Preface

This End of Life Plan has been created to address the holistic needs of the dying person by providing supportive and compassionate person-centred care. It is imperative that all treatment and care provided is of the highest standard and quality. This care must be respectful and dignified and delivered by all involved in a spirit of cooperation and collaboration. The dying person and their family must be at the centre of all care provided. To achieve this, the principles of dignity conserving care¹ will be adopted to guide all decisions and care provided.

A.	Attitudes	Those caring for the dying must examine their own attitudes and assumptions towards death and dying. Positive attitudes will ultimately shape the experience of those in receipt of end of life care.
B.	Behaviour	Behaviour stems from attitudes and values. Behaviour should be predicated on kindness and respect. This can be reflected in the way even the smallest acts of care are performed. The aim of this End of Life Plan is to affirm the worth and self-esteem of the dying patient and their family.
C.	Compassion	Compassion is about recognising the suffering and pain in another and having the desire to alleviate and relieve this for the dying person. Compassion is more than just an intellectual awareness, it is something far deeper. Compassion moves beyond physical acts of care as it is felt and experienced emotionally and spiritually. Compassion is communicated through verbal and non-verbal channels, for example the way we approach the dying person or use touch to convey presence offering reassurance.
D.	Dialogue	Dialogue is the outcome of A, B, C working synonymously and effectively. Attitudes, behaviours and compassion will lead to a deeper engagement and understanding of the needs of the individual and their family and friends. Dialogue is about elucidating the personal narrative and biography of the individual. It is about knowing who they are and, glimpsing their own unique dignity and identity. Therefore, dialogue is essential if the dying person is to be understood and have their personhood affirmed. Dialogue is not a one-off activity but a continuous and cyclical process that captures and supports the dignity of the dying person as situations and needs change.

Adoption and adherence of these principles will provide a framework for promoting and preserving the dignity of the dying person. It involves all those involved in the implementation of the End of Life Plan being reflective and prepared to change long established attitudes and behaviours that may have a negative and detrimental impact on end of life care.

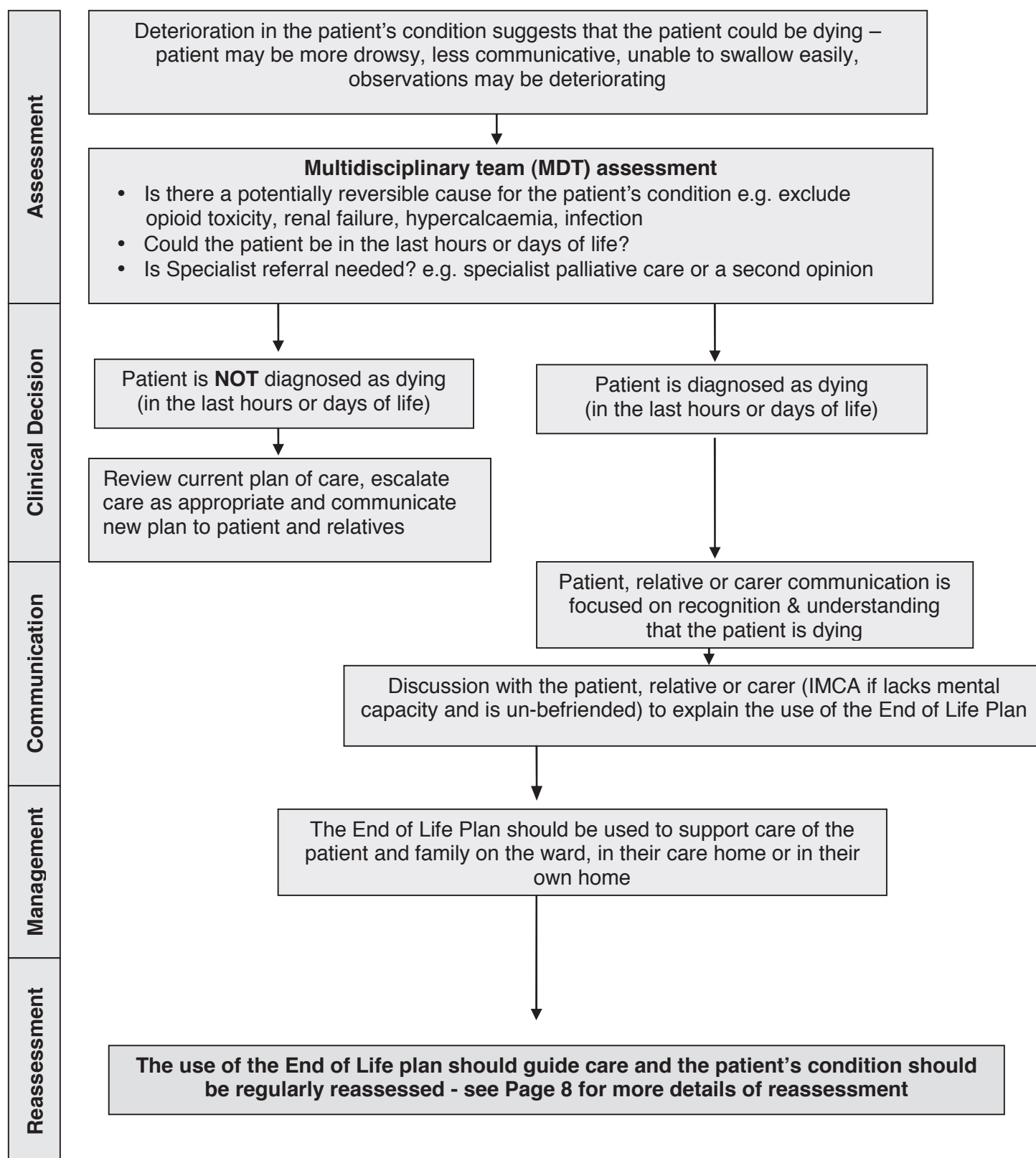
Fundamentally, the framework places the dying person and their dignity/identity at the centre of care delivery encouraging dialogue and a compassionate approach. The A, B, C, D will foster an environment and relationships where trust, honesty and openness flourish and the dignity of all is conserved.

¹ Chochinov, H M (2007) Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. British Medical Journal 335:184–187

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Diagnosing dying and using the End of Life Plan to support care in the last hours or days of life



Further help and advice on caring for dying patients is available from Severn Hospice (01743 236565 & 01952 221350). Their nurses and doctors are available 24/7.

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Initial assessment (to be completed by medical staff known to the patient)

The decision to use the End of Life Plan should be made by the doctor in charge of the patient's care. For patients at **home**, this plan must be initiated by the patient's GP, usually in conjunction with the district nursing team. The practice computer should be used to record additional information and the District Nursing team should continue to use their own records. In **residential or nursing homes** the End of Life Plan should be completed by a GP and senior nurse/care manager.

- The patient should be '**flagged**' with the **out of hours medical team** as receiving end of life care. This can be done by telephoning the **Care Co-ordination Centre** on 0333 222 66 55 or using your GP practice on line login at <https://shropdoc.advhc.net/awa>
- Please issue a **just in case box** in the community with anticipatory prescribing and complete the prescription sheet
- Please consider fast tracking the patient to the Continuing Health Care team by telephoning your local CCG

In **hospice or hospital**, this plan should be completed by a senior doctor at registrar level or above in conjunction with the most senior nurse on the ward, usually a ward sister or charge nurse.

Discussions with the patient and their relatives should be recorded in full. In hospital, this document should be completed and filed in the current admission section of the medical records and/or within nursing documentation. The community kept within patients homes, care home within patient records. The medical / nursing records should **continue to be used for documentation** after this initial assessment has been carried out and the following **3 pages** completed.

Date of decision to use this plan: _____ Time: _____

Name/Signature of decision-makers: _____

Grade: _____

Name of person completing document: _____ Grade: _____

Name of Consultant (if in Hospital) or GP if different from above: _____

Informed? Yes ☐ Date and Time: _____

(Please make the patient's usual team aware at earliest convenience)

Death very likely to occur in the next few hours and days and potentially reversible causes have been considered:

Main diagnosis if known-

Comments:

Patient's preferred place of care (home, hospital, hospice, care home, other) discussed with patient and family/carers, and discharge home has been considered if patient is in hospital.

If in hospital and wishing to go home for end of life care consider fast track checklist / communication with pharmacy re medication for discharge.

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Discontinuing inappropriate interventions

	Currently not being taken / or given	Discontinued	Continued
Routine blood tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intravenous Therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood glucose testing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recording vital signs (‘observations’)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oxygen therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-palliative medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intravenous re- cannulation if needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do Not Resuscitate decision

Do Not Resuscitate (DNR) / Allow Natural Death (AND) form already completed ☐
DNR/AND form completed now ☐

Implantable Cardioverter Defibrillators (ICD) if present needs to be deactivated –
contact cardiorespiratory at PRH or RSH, or CCU out of hours via the
hospital switch board RSH 01743 261000 or PRH 01952 641222

Advance directive completed ☐ Lasting power of attorney (Health and Welfare) ☐

Artificial hydration and nutrition

Support patient to take fluids by mouth for as long as they can. For most patients the use of artificial hydration and nutrition will not be required. A reduced need for fluids is part of the normal dying process and should be explained to patients and relatives.

Any artificial hydration & nutrition e.g. nasogastric or PEG feeds should be discontinued or reduced when patients are dying. Patients should be supported to eat as they feel able.

Good mouth care is essential. Symptoms of thirst / dry mouth do not always indicate dehydration but are often due to mouth breathing or medication.

Decision made at time of initial assessment that clinically assisted hydration is:

Not required ☐ Discontinued ☐ Continued ☐

(If in place consider reduction in rate / volume according to individual need. If required consider the s/c route, please briefly document reasons for decision Rationale and explanation discussed with patient and/or family) ☐

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Nursing / Therapy Issues

Spiritual Issues

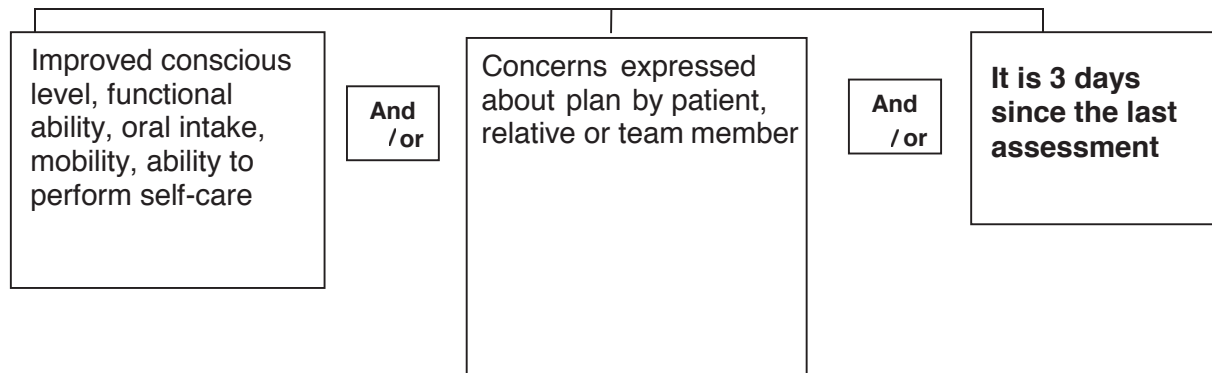
Please document any spiritual issues here. Spiritual issues may involve exploring personal, religious or spiritual beliefs including questions of faith, in self, others and for some people this may include belief in God, deity or higher power. Therefore, with the consent of the patient/next of kin, there may be a need to refer to the person's own religious / faith representative or chaplain. Spiritual issues may also involve questions about hope, trust, meaning and purpose and forgiveness. It may require discussion about peoples' values, love and relationships and questions about morality or what is fundamental to the preservation of their dignity and self-identity. Spiritual issues may also be expressed through creativity such as art, music and poetry.

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Repeat Assessment

Undertake an MDT assessment & review of the current management plan if:



Consider the support of the specialist palliative care team and/or a second opinion as required. Document reassessment dates and times in the medical and nursing notes. Please use the nursing continuation sheets for the End of Life Plan if the patient is being looked after at home.

If the patient improves and is no longer expected to die within the next few days then the End of Life Plan should be discontinued:

Date and Time End of Life Plan discontinued: _____ / _____ / _____ at _____

Reasons End of Life Plan discontinued:

Name/Sign: _____

Patient Name: _____ DOB: _____

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Care After Death

Verification of Death (please document here if patient dies at home or in a nursing/residential home, otherwise use the medical notes)

Verification of Death carried out as per policy/guidance and documentation completed ☐

Date of patient's death: ____/____/____ Time of patient's death: _____

Details of healthcare professional who verified death:

Name: _____ (please print)

Position: _____

Signature: _____

Contact telephone number: _____

Comments: _____

Persons present at time of death: _____

Relative / carer present at time of death: Yes ☐ No ☐

If not present, have they been notified: Yes ☐ No ☐

Is there any requirement for the medical team to inform / discuss with the coroner's office?
Yes ☐ No ☐ If Yes, Comments:

Any special requirements after death?

E.g. any cultural or religious requirements

Care after Death have been undertaken: Yes ☐ No ☐

Conversation with relative or carer explaining the next steps: Yes ☐ No ☐

'What to do after a death' or equivalent booklet given to relative: Yes ☐ No ☐

Document to be taken by District Nurses for storage in the Community / in Care Homes store in patient notes.

Prescribing Guidance for Dying Patients



Most patients are comforted by the knowledge that medication is helpful and available if required at the end of their life.

The following flow charts are to be used as a guide for patients in their last hours of life. Further information is available from the West Midlands Palliative Care Physicians “Guidelines for the use of drugs in symptom control” www.wmpcg.co.uk and the Palliative Care Formulary.

Please follow the below link for Opioid Conversion Guidance and other useful information.

<http://www.severnhospice.org.uk/for-healthcare-professionals/gp-info-hub/>

Review drug/ dose/ frequency for patients who are elderly, frail, have dementia or renal failure and seek advice.



PAIN AT THE END OF LIFE

Is patient already on opioid drugs and unable to tolerate or absorb oral medication?

YES

Patient on MR Morphine/Oramorph

- Divide 24 hour total dose of current **oral** Morphine by 3 and prescribe this as Diamorphine (mgs) via syringe pump over 24 hours
- Prescribe 1/6th Diamorphine syringe pump dose for breakthrough/rescue medication to be given hourly if needed
- Start syringe pump 4 hours before next oral opioid dose would have been due
- Discontinue oral opioid

Review within 24 hours

If extra medication has been needed for pain:

- Increase syringe pump dose by total amount of rescue Diamorphine given or by 50% whichever is less
- Adjust rescue/breakthrough dose to 1/6th of syringe pump Diamorphine dose to be given hourly if needed

If pain is controlled, make **NO** changes
Continue to review dose requirements regularly

Patient on weak opioid

(Codeine, Tramadol, Dihydrocodeine)

- Stop oral weak opioid
- Start Diamorphine 10mg/24 hrs by syringe pump soon after last oral dose
- Prescribe Diamorphine 2.5mg sub-cut hourly if needed for rescue/breakthrough pain

Review regularly and adjust as above

Fentanyl patch: continue patch and supplement with sc Diamorphine prn and add in a syringe pump **if** needed.

Renal impairment: GFR < 30 seek advice

NO

Scenario 1: "planning ahead"

Patient not in pain

- Prescribe Diamorphine 2.5mg - 5mg sub-cut hourly if needed
- If patient later develops pain, proceed to next box

Scenario 2: "act now"

Patient in pain

- Give Diamorphine 2.5mg sub-cut stat
- Prescribe and start Diamorphine 10mg/24h by syringe pump
- Prescribe Diamorphine 2.5mg sub-cut for rescue/breakthrough pain to be given hourly if needed

Review within 24 hours

If extra medication has been needed for pain:

- Increase syringe pump dose by total amount of rescue medication given or to 20mg/24hrs, whichever is less
- Increase rescue/breakthrough dose of Diamorphine to 5mg sub-cut to be given hourly if needed

If pain is controlled, make **NO** changes

Review within 24 hours

If extra medication has been needed for pain:

- Increase syringe pump dose by total amount of rescue Diamorphine given or by 50%, whichever is less
- Adjust rescue/breakthrough dose to 1/6th of syringe pump Diamorphine dose to be given hourly if needed

If pain is controlled, make **NO** changes
Continue to review dose requirements regularly

If symptoms persist or you need advice please contact the Palliative Care Team or Severn Hospice.



NAUSEA AND/OR VOMITING AT THE END OF LIFE

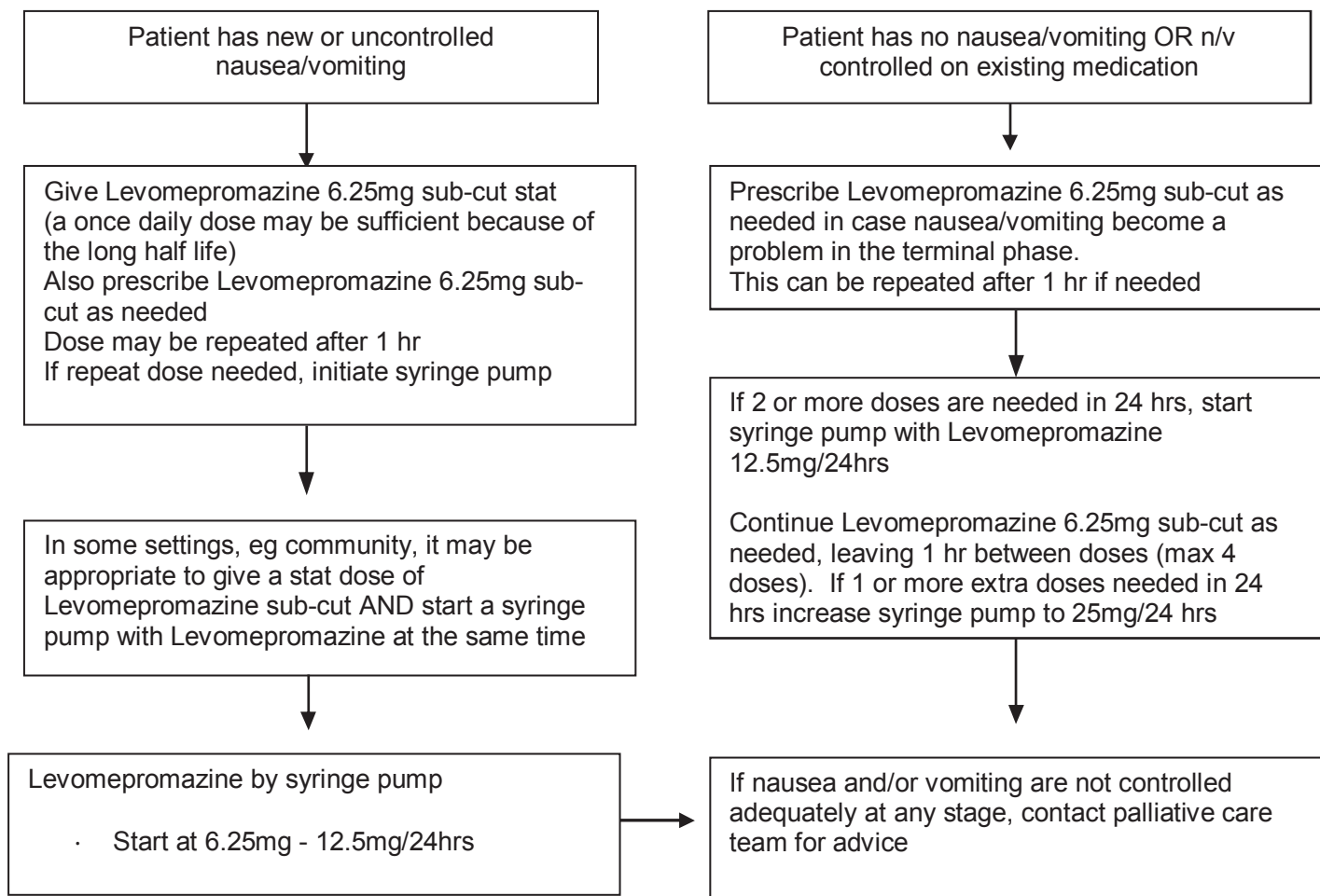
Important note: this guidance applies to the end of life ONLY

Effective palliation of nausea and vomiting earlier in the illness requires a cause-specific approach

Patients entering the terminal phase with **good symptom control** from an oral anti-emetic should **continue the same drug** given via a syringe pump when they are unable to take oral medication.

Domperidone should be replaced by Metoclopramide and Prochlorperazine (stemetil) by Cyclizine.

For new symptoms of nausea/vomiting that are difficult to control Levomepromazine (Nozinan) is recommended because of its broad spectrum of action.



Levomepromazine doses above 25mg/24 hr has a sedative effect.

If symptoms persist or you need advice please contact the Palliative Care Team or Severn Hospice.



RESTLESSNESS / AGITATION AT END OF LIFE

Consider and manage common causes of restlessness, eg. Urinary retention, faecal impaction, hypoxia and pain.

PATIENT IS RESTLESS/AGITATED

PATIENT IS NOT RESTLESS/AGITATED

Non-drug intervention is essential: reassurance, calm environment, consider the use of sound / music. Have you taken into account their spiritual needs?

Immediate management

Give medication sub-cut stat:

Midazolam 2.5 - 5mg

OR

Haloperidol 2.5mg

Start syringe pump:

Midazolam 10 - 20mg/24h

OR

Haloperidol 5mg/24h

Prescribe rescue doses sub-cut hourly:

Midazolam 2.5 - 5mg

AND/OR

Haloperidol 2.5mg

Planning ahead

Prescribe sub-cut hourly as needed

Either Midazolam 2.5mg

OR

Haloperidol 2.5mg

Review within 24 hrs

If 2 or more doses needed **and are effective**, start syringe pump of same drug (see left)

If 2 or more doses tried **but are not effective**, switch to the other drug or consider Levomepromazine (see below)

Review within 24 hours

Midazolam:

1-2 extra doses, increase driver dose by 50%,
3 or more extra doses, double driver dose
Continue rescue doses of 5mg sub-cut prn
If Midazolam driver dose > 40mg/24hrs, consider Levomepromazine and seek advice.

Haloperidol:

Any extra doses, increase driver dose to 10mg/24h and continue rescue doses
Max haloperidol dose 20mg/24hrs

Midazolam and Haloperidol are very effective when used in combination

Persistent symptoms

Levomepromazine:

- Is an effective **sedative**
- It may be added to Midazolam (if Midazolam partly effective) or used to replace haloperidol.
- Start syringe pump at 25mg/24h
- Use rescue dose 12.5mg sub-cut hourly as needed

Higher doses are sometimes needed please discuss with the Drs, Palliative Care Team or Severn Hospice if doses over 50mg/24hrs are used

If symptoms persist or you need advice please contact the Palliative Care Team or Severn Hospice.



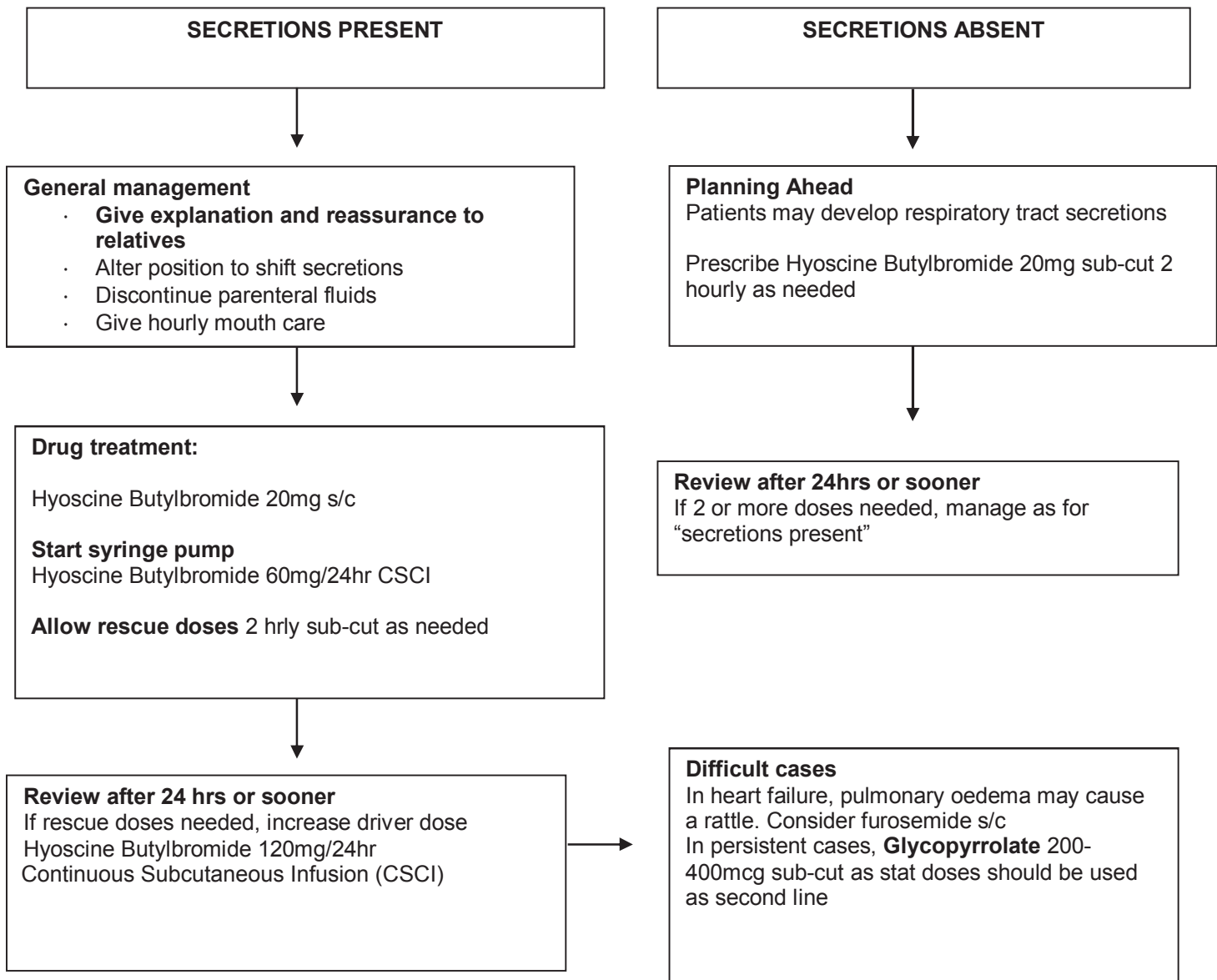
RESPIRATORY TRACT SECRETIONS IN A DYING PATIENT

Dying patients may be unable to cough effectively or swallow, which can lead to retained secretions in the upper respiratory tract. There is little evidence to support the effectiveness of drug treatment for this symptom. If the patient appears comfortable and not distressed reassure relatives and staff.

Hyoscine Butylbromide is our drug of choice to use for respiratory tract secretions at end of life

Hyoscine Butylbromide is non-sedating; Note it does not mix well with Cyclizine in a syringe and blocks the prokinetic antiemetic action of Metoclopramide

If rattling breathing is associated with breathlessness in a semiconscious patient add in an opioid +/- an anxiolytic sedative (midazolam)

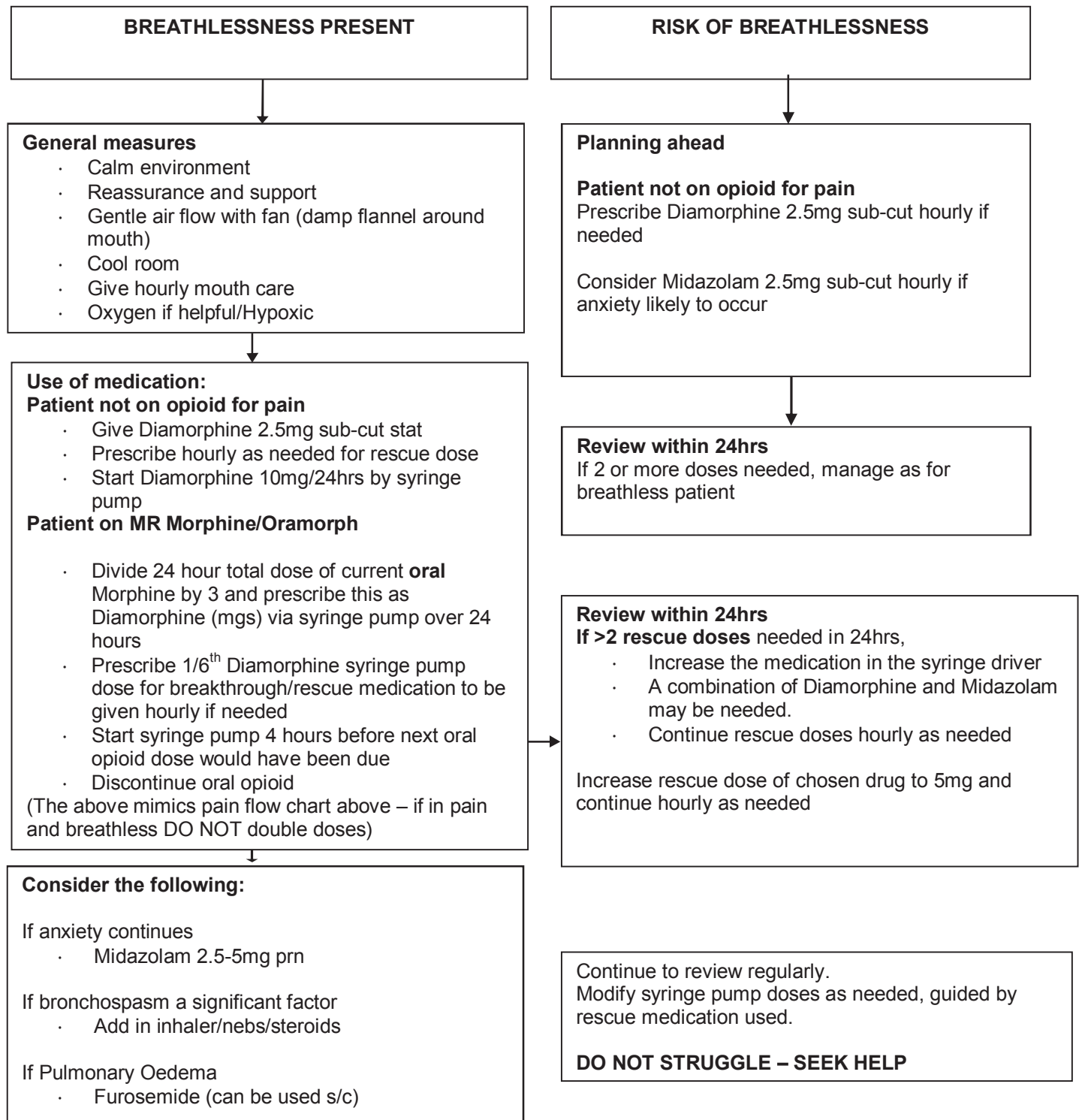


If symptoms persist or you need advice please contact the Palliative Care Team or Severn Hospice.



BREATHLESSNESS AT END OF LIFE

Terminal breathlessness is very frightening and must be treated as a serious symptom, untreated it can lead to escalation of symptoms, distress and terminal agitation.



If symptoms persist or you need advice please contact the Palliative Care Team or Severn Hospice.





Information sheet for relatives / friends following a discussion about end of life care.

The doctors and nurses will have explained to you that there has been a change in your relative's condition. They believe that they are now in the last hours or days of life.

The End of Life Plan helps doctors and nurses to give the best care to your relative. You will be involved in the discussion regarding the plan of care with the aim that you fully understand the reasons why decisions are being made. If your relative's condition improves then the plan of care will be reviewed and changed.

- **Communication**

Written information leaflets like this one can be useful, as it is sometimes difficult to remember everything at this time. The doctors and nurses will ask you for your contact details, as keeping you updated is a priority. There is space at the bottom of this leaflet to jot down any questions you may have for the doctors and nurses.

It can be very difficult to predict precisely when someone who is dying will pass away. For some relatives and friends it is very important that they are present at the moment of death. Others will feel they have already said their goodbyes. Please let us know your specific wishes so that we can try and ensure that they are carried out.

- **Medication**

Medicine that is not helpful at this time may be stopped. People often find it difficult to swallow lots of tablets. Some new medicines may be prescribed and these are often given as a small injection under the skin. Medicines for treating symptoms such as breathlessness, pain or agitation will be given when needed. Sometimes they can be given continuously in a small pump called a syringe pump, which can help to keep patients comfortable.

- **Reduced need for food and drink**

Loss of interest in eating and drinking is part of the dying process and it can sometimes be hard to accept. Your relative will be supported to eat and drink for as long as they want / are able to.

If a patient is in hospital and cannot take fluids by mouth, a drip may be considered, or may have been started before it became clear that your loved one is dying. Fluids given by a drip will only be used where it is helpful and not harmful. These decisions will be explained to you.

Good mouth care is very important at this time and can be more important than fluids in a drip in terms of feeling comfortable. The nurses will explain to you how mouth care is given and may ask if you would like to help them give this care.

- **Changes in breathing**

When someone is dying, their need for oxygen may lessen and the way they breathe may change. People who have been breathless may feel less breathless at this time. Their breathing may pause for a while and then start again. They use different muscles to breathe, which means their breathing may look different. Sometimes breathing can sound noisy or "rattling" because the person is no longer able to cough or clear their throat. This can sound upsetting but is generally not distressing for them.

- **Changes in how the person looks and behaves**

During the process of dying, a person's skin may become pale and moist. Their hands and feet can feel very cold and sometimes look bluish in colour. Dying people often feel very tired and will sleep more. Even when they are awake, they may be drowsier than they have been and they will be awake less and less. They may still be aware of the presence of family and friends so you can still talk to them.

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● **Support for family and friends**

It is sometimes easier to cope with things at this difficult time if you have someone outside your immediate family to talk to. For patients at home or in a residential home, the District Nurses, patient’s GP and Clinical Nurse Specialists can offer support. For patients in a nursing home the home’s nurses along with the patient’s GP will offer care and support and will have arrangements with various faith representatives to provide further comfort and support. For patients in hospital or in the hospice, the ward nurses can support you or contact the Specialist Palliative Care Team. The hospital chaplaincy is also very happy to offer comfort and support to people of all faiths or none, and can be contacted by the ward nurses or doctors.

Caring well for your relative or friend at the end of their life is very important to us. Please speak to staff and ask any questions that occur to you, no matter how insignificant you think they may be.

Other information or contact numbers:

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This space can be used for you to list any questions you may want to ask the doctors and nurses:

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