



In partnership with:

West Suffolk NHS Foundation Trust, The Ipswich Hospital, Suffolk Community Healthcare, St Nicholas Hospice Care, St Elizabeth Hospice, Adult Community Services, NHS Ipswich and East Suffolk Clinical Commissioning Group and NHS West Suffolk Clinical Commissioning Group

Suffolk End of Life Care Guidelines

Supporting the delivery of end of life care in Suffolk

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SECTION 1: INTRODUCTION

This document has been produced as a guideline for best practice end of life care in Suffolk. This should be used in conjunction with your individual organisation's own policies and procedures.

1.1 Key Guiding Principles for an Individual within the Last Year of Life

Five key principles of care for the dying patient, C.R.I.S.P:

- Communicate
- Recognise
- Involve
- Support
- Plan & Do

[Key Principles for the Dying Patient](#)

Suffolk Hospice and Hospital Contact Details:

West Suffolk Hospital Palliative Care Team: 01284 713776

St Nicholas Hospice Care: 01284 766133

The Ipswich Hospital: 01473 704932

St Elizabeth Hospice: 01473 727776

N.B. All care planning and associated documents should ideally be completed with the individual and those important to them.

SECTION 2: ASSESSMENTS AND ADVANCE CARE PLANNING

2.1 Recognising the need for Advance Care Planning

All key documents relating to Advance Care Planning and guidance on completion can be found within the My Care Wishes Folders (MCWs).

- **My Care Wishes**

The yellow My Care Wishes folder (MCWs) is a patient held record/folder that supports patients with long term conditions or at end of life by starting vital conversations earlier in an individual's care pathway to allow an individual and family/carer to make choices around their preferred place of care and death. MCWs also provides clear guidance on how an individual would like to be cared for in an emergency situation. All patients at the end of life should have a yellow MCWs folder, which should remain with the individual throughout their care pathway.

MCW folder contents:

- DNACPR and associated Guidance for completion
- Personalised Shared Care & Support Plan and associated Guidance
- Thinking Ahead
- Directory of Key contacts
- Rockwood Frailty Score
- SCRai information and consent
- Tissue donation

MCWs folders are funded and available directly from both Ipswich and East Suffolk CCG and West Suffolk CCGs. Most GP surgeries will hold a small stock. Please contact:

West Suffolk CCG on 01284 758016 or Ipswich & East Suffolk CCG on 01473 770000

To access the above documents [click here for WS CCG](#), and [here for I&ES CCG](#)

[Gold Standards Framework \(GSF\)](#)

2.2 Holistic assessment and other assessments

Each organisation will have their own paperwork to support holistic assessment providing a guide to what information should ideally be recorded.

A holistic assessment of the needs of the patient and those important to them should be conducted soon after identification of need or as likely to be in the last year/few months of life. Repeat assessments will be required at regular points and at times of change or worsening symptoms. The frequency of review should be adjusted according to the patient's needs and preferences, and those of the people important to them. Results of assessments should be shared (if consent is given) between hospital, general practice, community teams, hospices and any other relevant healthcare institutions. The nature and extent of the assessment may change between each care environment. It is acknowledged that all information might not be collected at the same time and that the process of a holistic assessment can be spread out over an extended period in order to not over burden patients or those important to them.

2.3 Mental Capacity Assessment (MCA)

The Mental Capacity Act 2005 is designed to empower and protect individuals who lack the mental capacity to make decisions about their care and treatment.

Everyone working with or caring for **adults** who lack the mental capacity to make decisions **must comply with the Mental Capacity Act** (MCA) when making decisions or acting for that person.

The Mental Capacity Act 2005 (MCA) says that, a person lacks capacity in relation to a specific matter at a particular time, if at the specific time s/he is unable to make a decision for himself/herself because of impairment in the functioning of, the mind or brain. However, the Act states that every adult has the right to make his own decisions and must be assumed to have capacity unless it is proved otherwise. It is this primary key principle on which the Act and this guidance is based.

The Act is upheld by **five Statutory Principles**:

- A person must be assumed to have capacity unless it is established that they lack capacity
- A person is not to be treated as unable to make decisions until all practical steps to help them to do so have been taken without success
- A person is not to be treated as unable to make a decision merely because they make an unwise decision
- An act done or decision made under the Act for or on behalf of a person who lacks capacity must be done or made in their best interests

- Before the act is done, or decision is made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action

For more information, please contact: www.suffolk.gov.uk/mca

2.4 Carers assessment

Assessment of carer's needs by healthcare staff is encouraged in section 3 of "Holistic common assessment of supportive and palliative care needs for adults requiring end of life care" (National Cancer Action Team, 2010). Proactively assessing the nature and level of care given by a carer is part of best practice. The act of assessing needs might be all that is needed. It might also be the vehicle for mobilising help that could enhance the care of the ill person, support the physical and mental health of the carer, and potentially prevent inappropriate institutional admission. The aim of a carer's assessment should be to judge the ability and willingness of the carer to sustain this role.

For more information, please contact: Suffolk Family Carers on 01473 835477.

SECTION 3: COMMUNICATION AND INVOLVEMENT

3.2 Care after dying

Verification of expected death (VOED) is an important stage in the process for relatives and carers. Until this has been performed, no further action can be taken with regard to the deceased. If this process is delayed because of the unavailability of a doctor, (especially out of hours, due to prioritisation of most urgent need) relatives and carers may be left for a significant time, unable to begin what should be a normal process.

All organisations will have a VOED Policy, produced to enable registered nurses to verify expected adult death and to ensure that verification of expected adult death is carried out promptly to reduce relatives anxiety and within legislative guidelines. Training is also available to support this process (see section 4 below).

3.3 Donation of corneas and other tissues

Most people are in favour of organ and tissue donation, but unaware that they may still be able to donate something, even if dying of cancer or other illnesses. Many people can donate their corneas, and a few can also donate other tissues. (Organ donation is generally only an option for a minority of people, dying in Intensive Care Units.) Donated tissues can offer huge benefits to many people, restoring sight and other functions, or in some cases saving lives. Local research with Suffolk individuals has shown that patients and families prefer to be given the option to decide for themselves, and do not find it distressing to be given this information.

For more information, please contact: [NHS Blood and Transfusion Service](http://www.nhs.uk/bloodandtransfusion) on 0800 432 0559 or [St Nicholas Hospice Care](http://www.stnicholas.org.uk). An information sheet is also available within the MCWs folder.

3.4 Communication

Effective communication should be maintained with patient, family and carers. An assessment should be made of the patient's insight into the situation together with the partner and family. Patient and carers should be given the information they require. Some patients do not wish to know they are dying but others are comforted by this knowledge. Consider informing the patient's GP.

- Any changes in medication or route of administration of drugs should be explained to patient and family. If necessary, reassure the family that medications are being administered appropriately and will not hasten or postpone death.
- Patients being discharged from hospital need to be given a realistic perception of community services, what can and cannot be provided and how to access support and advice.
- Clear, precise discharge summaries should be provided to include key information for every patient (and, where appropriate, the patient's carer) requiring community nursing services.
- Multi-disciplinary team assessments and planning should include the community nursing team when appropriate to minimise delays in discharging frail, older patients
- Information should be provided to the patient on discharge to include relevant contact numbers.

A list of key contacts and those involved in an individual's care can be found within the MCWs folder.

3.5 Keyworker / Care Co-ordinator

There should be a key worker/care co-ordinator (in the community) to track the patient from admission to discharge. A key worker/care co-ordinator is described as an existing member of the multidisciplinary team delivering care to a patient at home, who takes responsibility for the coordination of a patient's care, in partnership with the individual and their family. This practice is not new; good practitioners have always ensured that the patient and their carers understand the rationale behind their care plan and the aim of health care agencies involved has been to provide co-ordinated care.

Whilst every effort is made to ensure continuity of care with the key worker/care co-ordinator approach it's important to recognise that patient's needs change along the journey and with changes in service provision a change of key worker/care co-ordinator may be required. It is therefore essential that the most appropriate person takes responsibility for the on-going management of a patient within their pathway without compromising continuity of care.

The role may be undertaken by any number of health or social care professionals and this may vary according to the patient's needs, the stage in their treatment journey and the nature of their condition.

The most appropriate people could include (please note this list is not exclusive):

- Consultants
- GPs
- Nurses/ Nurse Specialists

- Care home workers
- Allied Health Professionals
- Social Care Workers/ Family Support Practitioners
- Family member or carer.

An example of a 'key worker or care co-ordinator' for patients being cared for at home at the end of their life would be the District Nurse, who would ensure coordination of the delivery of all health and personal care services, preventing any duplication of visits and minimising the disruption to the family

The key worker should be identified, in consultation with the patient, as soon as possible after the recognition that palliative care is now needed and the patient flagged, electronically that they are end of life. **The professional who identifies that the patient is palliative and EoL will take on the responsibility of being the interim/ associate key worker/care co-ordinator until a permanent replacement is identified.** It is recommended that either the main or associate key worker / care co-ordinator is the district nurse.

At the next team/MDT/Gold Standards Framework (GSF) meeting the permanent key worker/care co-ordinator should be agreed. The wishes of the patient and their carers must remain paramount and it must be made clear that the choice of key worker/care co-ordinator rests solely with them and their family. The name and contact details of this individual should also be entered in the patient's health and social care records and be clearly visible on the front page of the Personalised Shared Care & Support Plan within the MCWs folder. It is the responsibility of the key worker/care co-ordinator to maintain accurate documentation.

Some patients may not want or require a key worker/care co-ordinator; this wish must be respected and must be documented in the patient's health and social care records/MCWs folder.

3.6 Equipment

As a Multi-Disciplinary Team (MDT), the equipment needs of the patient need to be assessed in a reasonable amount of time by the most appropriate professional involved. This will ensure the equipment is ordered in a timely manner and under the most appropriate delivery and budget code.

Consideration should be given to:

- Pressure area care - Waterlow scores and assessment of pressure areas.
- Does the equipment need to be in place prior to discharge?
- Is the environment ready or appropriate for the equipment needs?
- Is the MDT aware of any potential delays in equipment provision due to delivery or awaiting the environment to be ready?
- Are there any concerns in regards to patient's level of cognition?
- If you are ordering a hospital bed, does it need to be low rise to eliminate issues with cot sides? If so, have you ordered a crash mat?
- Who is the most appropriate person to assess these needs? Who knows the patient best? i.e. Discharge Planning Nurse, Occupational Therapist, Physiotherapist or Early Intervention Team (EIT) / Crisis Action Team (CAT).
- Have we considered the manual handling needs of both the patient and the supporting carers?

3.7 Out of hours service in Suffolk

Access to non-emergency medical assessment during approximately 60-70% of the week is provided by the out of hours (OOH) service called NHS 111. It is therefore vital that staff communicate effectively with the OOH service to ensure continuity of care. NHS 111 is a 24/7 service.

Patients, carers and healthcare professionals can call the NHS 111 service for a number of non-emergency reasons, perhaps a medication or a medical concern. To speak to a clinical/medical practitioner ask the call handler to transfer your call to a clinical/medical practitioner, stating who you are and which patient the call is about (you get a quicker response if the call is made when you are with the patient). This service is complimented by the CCC and both Suffolk Hospices. If OOHs GPs or EEAST staff need additional information about an individual then please consider discussion with the local hospice as appropriate.

3.8 Summary Care Record with additional information (SCRai)

The Summary Care Record (SCR) has been enhanced to hold additional information relevant to the My Care Wishes folder, and now includes several new sections of data including end of life care and anticipatory care, replacing the EPaCCS system that was only specific to End of Life Care. This data is only shared if the patient specifically consents to do so with their GP. Within the My Care Wishes folder there is an information sheet with space for consent; patients should be encouraged to give consent, as this will ensure that their data is made available to all clinicians involved in their care and help to reduce any delay in their treatment. All GPs within Suffolk have access to SCRai.

SECTION 4: EDUCATION

4.1 St Nicholas Hospice Care

Education and advice service is available throughout our community for health and social care organisations including nursing and care homes and domiciliary care agencies.

All staff are welcome to attend irrespective of grade or experience in palliative care.

Meetings occur every month across our region. [Please click here](#) for information.

For further information please contact the Education Department on 01284 766133 or email: education@stnh.org.uk

4.2 St Elizabeth Hospice

Palliative care education is offered at St Elizabeth's Hospice, which is committed to constantly improving services to patients and their relatives through a programme of staff and volunteer education and training. The Hospice also aims to enhance the skills and knowledge of other healthcare professionals and agencies providing palliative care within the surrounding community. For further information please contact the Education Department on 01473 727776 or [click here](#).

4.3 Suffolk Brokerage

Suffolk Brokerage is an independent, non-profit making organisation dedicated to raising care standards in Suffolk by providing impartial advice, guidance and information to support the county's health and social care sector. They aim to: support the sector to implement new competencies needed to comply with legislation, seek and secure funding for the sector, and to ensure this is offered equitably assist care providers to deliver a suitable and competent workforce in Suffolk.

Suffolk Brokerage can be contacted on: 01449 720400, email: info@suffolkbrokerage.co.uk

4.4 Further specialist support and advice

Further advice on holistic assessment for health and social care staff including care homes and care agencies and action required to improve patient care at the end of life is available 24/7.

Contact details:

St Nicholas Hospice Specialist Palliative Care advice can be obtained by contacting the Telephone Advice Line on **01284 766133** - 24 hour 7 days a week

St Elizabeth Hospice Specialist Palliative Care advice from CNS or consultants in East Suffolk can be obtained via the **Onecall 0800 5670 111**, 24 hours a day, 7 days a week.

Hospital teams may also be able to offer advice for current hospital inpatients or those recently discharged from hospital and not yet known to community palliative care teams

Ipswich Hospital Trust Specialist Palliative Care Team (IHT) – 01473 712233

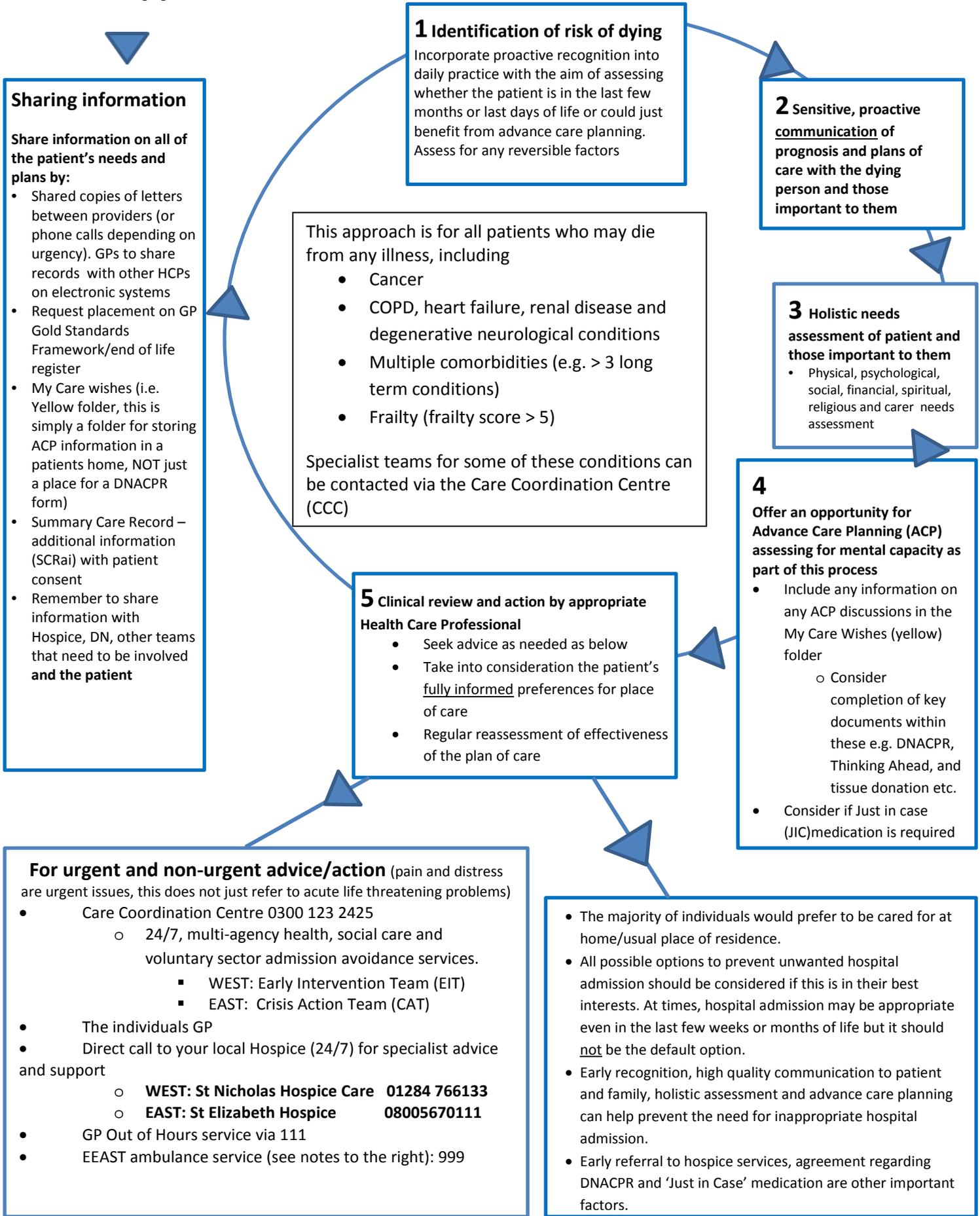
West Suffolk Hospital (WSFT) Palliative Care Team – 01284 713000

SECTION 5: APPENDICES

Appendix 1

The Suffolk End of Life Support Tool

Support tool for end of life care in Suffolk



1. Identification of risk of dying

Tools to help identify the last few months of life or those for whom advance care planning and assessment would be useful include the Gold Standards Framework (GSF) prognostic indicator guidance, Supportive and Palliative Care Indicators Tool (SPICT) and the 'Surprise question' (simply 'would you be surprised if this person dies in the next few months or year?')

Factors which might indicate a person is in the last few weeks include: progressive weight loss, increased fatigue, appetite loss and decreasing functional status with worsening mobility, communication and social withdrawal and in the last days of life agitation, Cheyne-Stokes breathing, deterioration in consciousness, mottled skin, noisy respiratory secretions. <http://www.goldstandardsframework.org.uk>

2. Communication

Check how much the dying individual/family carer wishes to know. Everyone should be given an opportunity to know as much as they wish, but equally they may wish not to know too much. The need for discussion about end of life issues can be predicted, based on your knowledge about diagnosis or prognosis or use of the Tools above, hence it is important to plan ahead and check if the dying person would wish to have someone with them during significant discussions. Those important to the patient can then be contacted to give opportunity for them to be with the patient when you have the discussions. This information should be recorded in the My Care Wishes (yellow) folder and used to inform subsequent discussion. Please remember to carefully assess and record an individual's mental capacity.

3. Holistic needs assessment

This should include fears and anxieties, goals and wishes and the dying person's views about future care, not just the purely physical elements of care. Financial issues and the needs of the carer should also be assessed. Spiritual assessment need not be just religion but can be what gives them peace; hope, strength or what is most important to them, remembering spiritual support is relevant to people of all faiths and none.

4. Advance Care Planning and My Care Wishes

Advance care planning is a voluntary process to help guide individuals to anticipate how a condition may affect them in future. Wishes and preferences should be explored. Factors to be considered include attempted resuscitation, preferred place of death (first and second choice) and tissue donation. Such planning can include legally binding advance decisions to refuse treatment, appointment of a lasting power of attorney or simply sharing of preferences via a 'My Care Wishes (yellow folder)' or letters between health professionals. Questions such as 'Have you thought about what will happen to your health in the future?' or 'Do you have any strong feelings about treatments that you would or would not want to receive?' may be useful. The benefits of this process are in providing greater control and input into their care, and patients are more likely to consider alternatives to hospital admission at the time of deterioration if they have clearer plans and expectations. Proactive identification of needs can enable plans to be put in place in a timely manner and avoid the need for crisis management.

My Care Wishes Folders can be obtained from WSCCG on 01284 758031/758039

5. Clinical Review and discussion of what to expect

Offering a discussion of what to expect as a patient is dying can help relieve anxiety or distress and help to prepare a dying person, and those important to them. Factors to discuss include decreasing energy levels, mobility and oral intake. It is important to discuss that uncontrolled pain; and other distressing symptoms are not inevitable. The majority of pain and distressing symptoms can be controlled with medication, care and attention. Noisy breathing can occur closer to dying, this may not always be controlled but it can be of comfort to relatives to know that the dying person is usually unaware of such symptoms.

Further advice and guidance (including access to education and training)

Both Hospices, in east and west will be able to advise on how to access and register for education and training.

Care after death: Guidance for care homes is available via the CCG website. Community, Hospital and Hospice teams will provide advice separately to relatives and carers of in-patients. Bereavement support can also be accessed via the Hospices.

In summary the key priorities for end of life care are:

Communicate Recognise Involve Support Plan & Do