
CENTRAL & EASTERN CHESHIRE
End of Life Care
SERVICE MODEL
Leading and facilitating best practice

**Supporting Equity for all : getting the balance right**

## KEY MESSAGES

End of life care – affects us all as Professionals & as members of the public ourselves!

We have only 1 chance to get it right for each individual & their family

1% of the UK population die each year – mainly elderly non-cancer patients; cancer equates to only about ¼ of deaths from advanced illness or frailty

Most people, given the opportunity, wish to die in their usual place of residence, yet the largest proportion still die (and often shortly ) following transfer to acute hospitals

What we know is that more people are more likely to be enabled to have their choices met when proactively assessed & planned for & when reasons why not are reviewed.

With this in mind, we need to find ways that help us develop our Palliative/GSF Registers (& thus prompt proactive care planning) in order to reflect this distribution to ensure equity for all those facing end of life care, regardless of age or disease

Using the 'Surprise Question' + prognostic indicators + needs based coding can help us identify need & prioritise & manage time in our regular multi disciplinary team (MDT) Palliative/GSF Meetings

## Definition of End of Life Care

People are 'approaching end of life' when *likely* to die within the next 12 months. This includes people whose death is imminent (within a few hours/days) & those with:

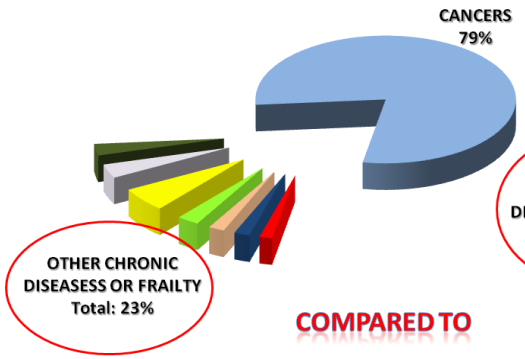
- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events

*General Medical Council , 2010*

Consider how many may be in care homes

**What's 'OUR BALANCE' currently *across Central & Eastern Cheshire?*** *(Average 20 patient deaths per annum per GP)*

**PATIENT GROUPS CAPTURED ON OUR REGISTERS ACROSS CENTRAL & EAST CHESHIRE**



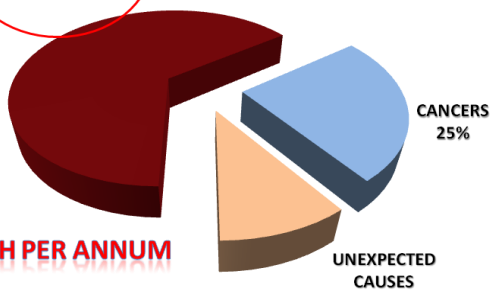

There is a strong correlation between care for patients with long-term conditions, such as heart failure & COPD, & those with advanced disease nearing end of life.

Close collaboration with case managers can reduce unplanned admissions & support good end of life care.

*GSF & RCGPs, 2011*

OTHER CHRONIC DISEASES or FRAILTY (74%

**COMPARED TO**




**COMMON CAUSES OF DEATH PER ANNUM**

EOLC Service Model Team (2012) . Acknowledgements: National Gold Standards Framework Guidance; NHS National End of Life Care Programme

# Prognosticating dying - not an exact science!

It doesn't stop us recognising decline & planning ahead
Get into 'rainy day thinking'
Hope for the best; prepare for the worst

Predicting needs rather than concerning ourselves with an exact prognostication means we can get on with focusing on anticipating patients' likely needs so the right care can be provided at the right time.
This is more important than working out the exact time remaining and leads to better proactive care in alignment with individual preferences & perceptions of quality outcomes.

*GSF & RCGPs, 2011*

## 3 STEPS TO SUPPORTING QUALITY END OF LIFE CARE

**STEP 1**

Ask the 'Surprise Question
Would you be surprised if the patient deteriorated & died over the next few months or so?

- NO
- DON'T KNOW
- YES → Reassess Regularly

**STEP 2**

Do they have general indicators of decline?

- YES
- DON'T KNOW
- NO → Reassess Regularly

**STEP 3**

Do they have specific clinical indicators ?

- YES
- NO → Reassess Regularly

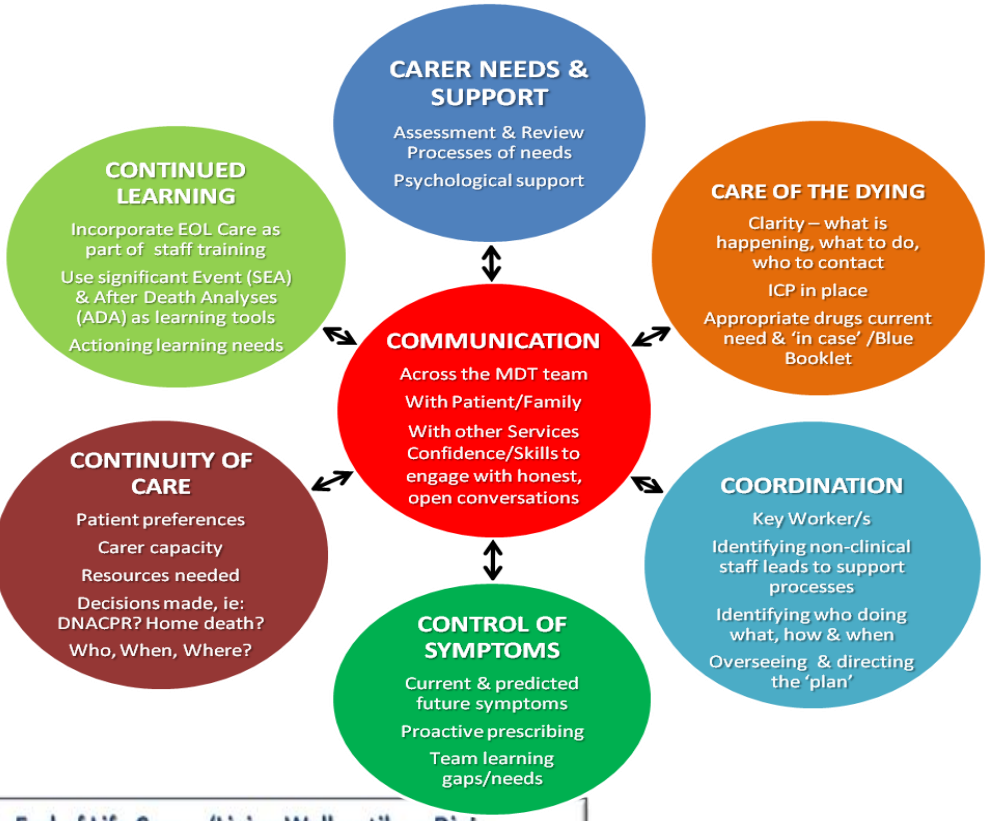
**BEGIN GSF PROCESS**

**IDENTIFY:** Inc on Palliative/GSF register; needs based coded. Discuss at MDT meeting
**ASSESS:** Discuss this with Pt/family carer. Assess needs – likely support needed & record.
**PLAN:** Plan & provide proactive care; communicate significant information & coordinate plan.

# We can't 'fix' dying, but we can make a difference to the QUALITY of life left & to death

## BEYOND THE PALLIATIVE/GSF REGISTER

**A register alone won't make a difference - Its implementing the 7 C's that will**




## 3 steps to Quality End of Life Care – 'Living Well until we Die'

### 3. PLAN

Develop an Action Plan of care.
Communicate significant from the plan to relevant others & action the plan.
Review at significant points.
information


### 2. ASSESS

Current & future clinical needs + personal needs
Use of Assessment Tools + Advance Care Planning (ACP) processes & tools.
Review at significant points.

### 1. IDENTIFY

Regardless of age or disease ALL Patients who may be in their last year of & identify their stage .
Using Surprise Question + prognostic indicators + needs based coding.
Review needs & adjust coding at significant points.

## HOLISTIC SYMPTOM ASSESSMENT - **PEPSICOLA** aide memoire

- **P** Physical
- **E** Emotional
- **P** Personal
- **S** Social Support
- **I** Information/Communication needs

- **C** Control & Autonomy
- **O** Out of Hours
- **L** Living with your illness
- **A** After care

# TIPS to guide PALLIATIVE/GSF MDT meetings

## EQUIPMENT:

**Updated copy of 'coded' register** – acts as checklist/prompt to ensure all relevant aspects are timely considered or each patients journey *(i.e. PPC reviews; DNACPR decisions, symptom assessments, changes in circumstances, record of out of hours notifications)*

**Agenda**, highlighting new patients and known existing patients highlighted/prioritised for discussion. Useful to provide agenda/patient list in advance of meeting

**Computer available** to check patient information that might be needed during the meeting

A shared lunch always goes down well!

**Appropriate meeting room,** conducive to enabling undisturbed, confidential, open and shared discussions

## PRIORITISING WHICH PATIENTs TO DISCUSS:

Useful to do much of the leg work (as feasible) in advance so meeting can be focused.

No need to automatically go through all of the patients on the Register; **prioritise based on need** from agreed agenda (briefly checking before starting any inclusions/amendments to agenda that have since arisen).

For example, updating on any changes, need for timely review, issues that need the MDT input to discuss, raising knowledge/information gaps, agreeing action points/changes to patients coding status on the register.

## WHO IS RESPONSIBLE FOR WHAT:

**Nominated GSF Register/MDT meetings co-ordinator(s) -** manages the GSF Register, Carer Register; co-ordinates/communicates meeting dates, agendas and minuted actions – this can often be non-clinical staff.

**Meeting Chairperson** - (can be a shared responsibility across meetings) to lead and keep discussions focused/moving forward, ensuring action points are agreed and keeping to time.

**Nominated key person(s) *(key worker)* for each patient** – responsible for overseeing the 'bigger picture' in relation to the patient (and family) journey. *This can ensure timely addressing of needs and prevent potential needs being overlooked until too late or crisis intervention/decision required.*

This (or one of these nominated) will lead the discussion. It is still the responsibility of **all staff** to share any new relevant information or take forward agreed actions that they are best placed to do.

**All relevant Staff -** responsible for informing (for the agenda) any patients they particularly wish to discuss at the MDT, including consideration of whether likely to be a 'quick update' or requiring a broader MDT problem solving discussion or raising a patient situation as part of 'learning opportunity/need' for the team such as through the Significant Event Analysis (SEA) or After Death Analysis (ADA) MDT discussion processes.

*If time is not available for SEA OR ADA, and it is appropriate to delay discussion, some teams find it helpful to allocate this time to lunch-time or protected learning time events.* These processes can be helpful when as many *relevant staff** are present

## WHO SHOULD ATTEND:

Important: remember the purpose of this meeting!

(a) to make the best possible decisions relating to these patients and families and (b) create the best opportunity of timely sharing of experience, knowledge, skills to create a proactive and retrospective reflective learning environment. So ideally,

**All GPs, relevant Nursing and relevant Practice non-clinical staff** should attend, where able

**Also** consider specific patient current/future needs – as a team, is there a gap in your skill/knowledge base that would benefit from inviting **other relevant Professionals*** at this stage.

# TIPS TO MANAGING YOUR PALLIATIVE/GSF REGISTER: 'NEEDS BASED CODING' ( A TO D): Prioritising the 'right care' at the 'right time'

| A | B | C | D | AFTERCARE |
|---|---|---|---|---|
| **PROGNOSIS** 1 YEAR + Advanced disease but stable | **PROGNOSIS** MONTHS Unstable advanced disease | **PROGNOSIS** WEEKS Continued deterioration | **PROGNOSIS** DAYS OR HOURS Dying | Family carer needs |
| Patient on GSF Register<br>Carer on Carer Register<br>Introduced at MDT meeting<br>Key Worker(s) Nominated<br>Timely ACP considerations *(NB: earlier capacity loss risks, i.e. those with dementia)*<br>Current/future risks of symptoms assessed<br>Family Carer needs-assessment?<br>Referral/Resource considerations?<br>Patient/family & other relevant services information needs met<br>Learning needs for MDT identified – what actions?<br>Significant Event Analysis (SEA) reviews required?<br>Agreeing/Assigning action plan & actions | Review of coding<br>DS 1500 or benefits review eligibility?<br>ACP review<br>Review of other patient/family needs *(i.e. psychological, financial, practical)*<br>Continuing Healthcare funding assessment planning<br>Symptom needs? plans/drugs prescribed in place<br>Palliative Prescribing & Administration of drugs 'Blue Booklet' in place/reviewed<br>DNACPR decisions recorded & communicated to relevant others in case of rapid deterioration<br>Patient/family & other relevant services information needs met<br>SEA reviews required?<br>Agreeing/Assigning action plan & actions | Review of coding<br>Continuing care funding needs reviewed/actioned<br>Symptom needs? plans/drugs prescribed in place<br>Local Palliative Prescribing & Administration of drugs 'Blue Booklet' in place/reviewed<br>Resource needs reviewed<br>Need of existing appointments (i.e. outpatients) reviewed/addressed<br>Family Carer needs reviewed<br>DNACPR decisions recorded & communicated to relevant others in case of rapid deterioration<br>Access to 'ICP for the Dying' available when required<br>Patient/family & other relevant services information needs met<br>SEA reviews required?<br>Agreeing/Assigning action plan & actions | Review of coding<br>' ICP for Dying' initiated<br>Unnecessary interventions, drugs & investigations discontinued<br>End of life care drugs prescribed in accordance with local Palliative 'Blue Booklet'<br>Patient/family & other relevant services information needs met (inc. what to do, who to call)<br>Family Carer needs reviewed<br>SEA reviews required?<br>Agreeing/Assigning action plan & actions | Family carer information or bereavement needs (or risks) assessed addressed actioned<br>Significant information communicated to relevant other services involved<br>After death analysis (ADA) *what went well\what could have been done differently. Team learning needs?*<br>Agreeing/ Assigning actions |


# More about the indicators

**SURPRISE QUESTION INDICATOR**

**GENERAL INDICATORS**

**WHEN TO CONSIDER PROACTIVE ADVANCE CARE PLANNING (ACP) FOR PATIENTS**

**SPECIFIC CLINICAL INDICATORS**

**PATIENT PSYCHOLOGICAL PREFERENCE INDICATORS**

ALSO if any triggers have prompted the patient or family to raise ACP cues to future concerns or direct future concern or preference issues themselves !

## STEP 1

**The Surprise Question** - For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social & other factors that give a whole picture of deterioration.

**If you would not be surprised**, then what measures might be taken to improve the patient's quality of life now & in preparation for possible further decline?

## STEP 2

**General Indicators** - Are there general indicators of decline & increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality & morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

**Functional Assessments**

Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence,toileting, transfers, mobility, coping with stairs etc .

**PULSE 'screening' assessment**

P (physical condition);
U (upper limb function);
L (lower limb function);
S (sensory);
E (environment).

**Karnofksy Performance Status**

Score
0-100 ADL scale

**WHO/ECOG Performance Status**

0-5 scale of activity.

STEP 3

**Specific Clinical Indicators** - flexible criteria with some overlaps, especially with those with frailty & other co-morbidities

**(a) Cancer – rapid or predictable decline**

**Metastatic cancer**

- More exact predictors for cancer patients are available e.g. *PiPS (UK validated Prognosis in Palliative care Study)*. PPI, PPS etc. 'Prognosis tools can help but should not be applied blindly'
- ' Single most important predictive factor in cancer is performance status & functional ability' - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less

**(b) Organ Failure – erratic decline**

**Renal Disease**

Stage 4 or 5 Chronic Kidney Disease (CKD); condition is deteriorating with at least 2 indicators:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

**Chronic Obstructive Pulmonary Disease (COPD)**

At least 2 indicators:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

**Heart Disease**

At least 2 indicators:

- CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

## General Neurological Diseases

- Progressive deterioration in physical and/ or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems > recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communications and progressive dysphasia. Plus:

### Motor Neurone Disease

- Rapid decline in physical status
- 1st episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms & medical complications
- Low vital capacity (< 70% of predicted; using standard spirometry)
- Dyskinesia, mobility problems & falls
- Communication difficulties.

### Multiple Sclerosis

- Significant complex symptoms & medical complications
- Dysphagia + poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment, notably onset of dementia.

### Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- Condition less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty.

## (c) FRAILTY , DEMENTIA & STROKE (gradual decline)

### DEMENTIA

**VITAL!** That discussions with individuals living with dementia are started at an early to ensure that **whilst they have mental capacity** they can discuss how they would like the later stages managed.

There are many underlying conditions which may lead to degrees of dementia & these should be taken into account.

Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance &
- Urinary & faecal incontinence, &
- No consistently meaningful conversation
- Unable to do Activities of Daily Living (AD
- Barthel score >3.

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage 3 or 4
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia

### STROKE

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- No improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

### FRAILTY

Individuals presenting with Multiple co morbidities with significant impairment in day to day living and:

Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofksy

Combination of at least three of the following symptoms:

- weakness
- slow walking speed
- significant weight loss
- exhaustion
- low physical activity
- depression