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| Image may contain: one or more people and close-up  preparation and recognising End of life care needs  Care Homes with and without nursing | This document is aimed to help Care Homes to use the Gold Standard Framework to recognise a resident in the last year of Life and Communicate the residents needs timely and effectively.  Nikki Still (Macmillan and Martlets Care Home Project Lead). Heather Jacobs (End of Life Care Facilitator for Nursing Homes) |

**Preparation and Recognising End of Life Care needs with your Residents**

This document is being developed at the request of some Care Homes in the knowledge that early recognition that a person is in their last year of life will improve the persons care.

This document will enable the Care Homes to use the Gold Stand Framework (GSF) and then plan to achieve a clear escalation process.

The GP’s of Brighton and Hove have regular GSF meetings to discuss their Palliative and End of Life Care Patients; however, residents living in Care Homes (with and without nursing) are often only highlighted for a rapid deterioration or with symptom management issues. The GSF is about proactive care planning and should anticipate problems and support residents where possible to be cared for in their preferred place of care. Identifying resident’s early will aim to improve advance planning for the resident and their family ensuring that their wishes and preferences are known and work towards these being met.

We hope that this document will help the Care Homes to highlight residents earlier and report to Community Health Professionals to enable a more planned approach to their care. This proactive approach should reduce the number of emergency hospital admissions or the need for a rapid response/crisis intervention.

Care Homes are a major provider of End of Life Care (EoLC). In 2015 111,738 died in Care Homes 23% of all deaths in England. There has been a 20% increase in Care Home deaths since 2011. In 2005 only 58% of permanent residents died in their Care Homes, this has increased to 70% in 2014. However, in 2015 29% of permanent Care Home residents died elsewhere those predominantly died in hospital. With the growing pressure on the health services and the need to provide the right care in the right place at the right time (\*1). We need to work together to care and support residents to die in their preferred place of care. The Ambitions document states that death isn’t a failure but poor care is. <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

**Preparation and Recognising End of Life Care needs with your Residents**

This tool is designed to help you recognise your residents that maybe entering their last year of Life. It will support you to assess the person, proved regular reviews and document changes using GSF. It will also enable you to communicate changes effectively with other health professionals and access support and any changes needed to the persons care in a timely manner.

This tool is based on the Gold Standard Framework to ensure early recognition and equity of best practice for End of Life Care. Using illness trajectories means residents needs can be better anticipated and addressed.

‘Earlier identification of people nearing the end of their life and inclusion on the register leads to earlier planning and better co-ordinated care’ (GSF National Primary Care Snapshot Audit 2010).

The aim is to anticipate problems and needs and ensure these can be managed rather than giving defined timescales. This ensures that the right care can be provided at the right time in the right place. This is more important than working out the exact time remaining and leads to better proactive care in alignment with resident’s preferences.

(Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas.K et al)

**Getting started**

Residents name … ……………………………………

Date of Birth ……… ……………………………………………..

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| **Definition of End of Life Care** **General Medical Council 2009** [**www.gmc-uk.org/static/documents/content/End\_of\_life.pdf**](http://www.gmc-uk.org/static/documents/content/End_of_life.pdf) |
| People are ‘approaching the end of life’ when they are **likely to die within the next   12 months**. This includes people whose death is imminent (expected within a few   hours or days) and 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. |
| Co-morbidities /Appropriate past medical history/Recent hospital admissions/Recent Clinical intervention. (add new information at each review). Include signs deteriorating health.  PMH:  Social information:  Cremation yes no  Weight:  Falls Risk/number of falls in Last 6 months:  Hospital admission:   * General physical decline, increasing dependence and need for support. * Repeated unplanned hospital admissions. * Advanced disease – unstable, deteriorating, complex symptom burden. * Presence of significant multi-morbidities. * 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. * Decreasing response to treatments, decreasing reversibility. * Patient choice for no further active treatment and focus on quality of life. * Progressive weight loss (>10%) in past six months. * Sentinel Event e.g. serious fall, bereavement, transfer to nursing home. * Serum albumin <25g/l * Consider eligibility for DS1500 payment. (please consider for self funders). |

**1)The Surprise Question**

Would you be surprised if this resident 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 and 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 and in preparation for possible further decline?*

Answer ………………………. If **Yes** continue to review monthly. (if no please continue to complete form)

**Monthly Review** (or sooner if condition changes) please include initials

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| Review date: |  |  |
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**2) Australian Karnofsky Performance Status (AKPS)**

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| AKPS  Score | Description of performance Status |
| 100% | Normal, no complaints, no evidence of disease |
| 90% | Able to carry on normal activity, minor signs or symptoms of disease |
| 80% | Normal activity with effort, some signs or symptoms of disease |
| 70% | Cares for self, but unable to carry on normal activity or do active work |
| 60% | Able to care for most needs, but requires occasional assistance |
| 50% | Considerable assistance and frequent medical care required |
| 40% | In bed more than 50% of the time |
| 30% | Almost completely bedfast |
| 20% | Totally bedfast and requiring extensive nursing care by professionals and/or family |
| 10% | Comatose or barely arousable, unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly |
| 0% | Dead |

**3) Specific Clinical Indicators** (Related to conditions)

Insert appropriate Clinical Indicator (Use the GSF PIG 2016 – Proactive Identification Guidance, page 8)

**Contact the residents GP to share your concerns and determine any reversible causes.**

**Give information using GSF information above:**

**Referral date………………………….. Date GP discussion………………………………………..**

**Date: End of Life Care agreed with Healthcare professional ……………….…………………………..**

**Current need…………………………………………………………………………………………………………….**

**Current Plan…………………………………………………………………………………………………………….**

**Community Services review date …………………………………………………………………………………..**

**GP review date as appropriate…………………………………………………………………………….**

**Planning individualised care**

**ACP with Treatment plan uploaded to IBIS for SECAMB Yes/No**

**Suspected last year of life (what to consider) Plan**

Review resident needs Monthly/bi weekly/Weekly/Daily (please circle as appropriate and review) (include initials and document if changes have been and if Health professional has been contacted)

|  |  |  |
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| Review date: |  |  |
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If condition has improved and the indicators no longer apply please inform all Heath Care Professionals involved.

Does the resident have any changing symptoms that need Health Care Professionals review? If yes

Date of referral and health care professional requested …………………………………………………………………..

Use the Adapted SBAR Tool to aid communication and ensure relevant and succinct information is given. (Adapted SBAR Tool on page 8)

Please report to GP if the patients’ needs have changed.

Needs Based Coding and Needs Support Matrices Identifying the stage of illness and anticipating needs and support– to deliver the right care at the right time for the right patient

* A - All stable from diagnosis years plus prognosis
* B - Unstable, advanced disease months prognosis
* C - Deteriorating, exacerbations weeks prognosis
* D - Last days of life pathway days prognosis
* E - After Care

For further details of use of Needs / Support Coding and Matrices as part of the GSF Programmes

**The GSF PIG 2016 – Proactive Identification Guidance (these have been taken directly from GSF PIG document please cut and paste as relevant to resident).**

1. **Cancer**

• Deteriorating performance status and functional ability due to metastatic cancer, multi-morbidities or not amenable to treatment – if spending more than 50% of time in bed/lying down, prognosis estimated in months.

• Persistent symptoms despite optimal palliative oncology. More specific prognostic predictors for cancer are available, e.g. PPS.

1. **Organ Failure**

**Heart Disease**

At least two of the indicators below:

• Patient for whom the surprise question is applicable.

• CHF NYHA Stage 3 or 4 with ongoing symptoms despite optimal HF therapy – shortness of breath at rest on minimal exertion.

• Repeated admissions with heart failure – 3 admissions in 6 months or a single admission aged over 75 (50% 1yr mortality).

• Difficult ongoing physical or psychological symptoms despite optimal tolerated therapy.

• Additional features include hyponatraemia <135mmol/l, high BP, declining renal function, anaemia, etc.

**Chronic Obstructive Pulmonary Disease (COPD)**

At least two of the indicators below:

• Recurrent hospital admissions (at least 3 in last year due to COPD).

• MRC grade 4/5 – shortness of breath after 100 metres on level.

• Disease assessed to be very severe (e.g. FEV1 6 weeks steroids in preceding 6 months, requires palliative medication for breathlessness still smoking.

**Kidney Disease**

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least two of the indicators below:

• Patient for whom the surprise question is applicable.

• Repeated unplanned admissions (more than 3/year).

• Patients with poor tolerance of dialysis with change of modality.

• Patients choosing the ‘no dialysis’ option (conservative), dialysis withdrawal or not opting for dialysis if transplant has failed.

• Difficult physical or psychological symptoms that have not responded to specific treatments.

• Symptomatic Renal Failure in patients who have chosen not to dialyse – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

**Liver Disease**

Hepatocellular carcinoma.

Liver transplant contra indicated.

Advanced cirrhosis with complications including:

• Refractory ascites

• Encephalopathy

• Other adverse factors including malnutrition, severe comorbidities, Hepatorenal syndrome

• Bacterial infection current bleeds, raised INR, hyponatraemia, unless they are a candidate for liver transplantation or amenable to treatment of underlying condition.

**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 (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure.

• Speech problems: increasing difficulty in communications and progressive dysphasia.

**Parkinson’s Disease**

• Drug treatment less effective or increasingly complex regime of drug treatments.

• Reduced independence, needs ADL help.

• The condition is less well controlled with increasing “off” periods.

• Dyskinesias, mobility problems and falls.

• Psychiatric signs (depression, anxiety, hallucinations, psychosis).

• Similar pattern to frailty – see below.

**Motor Neurone Disease**

• Marked rapid decline in physical status.

• First episode of aspirational pneumonia.

• Increased cognitive difficulties.

• Weight Loss.

• Significant complex symptoms and medical complications.

• Low vital capacity (below 70% predicted spirometry), or initiation of NIV.

• Mobility problems and falls.

• Communication difficulties.

**Multiple Sclerosis**

• Significant complex symptoms and medical complications.

• Dysphagia + poor nutritional status.

• Communication difficulties e.g., Dysarthria + fatigue.

• Cognitive impairment notably the onset of dementia.

1. **Frailty, dementia, multi-morbidity**

**Frailty**

For older people with complexity and multiple comorbidities, the surprise question must triangulate with a tier of indicators, e.g. through Comprehensive Geriatric Assessment (CGA).

• Multiple morbidities.

• Deteriorating performance score.

• Weakness, weight loss exhaustion.

• Slow Walking Speed – takes more than 5 seconds to walk 4 m.

• TUGT – time to stand up from chair, walk 3 m, turn and walk back.

• PRISMA – at least 3 of the following:

1. Are you older than 85 years?

2. Are you male?

3. In general, do you have any health problems that require you to limit your activities?

4. Do you need someone to help you on a regular basis?

5. In general, do you have any health problems that require you to stay at home?

6. If you need help, can you count on someone close to you?

7. Do you regularly use a stick, walker or wheelchair to move about?

If the respondent had 3 or more “yes” answers, this indicates an increased risk of frailty

**Dementia**

Identification of moderate/severe stage dementia using a validated staging tool e.g., Functional Assessment Staging has utility in identifying the final year of life in dementia. (BGS) Triggers to consider that indicate that someone is entering a later stage are:

• Unable to walk without assistance and

• Urinary and faecal incontinence, and

• No consistently meaningful conversation and

• Unable to do Activities of Daily Living (ADL)

• Barthel score >3

Plus any of the following: Weight loss, Urinary tract Infection, Severe pressures sores – stage three or four, Recurrent fever, Reduced oral intake, Aspiration pneumonia. NB Advance Care Planning discussions should be started early at diagnosis.

**Stroke**

• Use of validated scale such as NIHSS recommended.

• Persistent vegetative, minimal conscious state or dense paralysis.

• Medical complications, or lack of improvement within 3 months of onset.

• Cognitive impairment / Post-stroke dementia.

• Other factors e.g. old age, male, heart disease, stroke sub-type, hyperglycaemia, dementia, renal failure.

**What signs to look for when identifying deterioration**

**DYING PHASES**

* Increased sleepiness, fatigue
* Increasing symptoms (pain, breathless, nausea & vomiting)
* Anorexia/weight loss
* Dehydration
* Less communicative/interactive
* Reduced mobility
* Reduced bladder/bowel function – urinary retention, incontinence.
* Person appears more gaunt, pale
* Withdrawal from family, friends and life.
* Spending most of the time in bed.
* Difficulty swallowing and taking oral medications.
* Confusion/disorientation/visions.

**ACTIVELY DYING PHASE**

* Pulse and heart beat may be irregular or difficult to detect
* Increased perspiration

Nice guidelines Last days of Life

* Agitation
* Cheyne-stokes breathing
* Reducing conscious levels
* Mottled Skin
* Noisy respiratory secretions
* Progressive weight loss
* Increased fatigue and loss of appetite
* Changes in communication
* Deteriorating mobility
* Social withdrawal

**Adapted SBAR communication tool for Care Homes**

**To Be Used in Non-Life Threatening Cases, Please call 999 in an emergency**

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| S  Situation |  | [Logo - black and white](http://hellomynameis.org.uk/files/hello-my-name-is-logo-print-bnw.eps)  I am a nurse/carer at ………………..………… care home (which is nursing/non nursing)  I am calling about Mr/Mrs ………………………………………………..  I am calling because I am concerned that / I am unsure about / the resident needs / I need advice |
|  |  |  |
| B  Background |  | Mr/Mrs ……………….…. has been a resident here for…………………  Their normal condition is …………………………………………….……. (e.g. alert / drowsy / confused / self-caring)  Their relevant history includes ……………………………………..…….. (e.g. asthma, dementia, ischaemic heart disease)  ‘Do Not Attempt Cardio Pulmonary Resuscitation’ form is / is not in place. If Yes, it is signed and in date.  They do / do not have an Advance Care Plan in place.  If yes, this includes ………………………………………………………….. |
|  |  |  |
| A  Assessment |  | I have found that he / she is ……………………………………………….. (e.g. struggling to breathe / walk / has pain / has injured / confused)  Vital signs are ………………………………………………………………. (e.g. blood sugar, temperature, BP, pulse)  I think the problem is / may be …………………………………….………  **OR** I don’t know what’s wrong but I’m really worried |
|  |  |  |
| R  Recommendation  See guidance / notes below |  | I now need your assistance  I would like you to visit the resident (when?)  I would like your advice as to what to next / in the meantime |
|  |  |  |
| **Ask receiver to repeat key information to ensure understanding** | | |

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| --- | --- | --- |
| **GP – IN HOURS** | **GP – OUT OF HOURS** | **999**  **This is rarely appropriate** |
| **Call GP Surgery to request visit or call back**  **Discuss with GP to agree how to manage this patient** | **Can it wait until the resident’s own GP practice opens?**  **If YES, call when surgery opens**  **If NO, call 111 to discuss with GP** | **Consider all other options before this in a non-life threatening scenario** |
| **Martlets HUB 24/7**  **Phone support and guidance** | **01273 964164** |  |

The SBAR tool originated from the US Navy and was adapted for use in healthcare by Kaiser Permanente, Colorado, USA

**References**

<https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>

<https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf>

<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

Nice guidelines for End of Life Care for adults in the last year of life – Jan 2016

(\*1) NEoLIN, Public Health England, Sept 2017

**Additional information**

Please use [www.martlets.org.uk/macmillan-care-homes-project](http://www.martlets.org.uk/macmillan-care-homes-project)

[**http://www.camapcanada.ca/Barthel.pdf**](http://www.camapcanada.ca/Barthel.pdf)