CLINICAL PROTOCOL FOR
END OF LIFE CARE TOOLS

RATIONALE

The aim of this protocol is to support all health professionals in the use of evidence based End of Life Care Tools to promote evidence based advanced care planning:

- To potentially reduce inappropriate hospital admissions
- To support health professionals when implementing End of Life Care Tools
- To support appropriate referrals to Integrated Specialist Palliative Care Team
- To promote a proactive approach to advance care planning and on-going care
- To promote best practice for patients and carers who may have specific end of life care needs

End of life care (EoLC) does not focus just on the last few weeks of life. Any person who may be in the last year of life due to a condition or illness is considered for EOLC; the above model; the Wirral End of Life Care Plan summarises the key stages for end of life care. All patients should be registered on the Gold Standard Framework (GSF) held by the GP Practice during the last year of life.

The EOLC programme aims to help individuals to live and die in a place of their choice,
reducing the number of people being unnecessarily admitted to hospital in the last weeks/days of life, and ensuring that the services they receive are appropriate to their needs and preferences whenever possible.

TARGET GROUP

This protocol applies to all community nurses and integrated specialist palliative care nurses who are required to follow this protocol as part of their role and job description.

TRAINING

All staff in the Trust are required to comply with the mandatory training as specified in the Trusts Mandatory Training Matrix. Clinical Staff are also required to comply with the service specific mandatory training as specified within their service training matrix.

RELATED POLICIES

Please refer to relevant Trust policies and procedures.

EOLC ESSENTIAL QUALITY STANDARDS WITHIN THE TRUST

If these quality standards are not met then a rationale must be recorded in the patient's health records

- All palliative care patients diagnosed as being in the last year of life and on End of Life Care Plan will have an Advance Care Plan in the form of a ‘Patient and Carer Assessment’ (PACA). The PACA is a comprehensive holistic assessment which is responsive to the changing needs and preferences of patients and carers

- All patients must be offered a Preferred Priorities for Care Document and this must be recorded in the patients’ health records

- All patients approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences and recorded in the PACA

- All patients will have their pain assessed and recorded at every visit, preferably on the PACA to support continuity of care

- All patients will have a nutritional screening assessment using the Malnutrition Universal Screening Tool (MUST) to identify patients at risk of malnutrition according to the patient’s clinical needs. For patients identified at risk following a MUST assessment, a nutritional care plan will need to be in the records

- All patients should have medication prescribed for ‘anticipatory prescribing’ as per Wirral Care of the Dying Guidelines according to patient’s needs.
- All patients approaching the end of life who may benefit from specialist palliative care
are offered this care in a timely way appropriate to their needs and preferences

- The PACA should include the Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) status of the patient.

- All informal main carers must be offered a carer assessment, if carer declines this must be documented in the patients’ health records

- All patients will be commenced on the Wirral End of Life Care Plan.

- All patients will have a syringe driver set up within 4 hours

- All patient records will have evidence of Out of Hours referral updates at least monthly

- All carers will be offered bereavement support visit

**TRIGGER QUESTION**

Trigger question for assessment to decide if the patient may have end of life needs regardless of diagnosis

- The surprise question, “Would you be surprised if this patient were to die in the next 6-12 months” – an intuitive question integrating co-morbidity, social and other factors (Gold Standard Framework, 2008).

**ASSESSMENT AND PALLIATIVE CARE STANDARDS**

The advance care planning in the community ‘insight score’ can be completed at initial assessment or at a later date if patient is not aware of prognosis or reluctant to talk about end of life care. However, this does not stop initiating appropriate conversations for advance care planning or end of life care

**FREQUENCY OF CONTACTS**

Frequency of contacts with patients is based on clinical need as regular ongoing visits promote proactive management of patient care which evidence suggest helps to reduce unnecessary hospital admissions. Patients must be offered as a minimum a monthly visit; any variances with patients must be documented. If the patient requests alternative arrangements i.e. regular phone calls this must be recorded in the patients records. Any difficulties in making contact with the patient should be recorded in the health records and discussed with the team leader.
GOLD STANDARD FRAMEWORK (GSF)

- Any patient who is considered to be in the last year of life should be added to the GSF register; that is held at the GP practice.
- Out of Hours palliative care communication handover form must be completed and faxed to relevant disciplines to improve communication and coordination of care.
- Out of Hours forms must be updated and faxed monthly or if any changes in clinical need.
- Out of Hours forms must be completed weekly once a patient has commenced on a syringe driver or more frequently according to the clinical needs of the patient.

NUTRITIONAL ASSESSMENT

- All patients to be assessed using Malnutrition Universal Screening Tool (MUST) as per Community Contract Standard (2010-2013), once the patient’s MUST score has been established, all staff to follow nutritional assessment and referral pathway to ensure appropriate action is taken. The nurses can use clinical discretion when undertaking an assessment as body weight and further measurements may not be clinically appropriate.
- Consider specialist referral to dietician.
- If a patient declines an assessment this must be recorded in the patient’s records.

SPIRITUAL NEEDS

- Spiritual needs are an integral aspect of palliative care and have been added to the Advance Patient and Carer Assessment, to ensure spiritual needs are discussed as appropriate to each patient’s needs. If a patient declines an assessment of their spiritual needs please record in the patient’s records.

PAIN ASSESSMENT

- All patients must have their pain assessed and recorded at each visit to ensure pain is being formally assessed to promote continuity of care across health professionals and to meet patient’s clinical needs.

PATIENTS SYMPTOM SCORE

- Nurses do not need to systematically ask about each symptom listed in the PACA (this excludes pain), guided discussions about how the patient is feeling will give rise to presenting symptoms.
- The scoring system enables practitioners to monitor the effectiveness of interventions which aim to relieve symptoms.
- Referral to the Integrated Specialist Palliative Care Team may be indicated if symptoms are not relenting despite generalist intervention.
- The individual scores are not totalled or added together to obtain an overall score, each individual score provides an indicator if the patient’s individual symptom(s) require
referral to specialist services or reassessment by General Practitioner or ISPCT.

CARERS ASSESSMENT

- The EOLC strategy (DH 2008) clearly states that carers are entitled to an assessment and care plan in their own right – all informal main carers must be offered a carers assessment and any variances to be recorded in the patient’s records to explain why this has not been achieved.

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PREFERRED PRIORITIES FOR CARE DOCUMENT

- The PPC document is a patient completed/held tool and completion of the document remains the choice of the patient.
- Before the PPC is introduced to the patient discussions with the patient should have taken place regarding the value of having the opportunity to consider their future care in relation to any worries, concerns or anxieties as well as any particular preferences
- Where the PPC has been offered this should be recorded in the patient’s records.
- The patient may choose to update their PPC document frequently and therefore any changes must be updated and re-communicated.
- If patient and/carer are finding it difficult to talk about end of life care issues after a number of visits, regarding their concerns or their PPC, seek advice from the End of Life Care team as further specialist advice may support future advance care planning and timely communication

RATIONALE FOR PATIENT AND CARER ASSESSMENT (PACA)

The PACA document is a standardised advance care planning assessment tool developed to evaluate the outcome of interventions made with regard to symptom control and changes in the patients/carer’s insight as well as the effect on their quality of life. (Ellershaw, 1995).

Benefits:-

- Promotes acting in patients best interests whenever possible, they know their own best interests not the health professional
- Reduces potential risk of avoidable hospital admissions as patients monitored effectively
- Helps to avoid harm as disease progresses as urgent unplanned interventions can be burdensome for the patient and family, i.e. waiting for out of hours care
- Respects autonomy, patient cannot be autonomous unless they are informed as part of their advance care planning
- The tool supports effective clinical management of symptoms as they arise
• Promotes seamless care across nursing teams as assessments clearly document clinical needs during end of life care
• Prompts referral to specialist services, e.g. Integrated Specialist Palliative Care Team (ISPCT), Tissue Viability Service

If patient and/carer unable to talk about end of life care issues after a number of visits, regarding their concerns or completion of the PACA, seek advice from the End of Life Care Team as further specialist advice may support future advance care planning and timely communication

EASTERN CO-OPERATIVE ONCOLOGY GROUP (ECOG) TOOL

The ECOG tool is a performance status tool that is designed to support the assessment of the functional status of a patient’s disease progression.

• The tool promotes an objective clinical assessment, across a range of health professionals of an individual’s disease affecting their daily living abilities.
• The tool supports clinical decision making when there is a change in the patients quality of life and can be used as a guide to initiate appropriate clinical care to support appropriate advance care planning (Oken et al 1982).

In palliative care, Performance Status (PS) is an attempt to quantify a patient’s general wellbeing; it can be used as a measure for the required intensity of appropriate palliative care nursing input. The higher the patient’s PS score the greater the need for symptom management, hence the need for more regular palliative care assessment, monitoring and nursing care e.g. if ECOG score 2 or above consider referral to the integrated specialist palliative care team.

INSIGHT SCORE

Complete on initial assessment and update if any change to patients/carers insight score. The score is a useful tool to determine if the patient and the carer are aware of the prognosis.

If carers or patients are reluctant to discuss awareness of diagnosis / prognosis consider discussions or referral to the ISPCT as patients and carers need timely support to understand the disease progression and the best options to deliver end of life care in the patients preferred place for care. This may also help avoid unnecessary hospital admissions

If the assessing nurse does not feel that it is appropriate to leave the insight score in the patient’s home records then store in base notes and document where it is stored in the patients’ health records.
EMERGENCY CARE PLAN

All palliative care patients must have an emergency care plan in place to prevent unnecessary hospital admissions; the plan on the front of the PACA must include the following information:

- A telephone number for who to contact in an emergency (if appropriate)
  - GP Out of Hours telephone number
- Evidence that discussion has taken place and patients and carers wishes are recorded on the care plan
- Any personalised comments or wishes

DO NOT ATTEMPT CARDIO PULMONARY RESUSCITATION (DNACPR)

The PACA should include the CPR status of the patient. This decision should have been discussed at the GSF Practice meetings or with the GP.

"If the patient has an irreversible condition where death is the likely outcome the patient should be allowed to die a natural death and it may not be appropriate in these circumstances to discuss a DNACPR decision with the individual"

(Trust Policy ‘Do Not Attempt Cardio Pulmonary Resuscitation’)

WIRRAL END OF LIFE CARE PLAN

(Always use the current version on the Trust web site)

The Wirral End of Life Care Plan (herein referred to as Care Plan) is a best practice multi-professional tool that provides an evidence-based framework for nurses and doctors to use when patients are entering the dying phase. This care plan is to be used for all dying patients irrespective of diagnosis. The care plan improves inter-professional communication and coordination to promote continuity of care and delivery of best practice.

The care plan provides guidance on all aspects of individualised care to ensure patients physical, psychosocial and spiritual/religious aspects of care are managed appropriately, including family/carer support during the patient’s life and bereavement in line with NHS England guidelines.

MANAGING HYDRATION AND NUTRITION NEEDS

Whilst a person is fully conscious and able to swallow it is essential that fluids and nutrition are offered. The patient may demonstrate loss of appetite for nutrition and fluids. This is part of the dying phase. Once a person has lost consciousness oral fluids and nutrition are no longer appropriate.

It is best practice to ensure particular attention is given to good oral care provided by family members and nursing staff.

Hydration via subcutaneous fluids could be considered if in the best interest of the patient.
patient if the patient is deemed medically dehydrated. This would be discussed with the family and the GP/MDT.

“The patient should be assessed regularly and frequently so that the end of life care plan can be made or adjusted, taking into account the patient’s wishes (where known) and families’ views. Symptom control and comfort measures (including offering oral fluids and good mouth care), and provision of psychological, social and spiritual care, are core to the care of the dying person”

NHS England (2013)

INFORMATION AND LEAFLETS

To ensure that patients and their carers receive appropriate and timely information, the following booklets should be available along with the Wirral End of Life Care Plan:

The Marie Curie Care of the Dying leaflet can be obtained from the Community Nursing Office.
Bereavement Leaflet

Staff will need to discuss the benefits of referral to Marie Curie Services to provide day and/or night sitting services to support carers at home

IMPLEMENTATION

All registered staff should be able to assess and have an understanding of a change in the patient’s condition, using their clinical knowledge and skill to identify that the patient has now reached the dying phase. This allows the patient and their family adequate time to prepare for the impending death of a relative or loved one. The family, including children, close friends and informal carers of people approaching the end of life, have a vital role in the provision of care.

JOINT DECISION MAKING

- The Wirral End of Life Care Plan requires a multidisciplinary team (MDT) joint decision making when diagnosing dying and implementation of the Wirral End of Life Care Plan to provide supportive care in the last hours or days of life.
- For the purpose of clinical decision making the MDT should be at least a GP and a registered nurse but may also involve other personnel according to the patient’s individual needs.
- If assessment visits are not performed jointly by the GP /registered nurse then separate visits can be undertaken within 4 hours of each other on the same working day and the documentation signed by both parties to constitute a ‘joint assessment’.

If a GP visits and does not document/sign the Wirral End of Life Care Plan this should be recorded in the variance section, and if GP refuses to visit the patient also record in
variance section and report using Trust Datix Incident Reporting System.

When commencing a patient on the Wirral End of Life Care Plan, if the patient requires a syringe driver, this must be set up within 4 hours. If this is not achievable a Trust Datix Incident Report must be completed clearly stating the reasons why the syringe driver was not commenced.

DOCUMENTATION

All documentation and evaluation should be on the Wirral End of Life Care Plan documentation and all other care plans and evaluation forms should be discontinued, except syringe driver documentation.

ASSESSMENT / NAMED NURSE

The Wirral End of Life Care Plan needs an initial assessment and on-going assessment at each visit and care after death, health professionals need to record whether goals have been achieved. Any deviations from the pathway the reasons need to be recorded, documenting actions taken and outcomes on variance sheet. Seeking specialist advice as required.

CORONER’S LETTER

Managing expected deaths out of hours requires a co-ordinated approach across all agencies. To help avoid any unnecessary stress or inappropriate calls to the police or ambulance service, the Wirral Coroner’s Office has written a supporting letter attached to each Wirral End of Life Care Plan.

Relatives need to be made aware of the letter and the correct procedure to follow when a patient dies, should their relative die out of normal working hours.

STORAGE

Once a patient has died the Wirral End of Life Care Plan should be stored at the front of the nursing documentation for auditing purposes and retained in base for 6 months. The records of patients who had a Wirral End of Life Care Plan need to be stored separately in the file, for ease of access when auditing the records. Patients’ health records (with a Wirral End of Life Care Plan) need to be filed chronologically by date of death.

BEREAVEMENT VISITS

- Following the death of a patient the informal main carer must be offered a bereavement visit by a registered nurse within the first month (this is in addition to any contact to collect equipment/records at time of death. Any variance to be recorded in the patients records to explain why this has not been achieved.
• When carers have received a bereavement visit this must be documented in deceased patients records

• Carers need to be informed who to contact should they require any support in the following months

WHERE TO GET MEDICATION / SPECIALIST ADVICE FROM

Information relating to starting dose, dose conversions and formulations may be found in the following texts:-

• Wirral Care of the Dying Non-Renal Clinical Guidelines – on Trust intranet

• Wirral Care of the Dying Severe Renal Failure Clinical Guidelines – on Trust intranet

• Summary of Product Characteristics of Individual products are available at www.medicines.org.uk

• Merseyside and Cheshire Palliative Care Network Guidelines (copy available from each Team leader)

PHONE ADVICE:

• Integrated Specialist Palliative Care Advice and Information Line. 9.00-17.00 hours 0151 328 0481 - 7 days a week

• Contact Palliative Advice and Information Line (P.A.I.L ) Evenings only 17.00 - 09.00 hours 0151 343 9529

• End of Life Care Team: advice available from 09:00 till 17:00 Monday to Friday Tel: 0151 514 2331

CLINICAL AUDIT

This clinical protocol will be audited every year and the questions in the audit will be based on standards set out in this protocol.

INCIDENT REPORTING

Clinical incidents or near misses must be reported using the Trust Datix Incident Reporting System
SAFEGUARDING

In any situation where staff may consider the patient to be a vulnerable adult, they need to follow the Trust Safeguarding Adult Policy and discuss with their line manager and document outcomes.

EQUALITY ASSESSMENT

During the development of this protocol the Trust has considered the clinical needs of each protected characteristic (age, disability, gender, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation). There is no evidence of exclusion of these named groups.

If staff become aware of any clinical exclusions that impact on the delivery of care a Trust Incident form would need to be completed and an appropriate action plan put in place.
REFERENCES


End of Life Care Programme (2009) www.endoflifecare.nhs.uk/eolc/


**CONTROL RECORD**

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Status – New / Revised / Trust Change