

## **Toolkit and Resources – On protected section of the website**

### **Session 1 – Awareness and Overview**

1. NICE EoLC Standards
2. Summary of Evidence
  - 2.1. References
3. Use of PIG in Hospital
4. Summary of GSF Hospitals Programme
5. GSF Overview
6. How GSF Fits in with other End of Life Care tools
7. Dementia Care: Ten Top Tips
8. Leaflet for patients
9. GP letter
10. Target Exercise
11. Umbrella

### **Session 2 - Identify**

12. Prognostic Indicator Guidance (PIG)
13. The GSF Needs Support Matrices
14. SCR1
15. SCR2

### **Session 3 - Assessment**

16. SCR 3 PACA Score
17. SCR 4 Pepsi Cola
18. Distress Thermometer
19. Advance Care Planning
20. Dignity

### **Session 4 – Plan Cross Boundary Care**

21. Passport
22. Suggested Clinical flow diagrams of four main symptoms

### **Session 5 – Plan Care in Final Days**

23. Minimum Protocol

### **Session 6 – Embed and Next Steps**

24. Significant Event Analysis
25. Useful Website Links

## 1. NICE EoLC Standards

1	People approaching the end of life are identified in a timely way.
2	People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
3	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
4	People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
5	People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
6	People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
7	Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
8	People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
9	People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
10	People 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, at any time of day or night.
11	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
12	The body of a person who has died is cared for in a culturally sensitive and dignified manner.
13	Families and carers of people who have died receive timely verification and certification of the death.
14	People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
15	Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
16	Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

This NICE quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.

## 2. Summary of Evidence for Gold Standards Framework Primary Care National GSF Centre (see full Evidence Summary on GSF website )

### Key summary of findings

Summary of evaluations show that GSF supports improvements in these 3 areas

- a) **Qualitative - Attitudes, awareness and ethos in line with core values –**
  - Affirming the importance of good delivery of home based palliative care for all patients nearing the end of their lives
  - Positively life affirming - aiming to help people live well until they die
  - Staff confidence, morale and motivation- especially the community nurses
  - Enables greater alignment with the core values of staff, enshrined in philosophy of care
  - Improves job satisfaction, staff recruitment and retention
  - Encourages an open realistic approach to discussing dying and quality of care for dying
  
- b) **Patterns of working, structures and processes**
  - Improving communication within and between teams and with patients and their carers.
  - Improving the consistency and reliability of care - so fewer patients 'slip through the net'
  - Improving anticipatory care and proactive planning
  - Some specific benefits such as anticipatory prescribing of drugs left in the home, handover forms, greater team involvement in care of dying patients e.g. with a white board
  - Improved working with care homes
  
- c) **Outcomes**
  - Significant reduction in numbers of hospital deaths (e.g. halved) and admissions
  - Fewer crisis calls out of hours
  - More documented advance care plans and DNACPR forms
  - Significant **Cost savings for NHS**

For more details of the evidence of evaluation and independent research evidence for Primary Care and Care Homes programmes, see GSF website or contact the GSF team. Individual case studies demonstrating examples of best practice can also be provided.

Evidence of evaluation and independent research evidence for Primary Care and Care Homes programmes can be found on the Library section of the website, accessible via the link below:

<http://www.goldstandardsframework.org.uk/library-4#>

## 2.1 References

- Thomas K Caring for the dying at home: Companions on the journey *Radcliffe Medical Press* 2003
- Thomas K *British Medical Journal* ABC in palliative care chapter on 'Community Palliative Care' Ed Fallion et al London (accepted 2005- in press)
- Ed Watson.M Lucas C, Hoy .A *Adult Palliative Care Guidance* Thomas K (2003, revised 06) *Community Palliative Care chapter* SWSH
- Ed Watson M, Hoy A, Beck A et al *Oxford Handbook of Palliative Medicine* Thomas K (2003) Chapter 12 on *Community palliative care* OUP2005
- King N, Thomas K, Martin N, Bell D, Farrell S, & "Now nobody falls through the net Practitioners perspectives on the Gold Standards Framework for community palliative care *Palliative Medicine*2005;19:619-627
- Murray S, Boyd K, Sheikh A, Thomas K, Higginson I Developing primary palliative care Editorial *BMJ* 2004;329:1056-1057
- Murray .S **Thomas K et al** How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers *Family Medicine* December 05
- Thomas K Ellershaw J Improving Palliative care services; *British Journal Surgical Oncology* March05
- Thomas K (2003) The Gold Standards Framework in Community Palliative Care, *European Journal Palliative Care* 03:10(3) 113-115
- King N, Bell D & Thomas K (2004) Family carers' experiences of out of hours community palliative care: a qualitative study. *International Journal of Palliative Nursing* 10 (2), 76-83
- King N, Thomas K, Bell D (2003) An out of hours protocol for community palliative care: practitioners' perspectives, *international Journal of Palliative Nursing*, 9 (7), 277-282
- Thomas K, (2003) The Gold Standards Framework in Community Palliative Care, *European Journal Pall Care* 03:10(3) 113-115
- Thomas K (2001) The Gold Standards Framework Project *Journal of Primary Care* Dec 03
- Thomas K, Noble B. Improving the delivery of palliative care in general practice: an evaluation of the first phase of the Gold Standards Framework. *Palliat Med* 2007;21:49-53
- King N, Bell D, Martin N, Farrell S. Gold Standards Framework, phase 2: qualitative case study evaluation /final report. Primary Care Research Group, School of Human and Health Sciences, University of Huddersfield, 2003.
- Dale J, Koistinen J, Mahmood K, Munday D, Petrova M, Thomas K. Evaluation of the Gold Standards Framework for Palliative Care, Macmillan Phases 3-6 (2003-2005). Report to Macmillan Cancer Support. Warwick Medical School, 2007.
- Kelt S, Munday D, Dale J. Patients' experience of receiving GSF-led primary palliative care. *End of life Care* 2008;2;47-53.
- Dale J, Petrova M, Munday D et al. A national facilitation project to improve primary palliative care: the impact of the Gold Standards Framework on process and self-ratings of quality. *Quality and Safety in Health Care* 2009;18;174-180.
- Munday D, Mahmood K, Dale J, King N. Facilitating good processes in primary palliative care: does the Gold Standards Framework enable quality performance? *FamPract* 2007;1-9.
- Mahmood-Yousuf K, Munday D, King N, Dale J. Interprofessional relationships and communication in primary care: impact of the Gold Standards Framework. *Br J Gen Pract* 2008;58:256-63.
- Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 7 in Primary Care.School of Health Sciences, June 2006.[http://www.goldstandardsframework.nhs.uk/content/evaluation\\_and\\_research/](http://www.goldstandardsframework.nhs.uk/content/evaluation_and_research/)
- Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 8 in Primary Care.School of Health Sciences, University of Birmingham. November 2006.[http://www.goldstandardsframework.nhs.uk/content/evaluation\\_and\\_research/](http://www.goldstandardsframework.nhs.uk/content/evaluation_and_research/)
- Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 9 in Primary Care.School of Health Sciences, University of Birmingham. March 2007.[http://www.goldstandardsframework.nhs.uk/content/evaluation\\_and\\_research/](http://www.goldstandardsframework.nhs.uk/content/evaluation_and_research/) [
- Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 10 in Primary Care.School of Health Sciences, University of Birmingham. Sept 2007.[http://www.goldstandardsframework.nhs.uk/content/evaluation\\_and\\_research/](http://www.goldstandardsframework.nhs.uk/content/evaluation_and_research/)
- Walshe C, Caress A, Chew-Graham C, Todd C. Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three primary care trusts. *Palliat Med* 2008;22:736-43.
- King N, Melvin J, Ashby J. Community Nursing Roles and The Gold Standards Framework For Community Palliative Care: Final Report. Centre for Applied Psychological Research, School of Human and Health Sciences, University of Huddersfield, 2008.
- F Badger, C Clifford, A Hewison, K Thomas An evaluation of the implementation of a programme to improve end of life care in nursing home, *Pall Med* 2009; 23; 502 originally published online 28 May 09;
- Badger F, Thomas K, Clifford C Raising Standards for Elderly People Dying in Care Homes *European Journal of Palliative Care* for publication 2007; 14 (6)
- Hockley J, Watson J, Murray S The Midlothian 'Gold Standards Framework in care homes' project 2008, University of Edinburgh 2 papers in press
- Pending publication- , Hall S, Goddard C, Stewart S, Higginson IJ Benefits of and Barriers to Implementing the Gold Standards Framework to Improve End of Life Care in Care Homes: A qualitative study 2009 King's College London
- London Primary care Journal Nov 09 in press
- BOYD, K.J., WORTH, A., KENDALL, M., PRATT, R., HOCKLEY, J., DENVIR, M. and MURRAY, S.A., 2009. Making sure services deliver for people with advanced heart failure: a longitudinal qualitative study of patients, family carers, and health professionals. *Palliative medicine*, **23**(8), pp. 767-76.
- BUXTON, K.L., STONE, R.A., BUCKINGHAM, R.J., PURSEY, N.A. and ROBERTS, C.M., 2010. Current and planned palliative care service provision for chronic obstructive pulmonary disease patients in 239 UK hospital units: comparison with the gold standards framework. *Palliative medicine*, **24**(5), pp. 480-485.
- FENNING, S., WOOLCOCK, R., HAGA, K., IQBAL, J., FOX, K.A., MURRAY, S.A. and DENVIR, M.A., 2012. Identifying Acute Coronary Syndrome Patients Approaching End-of-Life. *PLoS One*, **7**(4)
- GARDINER, C., GOTT, M., INGLETON, C., SEYMOUR, J., COBB, M., NOBLE, B., BENNETT, M. and RYAN, T., 2013. Extent of palliative care need in the acute hospital setting: A survey of two acute hospitals in the UK. *Palliative medicine*, **27**(1), pp. 76-83

HAGA, K., MURRAY, S., REID, J., NESS, A., O'DONNELL, M., YELLOWLEES, D. and DENVIR, M.A., 2012. Identifying community based chronic heart failure patients in the last year of life: a comparison of the Gold Standards Framework Prognostic Indicator Guide and the Seattle Heart Failure Model. *Heart*, **98**(7), pp. 579-583.

MACPHERSON, A., WALSH, C., O'DONNELL, V. and VYAS, A., 2013. The views of patients with severe chronic obstructive pulmonary disease on advance care planning: A qualitative study. *Palliative medicine*, **27**(3), pp. 265-272.

MCKEOWN, A., AGAR, R., GAMBLES, M., ELLERSHAW, J.E. and HUGEL, H., 2008. Renal failure and specialist palliative care: an assessment of current referral practice. *International journal of palliative nursing*, **14**(9), pp. 454-458.

ABEL, J., RICH, A., GRIFFIN, T. and PURDY, S., 2009. End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year. *Palliative medicine*, **23**(7), pp. 616-22.

ANDERSON, A. and CHOJNACKA, I., 2012. Benefits of using the Liverpool Care Pathway in end of life care. *Nursing Standard*, **26**(34), pp. 42-50

DAVISON, S.N., 2011. Integrating Palliative Care for Patients with Advanced Chronic Kidney Disease: Recent advances, remaining challenges. *Journal of palliative care*, **27**(1), pp. 53-61.

DESAI, A.K. and GROSSBERG, G.T., 2011. Palliative and end-of-life care in psychogeriatric patients. *Ageing Health*, **7**(3), pp. 395-408.

GREAVES, C., BAILEY, E., STOREY, L. and NICHOLSON, A., 2009. Implementing end of life care for patients with renal failure. *Nursing Standard*, **23**(52), pp. 35-41.

GROVES, K., 2009. Imagine: a creative challenge towards holism. *Palliative medicine*, **23**(1), pp. 5-7.

JONES, L., HARRINGTON, J., BARLOW, C.A., TOOKMAN, A., DRAKE, R., BARNES, K. and KING, M., 2011. Advance care planning in advanced cancer: Can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. *Palliative & Supportive Care*, **9**(1), pp. 3-13.

MCGINN, M., 2010. End of life care... 'Online cancer education forum'. *European Journal of Cancer Care*, **19**(2), pp. 144-144.

ORITA, T., MIYASHITA, M., YAMAGISHI, A., AKIYAMA, M., AKIZUKI, N., HIRAI, K., IMURA, C., KATO, M., KIZAWA, Y., SHIRAHIGE, Y., YAMAGUCHI, T. and EGUCHI, K., 2013. Effects of a programme of interventions on regional comprehensive palliative care for patients with cancer: a mixed-methods study. *Lancet Oncology*, **14**(7), pp. 638. #

MURRAY, S. and BOYD, K., 2011. Using the 'surprise question' can identify people with advanced heart failure and COPD who would benefit from a palliative care approach. *Palliative medicine*, **25**(4), pp. 382.

PORDES, P., ASHCROFT, A. and WILLIAMS, P., 2011. An electronic resource to support staff providing end of life care. *Nursing Standard*, **26**(12), pp. 41-6.

SAMPSON, E.L., JONES, L., THUNÉ-BOYLE, I.C., KUKKASTENVEHMAS, R., KING, M., LEURENT, B., TOOKMAN, A. and BLANCHARD, M.R., 2011. Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention. *Palliative medicine*, **25**(3), pp. 197-209.

SAWKINS, N., 2010. Nurses need to speak the language of compassion. *Nursing Times*, **106**(37), pp. 28.

SINGLETON, C., 2010. Developing Practical Adult Nursing Skills - 3rd Edition. *Journal of Community Nursing*, **24**(6), pp. 35.

TRUEMAN, J. and TRUEMAN, I., 2011. COPD: criteria to assist in the identification of the palliative phase. *British Journal of Nursing*, **20**(10), pp. 635-639.

TRUEMAN, J. and TRUEMAN, I., 2011. Developing criteria to assist in the palliative phase of COPD. *British Journal of Nursing*, **20**(6), pp. 364-369.

YOHANNES, A.M., 2011. Palliative care and management principles in older patients with advanced chronic obstructive pulmonary disease. *Ageing Health*, **7**(3), pp. 409-421.

O'Callaghan A<sup>1</sup>, Laking G<sup>2</sup>, Frey R<sup>3</sup>, Robinson J<sup>4</sup>, Gott M<sup>3</sup>, 2014. Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting.

### 3. Use of PIG in hospital

## Main message- 30% hospital patients are in final year more in men, over 85, deprived, admitted to medical specialty

Palliat Med. 2014 Mar 17;28(6):474-479. [Epub ahead of print]

**Imminence of death among hospital inpatients: Prevalent cohort study.**

Clark D<sup>1</sup>, Armstrong M<sup>2</sup>, Allan A<sup>3</sup>, Graham F<sup>4</sup>, Carnon A<sup>3</sup>, Isles C<sup>5</sup>.

#### **Author information**

#### **Abstract**

#### **BACKGROUND:**

There is a dearth of evidence on the proportion of the hospital population at any one time, that is in the last year of life, and therefore on how hospital policies and services can be oriented to their needs.

#### **AIM:**

To establish the likelihood of death within 12 months of a cohort of hospital inpatients on a given census date.

#### **DESIGN:**

Prevalent cohort study.

#### **PARTICIPANTS:**

In total, 10,743 inpatients in 25 Scottish teaching and general hospitals on 31 March 2010.

#### **RESULTS:**

**In all, 3098 (28.8%) patients died during follow-up: 2.9% by 7 days, 8.9% by 30 days, 16.0% by 3 months, 21.2% by 6 months, 25.5% by 9 months and 28.8% by 12 months. Deaths during the index admission accounted for 32.3% of all deaths during the follow-up year. Mortality rose steeply with age and was three times higher at 1 year for patients aged 85 years and over compared to those who were under 60 years (45.6% vs 13.1%;  $p < 0.001$ ). In multivariate analyses, men were more likely to die than women (odds ratio: 1.18, 95% confidence interval: 0.95-1.47) as were older patients (odds ratio: 4.99, 95% confidence interval: 3.94-6.33 for those who were 85 years and over compared to those who were under 60 years), deprived patients (odds ratio: 1.17, 95% confidence interval: 1.01-1.35 for most deprived compared to least deprived quintile) and those admitted to a medical specialty (odds ratio: 3.13, 95% confidence interval: 2.48-4.00 compared to surgical patients).**

#### **CONCLUSION:**

Large numbers of hospital inpatients have entered the last year of their lives. Such data could assist in advocacy for these patients and should influence end-of-life care strategies in hospital

## Main Message- GSF PIG helps identify patients in last year of life and helps in anticipating needs- both current unrecognised and future anticipated -giving systematic EOLC and improving outcomes

Palliat Med. 2014 May 22. pii: 0269216314536089. [Epub ahead of print]

**Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting.**

O'Callaghan A<sup>1</sup>, Laking G<sup>2</sup>, Frey R<sup>3</sup>, Robinson J<sup>4</sup>, Gott M<sup>3</sup>.

#### **Abstract**

**BACKGROUND:** Screening to identify hospital inpatients with a short life expectancy may be a way to improve care towards the end of life. The Gold Standards Framework Prognostic Indicator Guidance is a screening tool that has recently been advocated for use in the hospital setting.

**AIM:** To assess the clinical utility of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in an acute hospital setting.

**MAIN OUTCOME MEASURES:** Mortality at 6 and 12 months and sensitivity, specificity and predictive value of the Gold Standards Framework Prognostic Indicator Guidance at 1 year.

**DESIGN, SETTING AND PARTICIPANTS:** Prospective cross-sectional study of 501 adult inpatients in a tertiary New Zealand teaching hospital screened utilising the Gold Standards Framework Prognostic Indicator Guidance.

**RESULTS:** A total of 99 patients were identified as meeting at least one of the Gold Standards Framework Prognostic Indicator Guidance triggers. In this group, 6-month mortality was 56.6%

and 12-month mortality was 67.7% compared with 5.2% and 10%, respectively, for those not identified as meeting the criteria. The sensitivity and specificity of the Gold Standards Framework Prognostic Indicator Guidance at 1 year were 62.6% and 91.9%, respectively, with a positive predictive value of 67.7% and a negative predictive value of 90.0%.

**CONCLUSION:**

**The sensitivity, specificity and predictive values of the Gold Standards Framework Prognostic Indicator Guidance in this study are comparable to, or better than, results of studies identifying patients with a limited life expectancy in particular disease states (e.g. heart failure and renal failure). Screening utilising the Gold Standards Framework Prognostic Indicator Guidance in the acute setting could be the first step towards implementing a more systematic way of addressing patient need - both current unrecognised and future anticipated - thereby improving outcomes for this population**

**Message- GSF helps predict the 30% patients nearing the end of life**

[Palliat Med.](#) 2013 Jan;27(1):76-83. doi: 10.1177/0269216312447592. Epub 2012 May 22.

**Extent of palliative care need in the acute hospital setting: a survey of two acute hospitals in the UK.**

[Gardiner C<sup>1</sup>](#), [Gott M](#), [Ingleton C](#), [Seymour J](#), [Cobb M](#), [Noble B](#), [Bennett M](#), [Ryan T](#).

Author information

**Abstract**

**BACKGROUND:**

In common with international health policy, The End of Life Care Strategy for England has highlighted the delivery of high quality palliative care in the acute hospital setting as an area of priority.

**AIM:**

The aim of this study was to explore the extent of palliative care need in the acute hospital setting, and to explore agreement between different sources in the identification of patients with palliative care need.

**DESIGN:**

A cross-sectional survey of palliative care need was undertaken in two UK acute hospitals. Hospital case notes were examined for evidence of palliative care need according to Gold Standards Framework (GSF) prognostic indicator criteria. Medical and nursing staff were asked to identify patients with palliative care needs. Patients (or consultees) completed assessments of palliative care need.

**PARTICIPANTS:**

Of a total in-patient population of 1359, complete datasets were collected for 514 patients/consultees.

**RESULTS:**

36.0% of patients were identified as having palliative care needs according to GSF criteria. Medical staff identified 15.5% of patients as having palliative care needs, and nursing staff 17.4% of patients. Patient self-report data indicated that 83.2% of patients meeting GSF criteria had palliative care needs.

**CONCLUSION:**

**The results reveal that according to the GSF prognostic guide, over a third of hospital in-patients meet the criteria for palliative care need.** Consensus between medical staff, nursing staff and the GSF was poor regarding the identification of patients with palliative care needs. This has significant implications for patient care, and draws into question the utility of the GSF in the hospital setting

**Message - GSF PIG helped identify a fifth of patients nearing the end of life ('palliative care need')**

[BMC Palliat Care.](#) 2013 Mar 28;12:15. doi: 10.1186/1472-684X-12-15.

**Palliative care need and management in the acute hospital setting: a census of one New Zealand Hospital.**

[Gott M<sup>1</sup>](#), [Frey R](#), [Raphael D](#), [O'Callaghan A](#), [Robinson J](#), [Boyd M](#).

[Author information](#)

**Abstract**

**BACKGROUND:**

Improving palliative care management in acute hospital settings has been identified as a priority internationally. The aim of this study was to establish the proportion of inpatients within one acute hospital in New Zealand who meet prognostic criteria for palliative care need and explore key aspects of their management.

**METHODS:**

A prospective survey of adult hospital inpatients (n = 501) was undertaken. Case notes were examined for evidence that the patient might be in their last year of life according to Gold Standards Framework (GSF) prognostic indicator criteria. For patients who met GSF criteria, clinical and socio-demographic information were recorded.

**RESULTS:**

Ninety-nine inpatients met GSF criteria, representing 19.8% of the total census population. The patients' average age was 70 years; 47% had a primary diagnosis of cancer. Two thirds had died within 6 months of their admission. Seventy-eight of the 99 cases demonstrated evidence that a palliative approach to care had been adopted; however documentation of discussion about goals of care was very limited and only one patient had evidence of an advance care plan.

**CONCLUSION:**

One fifth of hospital inpatients met criteria for palliative care need, the majority of whom were aged >70 years. *Whilst over three quarters were concluded to be receiving care in line with a palliative care approach, very little documented evidence of discussion with patients and families regarding end of life issues was evident. Future research needs to explore how best to support 'generalist' palliative care providers in initiating, and appropriately recording, such discussions*

**Message – predicting heart failure patients nearing end of life is difficult- GSF PIG can help (86% identified for final year ) but more help might be useful to improve identification**

*(NB They assume here that PIG relates to one year, which it does not, so queries on specificity are not helpful )*

[Heart](#). 2012 Apr;98(7):579-83. doi: 10.1136/heartjnl-2011-301021.

**Identifying community based chronic heart failure patients in the last year of life: a comparison of the GoldStandards Framework Prognostic Indicator Guide and the Seattle Heart Failure Model.**

[Haga K<sup>1</sup>](#), [Murray S](#), [Reid J](#), [Ness A](#), [O'Donnell M](#), [Yellowlees D](#), [Denvir MA](#).

[Author information](#)

**Abstract**

**OBJECTIVE:**

To assess the clinical utility of the Gold Standards Framework Prognostic Indicator Guide (GSF) and the Seattle Heart Failure Model (SHF) to identify patients with chronic heart failure (CHF) in the last year of life.

**DESIGN, SETTING AND PATIENTS:**

An observational cohort study of 138 community based ambulatory patients with New York Heart Association (NYHA) class III and IV CHF managed by a specialist heart failure nursing team.

**MAIN OUTCOME MEASURES:**

12 month mortality, and sensitivity and specificity of GSF and SHF.

**RESULTS:**

138 CHF patients with NYHA class III and IV symptoms were identified from a population of 368 ambulatory CHF patients. 119 (86%) met GSF criteria for end of life care. The SHF model identified six (4.3%) patients with a predicted life expectancy of 1 year or less. At the 12 month follow-up, 43 (31%) patients had died. The sensitivity and specificity for GSF and SHF in predicting death were 83% and 22%, and 12% and 99%, respectively. Receiver



operator characteristic analysis of SHF revealed a C index of  $0.68 \pm 0.05$  (95% CI 0.58 to 0.77). Chronic kidney disease (serum creatinine  $\geq 140 \mu\text{mol/l}$ ) was a strong univariate predictor of 12 month mortality, with a sensitivity of 56% and specificity of 72%.

#### **CONCLUSIONS:**

Neither the GSF nor the SHF accurately predicted which patients were in the last year of life. The poor prognostic ability of these models highlights one of the barriers to providing timely palliative care in CHF.

#### **Comment in**

- [Additional recent data from The Netherlands, on the last year of living with heart failure.](#) [Heart. 2012]
- [Prognostication or identification of palliative needs in advanced heart failure: where should the focus lie?](#) [Heart. 2012]

## **Message -GSF PIG helps predict COPD patients in the last year of life**

[BMJ Support Palliat Care.](#) 2014 Mar 25. doi: 10.1136/bmjspcare-2012-000432. [Epub ahead of print]

### **Predictors of survival in patients with chronic obstructive pulmonary disease receiving long-term oxygen therapy.**

[Law S<sup>1</sup>](#), [Boyd S](#), [Macdonald J](#), [Raeside D](#), [Anderson D](#)

#### **AIM:**

Chronic obstructive pulmonary disease (COPD) affects 2-4% of the UK's population and has significant mortality, however prognostication is difficult. Long-term oxygen therapy (LTOT) has been identified by the Gold Standards Framework as a clinical indicator of advancing disease. We hypothesised the ADO index (for 'Age, Dyspnoea and airflow Obstruction'), which predicts mortality, could be applied to our LTOT population to help identify patients with poor prognosis. We aimed to compare this to the Medical Research Council dyspnoea scale, body mass index, forced expiratory volume in 1 s and gas transfer.

#### **METHODS:**

This was a retrospective study on 136 patients with COPD started on LTOT, June 2003 to August 2010. Data were collected from LTOT databases and medical records. Patients' length of survival was calculated from initiation of LTOT. Patients were grouped by individual parameters. Survival rates at 6 months, 1 year and 4 years were calculated. GraphPad Prism V.5.0 software was used to construct Kaplan-Meier curves and perform log-rank tests.

#### **RESULTS:**

The ADO index discriminated survival at 6 months, 1 year and 4 years,  $p=0.0027$ . Low body mass index ( $<20$ ) was associated with poor prognosis after 1 and 4 years,  $p=0.0015$ . Medical Research Council grade predicted survival at 4 years. Diffusion capacity of the lung for carbon monoxide (DLCO)% predicted and forced expiratory volume in 1 s (FEV<sub>1</sub>)% predicted did not predict survival.

#### **CONCLUSIONS:**

This study showed wide variation in survival in a patient population on LTOT. The ADO score could be used as an early trigger for referral to palliative services, thus enhancing end-of-life care, which improves quality of life in COPD. A prospective study of this application would be required to prove this hypothesis.

#### **KEYWORDS:**

Chronic obstructive pulmonary disease; Prognosis; Quality of life

## **Message - GSF PIG helps identify patients with a high symptom burden in hospital**

[BMC Palliat Care.](#) 2013 Feb 26;12:11. doi: 10.1186/1472-684X-12-11.

### **Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals.**

[Ryan T<sup>1</sup>](#), [Ingleton C](#), [Gardiner C](#), [Parker C](#), [Gott M](#), [Noble B](#).

### [Author information](#)

#### **Abstract**

#### **BACKGROUND:**

The requirement to meet the palliative needs of acute hospital populations has grown in recent years. With increasing numbers of frail older people needing hospital care as a result of both malignant and non-malignant conditions, emphasis is being placed upon understanding the physical, psychological and social burdens experienced by patients. This study explores the extent of burden in two large UK hospitals, focusing upon those patients who meet palliative care criteria. Furthermore, the paper explores the use of palliative services and identifies the most significant clinical diagnostic and demographic factors which determine physical and psychological burden.

#### **METHODS:**

Two hospital surveys were undertaken to identify burden using the Sheffield Profile for Assessment and Referral to Care (SPARC). The Gold Standards Framework (GSF) is used to identify those patients meeting palliative care criteria. Participants were identified as being in-patients during a two-week data collection phase for each site. Data was gathered using face-to-face interviews or self-completion by patients or a proxy. Descriptive analyses highlight prevalence and use of palliative care provision. Binary logistic regression assesses clinical diagnostic predictor variables of physical and psychological burden.

#### **RESULTS:**

The sample consisted of 514 patients and elevated physical, psychological and social burden is identified amongst those meeting palliative care criteria (n = 185). Tiredness (34.6%), pain (31.1%), weakness (28.8%) and psychological discomfort (low mood 19.9%; anxiety 16.1%) are noted as being prevalent. A small number of these participants accessed Specialist Palliative Care (8.2%). Dementia was identified as a predictor of physical (OR 3.94; p < .05) and psychological burden (OR 2.88; p < .05), being female was a predictor of psychological burden (OR 2.00; p < .05).

#### **CONCLUSION:**

The paper highlights elevated levels of burden experienced by patients with palliative care requirements. Moreover, the paper also indicates that a large proportion of such patients are not in receipt of palliative approaches to their care. Furthermore, the paper identifies that those with non-malignant illnesses, especially dementia, may experience high levels of physical and psychological burden.

### **Message - GSF PIG helps identify patients with acute coronary syndrome in hospital**

[PLoS One](#). 2012;7(4):e35536. doi: 10.1371/journal.pone.0035536. Epub 2012 Apr 18.

## **Identifying acute coronary syndrome patients approaching end-of-life.**

[Fenning S<sup>1</sup>](#), [Woolcock R](#), [Haga K](#), [Iqbal J](#), [Fox KA](#), [Murray SA](#), [Denvir MA](#).

### [Author information](#)

- <sup>1</sup>Edinburgh Heart Centre, Royal Infirmary of Edinburgh, Little France Crescent, Edinburgh, United Kingdom.

#### **Abstract**

#### **BACKGROUND:**

Acute coronary syndrome (ACS) is common in patients approaching the end-of-life (EoL), but these patients rarely receive palliative care. We compared the utility of a palliative care prognostic tool (Gold Standards Framework (GSF)) and the Global Registry of Acute Coronary Events (GRACE) score, to help identify patients approaching EoL.

#### **METHODS AND FINDINGS:**

172 unselected consecutive patients with confirmed ACS admitted over an eight-week period were assessed using prognostic tools and followed up for 12 months. GSF criteria identified 40 (23%) patients suitable for EoL care while GRACE identified 32 (19%) patients with  $\geq 10\%$  risk of death within 6 months. Patients meeting GSF criteria were older (p = 0.006), had more comorbidities ( $1.6 \pm 0.7$  vs.  $1.2 \pm 0.9$ , p = 0.007), more frequent hospitalisations before (p = 0.001) and after (0.0001) their index admission, and were more likely to die during follow-up (GSF+ 20% vs GSF- 7%, p = 0.03). GRACE score was predictive of 12-month mortality (C-statistic 0.75) and this was improved by the addition of previous hospital admissions and previous history of stroke (C-statistic 0.88).

#### **CONCLUSIONS:**

This study has highlighted a potentially large number of ACS patients eligible for EoL care. GSF or GRACE could be used in the hospital setting to help identify these patients. GSF identifies ACS patients with more comorbidity and at increased risk of hospital readmission.

## 4. Summary of GSF Hospitals Programme

### Summary of GSF Hospitals Programme in the UK. Aug 2014

- The GSF Acute Hospital service improvement programme aims to enable high quality end of life care in hospitals by improving
  - the quality of care provided and patient experience of care
  - the team working and coordination of cross boundary care
  - patient outcomes by enabling more to live and die in their preferred place of care, reducing hospitalisation and thereby improving cost effectiveness
- GSF Hospitals programme in Acute and Community Hospitals -grew from successful use of GSF in community i.e. in primary care since 2000 and care homes since 2004, and request to integrate some proactive GSF-type thinking in a hospital environment, to support improved end of life care, and also improve cross boundary care and coordination with community, for in-patients, patients coming into hospitals, discharged out of hospital and as outpatients.

#### The GSF Acute Hospital programme began 2008

- Phase 1 pilot in 2008-10 with initially 12 hospitals – including Southport whole hospital , Phase 2 pilot 2011-8 hospitals – including Airedale whole hospital
- Phase 3 2012- 7 hospitals - full 2 year programme began, Phase 4 2013- 8 hospitals -
- Phase 5 2014 – 5 hospitals 10 wards – beginning Sept 2014
- Total of 40 hospitals involved so far, with 5 whole-hospital projects - Morecombe Bay (31 wards) , Exeter (14 wards) , Clatterbridge (3 wards) , Airedale (10 wards ) and Southport and Ormskirk Hospital
- The Training Programme includes train-the trainers programme with 6 workshops over the 2 years, all resources and tools needed, individualised support and coaching, including some visits and ongoing and independent evaluation
- Summaries of the evaluation reports are sent to each participating ward and hospital – summarised together in the ICF GHK Reports from Phases 3 and 4.
- The aim is to support wards to attain Foundation Level and progress to Accreditation and the Quality Hallmark Award
- **GSFAH Accreditation.** Our Accreditation endorsing partner for Acute Hospitals is the British Geriatric Society, who has contributed to the development of the accreditation guidance document and evaluation tools and will be a panel member for the accreditation process.
- The first Quality Hallmark Award for Acute Hospitals is in March 2015. 10 wards have applied, 5 from Royal Devon and Exeter, and 5 from Morecambe Bay Hospital Trust.

#### There are 4 parts to the GSF Accreditation process

**Part 1: Outcome measures-** Summary of **key outcome ratios** - evidence of measurable change in key areas as a snapshot summary of the key outcomes that have changed after training intervention

**Part 2: Comparative Audit- measuring change before and after**

- a) **Patient** - After Death Analysis x 30 (15 deaths+15 discharges) to demonstrate patient level change
- b) **Organisation-** Foundation level questionnaire- attainment of key changes for your organisation
- c) **Staff-** Self reported staff survey of confidence and competence

**Part 3: Portfolio** of evidence demonstrating attainment of the 5 standards

- Development of Acute hospital EOLC protocol from action plan
- Case study of one patient
- Carers feedback where appropriate
- Qualitative feedback on the difference made

**Part 4: Assessment** - visit from GSF Assessment team

to assess against suggested key questions and report on evidence of good implementation, team awareness and impact plus longer term sustainability.

## Key Findings from evaluation from GSFAH Independent Evaluation

### GSFAH Phase 2

- Greater staff confidence and earlier recognition
- Decrease length of stay - 6 days
- Better communication with GPs
- Better integration with community
- Earlier recognition of decline by staff
- Greater staff confidence
- More patient views sought (ACP)

### GSFAH Phase 3

- **Decrease length of stay - 3 days**
- **Most areas of EoL care practice have improved since implementing GSF**
- **Particularly large improvements were seen in:**  
*The collection and transference of passport information; the use of DS1500s; the use of SCAs; and the proportion of patients on RDPs*
- **More modest improvements were seen in:**  
*The use of ACPs/PPCs, the recording of DNAR/NCR/AND, and discussions with patients and carers*  
*Several hospitals attained Foundation Level – (see below )*



### GSF AH –Enhanced Level leading on to Accreditation



### GSF AH Foundation Level



#### 1. Identify - Right person

1. Identify patients and record in patient's notes, flagged or on electronic system/ Register
2. Code and triggers key actions – (Needs Support Matrices)
3. Discussed plan of care at ward round/MDT

#### 2. Assess - Right care

1. Assess clinical needs
2. Assess personal needs - offer ACP discussion/give leaflets
3. Supporting carers

#### 3. Plan - Right Place

1. Communicate with GP - discharge letters - inclusion on register/ EPaCCS + ACP update
2. Rapid discharge - reducing hospitalisation
3. Cross boundary care discussion with care homes, primary care etc.

#### 4. Plan - Right Time

1. Anticipatory care to prevent crises
2. Ensure patients have a personalised support plan for care in their final days
3. Carers supported after death and in bereavement

#### 5. Every time

1. Develop the hospital culture to ensure compassion and empathy
2. Demonstrate consistency and sustainability through the development of an EOLC protocol
3. Demonstrate on going learning

#### Identify

1. Every patient nearing the end of life (final months, weeks, days) is identified
2. They are included on the appropriate hospital register/tagged
3. A plan of care is discussed at ward round/MDT meeting

#### Assess

4. Clinical needs assessed using appropriate clinical assessment tool/measures
5. There is an initial discussion with the patient and carers and information given e.g. GSF card/leaflet
6. This includes beginning an advance care planning discussion, proxy nominated person noted (or LPoA), DNACPR status, preferred place of care and information leaflet given.

#### Plan

7. Communication with GP - discharge letters including ACP, follow up suggesting inclusion on GP's Palliative Care/GSF registers for regular discussion at GSF meeting and proactive care
8. Rapid discharge process for those who wish to go home
9. Ensure patients have a personalised support plan for care in final days of life

### GSF Community hospitals – began 2010

- Similar programme to GSFAH and 2-3 year support, with 6 workshops, adapted to community hospital setting
- Based on Foundation and Enhanced Levels above
- So far 41 community hospitals have undertaken training in 3 areas- Cornwall, Dorset and Cumbria.

### GSF Community Hospital Accreditation

- Accreditation with endorsing partner National Community Hospitals Association
- March- Sept 2014 - 12 wards have gone through the Accreditation process, along similar lines as the Acute Hospital Accreditation, and are being awarded the Quality Hallmark Award at the next conference on September 26<sup>th</sup> 2014



**Enabling a gold standard of care for all  
people nearing the end of life**



**The work of the National Gold Standards  
Framework Centre in End of Life Care**

## GSF Overview

[info@goldstandardsframework.co.uk](mailto:info@goldstandardsframework.co.uk)

[www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

Victoria Mews, 8-9 St Austin's Friars, Shrewsbury, Shropshire, SY1 1RY  
Telephone: 01743 291 891

## Our Core Purpose - training frontline staff to enable a gold standard of care for people nearing the end of life

The GSF Centre team have for over fifteen years ,helped generalist frontline staff care better for all people in the final years of life, enabling them to live well until they die. Many thousands of doctors, nurses and carers have received training, affecting the care of several million people over the years, ensuring they are more likely to live well and die well in the place and the manner of their choosing.

GSF is a systematic, evidence based approach to optimising care for all people approaching the end of life, given by generalist front-line care providers. We provide quality improvement, quality assurance and quality recognition.

The GSF Centre provides nationally recognised training and accreditation programmes enabling transformational cultural change that leads to a 'gold standard' care for people nearing the end of life. This includes care for people with any life limiting condition, in any setting (home, care home, hospital and others) pro-actively at any time in the last years of life.

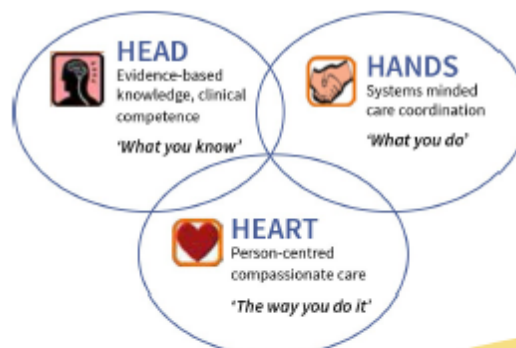
We aim to improve:-

- the quality of care received, by up-skilling the workforce
- the coordination and communication across boundaries of care and
- patient outcomes, enabling more to live well and die well where they choose, and reducing inappropriate hospitalisation

We do this by providing training programmes, tools, measures and support to improve care for all people in the last years of life.

The GSF Centre both influences national policy developments, and helps put policy into practice, supporting practical grass-roots change in line with NICE Guidance, DH EOLC Strategy, Care Quality Commission (CQC), Skills for Care and all national policy. The focus is on directing special 'VIP' 'gold standard' care to anyone whose life may be limited so that the right person receives the right care, at the right time, in the right place, every time.

To do this we combine all three elements of head, hands and heart working together...



## What we are most proud of and well-known for

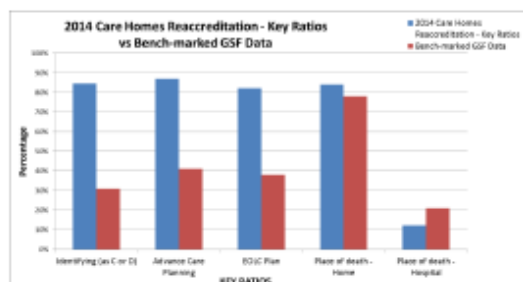
- Making a difference – training that has made a real and practical difference to care for people at grassroots level – for example more dying at home, fewer hospital admissions or crises, better care.
- Influencing national policy, government developments, QOF Department of Health, CQC regulator, amongst others.
- Enabling and motivating staff – boosting the confidence and competence of thousands of health and social care staff to mobilise the workforce and release their talents, passion and commitment.
- One of the UK's longest established end of life care organisations, well known and active for over 15 years.
- Spread to all settings – the biggest training centre and the most end of life care programmes used across all settings.
- GSF is internationally recognised with some GSF affiliated centres in over 8 countries.
- Transformational change – teams are assessed less by what they know, but more by what they do, leading to long-lasting culture change.
- GSF Accreditation is externally recognised by CQC, NICE, RCGP etc.
- Compassionate care – integrating compassionate care and spiritual awareness in all programmes, affirming their vital importance in all we do.
- Developing integrated cross-boundary care across a wider community through training, strategic planning and support.

### Awards

- Skills Academy – Excellent Providers
- BMJ Education Award Finalist for Primary Care Programme
- Recognition by Royal College of GP's, British Medical Association, British Geriatric Society, NCPCC, English Community Care Association, Community Hospital Association, National Care Forum, Registered Nursing Home Association

## The outcomes of our programmes include

- Halving hospital admissions and hospital deaths in care homes.
- Greater staff confidence, job satisfaction, boosted morale, staff retention.
- Spread to all settings adapting training to suit needs of staff in all areas.
- Earlier identification of patients declining or in the final year of life.
- Earlier and better listening to patients' wishes through advance care planning discussions and providing care to meet their needs.
- Improved proactive care for those with life limiting conditions.
- Better integrated cross boundary coordination - improved communication with GPs, care homes and hospitals.
- Formalised measured outcomes and evaluation and well-recognised accreditation process, plus strong evidence base.





## GSF Training Programmes



### Primary care

- Since 2000, 98% GP practices use foundation Level basic GSF principles (palliative care registers and meetings) – now next stage GSF Going for Gold programme undertaken by over 500 practices, with many going for Accreditation Quality Hallmark Award (*partner RCGP*) – BMJ Award Finalist. Launch of the GSF Silver programme autumn 2014. the programme includes 2 workshops to support practices improving the numbers of patients on their registers and advance care planning



### Care homes

- Over 2,500 care homes since 2004 with over 500 accredited with Quality Hallmark Award (*partners ECCA, NCF, NCA, RNHA*) and over 100 re-accredited 3 years on, GSF Care Homes recognised by CQC as examples of best practice.



### Acute hospitals

- 40 hospitals involving individual wards or whole hospital projects, many attaining Foundation Level and moving to accreditation and the Quality Hallmark Award 2014 (*partner British Geriatrics Society*).



### Community hospitals

- 41 hospitals so far in 3 areas- Cornwall, Dorset, Cumbria, 14 currently being accredited with Quality Hallmark Award 2014 (*partner National Community Hospitals Association*).



### Domiciliary care

- 5 large project groups involving several hundred carers through train the trainers cascade programme. Certificate course - radical changes demonstrated plus improved confidence of staff and collaboration with primary care.



### Dementia care

- Pilot phase 1 (50) and now Phase 2 under way through distance learning, focusing on end of life care, improving pain assessment, care planning and reducing hospitalisation.



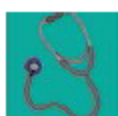
### Integrated cross boundary care (XBC) foundation sites

- Three current sites plus others developing involving training in primary care, care homes, hospital, domiciliary care and strategic cross boundary working.



### Hospice Support

- Launch May 2014 – 6 hospices - mainly home care/day care units supporting use of GSF for patients at home, and improving cross boundary care and collaboration.



### Clinical Skills Course

- Re-launched Autumn 2014 – on VLZ for nurses, healthcare assistants and later for GPs, improving clinical skills in caring for residents in care homes.



### Spiritual Care Course

- Launch Autumn 2014 – on VLZ plus tailored workshops/roadshow for all health and social care providers, includes enhancing compassionate care.

## Current GSF projects across the UK

### North

- Lancashire – 15 GP practices, 1 large Hospital Trust (5 sites) 38 accredited care homes with 14 re-accredited
- Airedale, Yorkshire – all wards in acute hospital, 22 care homes, 30 GP practices, XBC 'Foundation Site'
- Kirklees, West Yorkshire – 76 care homes, 29 accredited with 14 re-accredited (GSF Regional Centre, Locala) now in this area
- Manchester – 85 care homes, 2 acute hospitals 4 wards, 10 Domiciliary care agencies, 100's of Domiciliary workers
- North Teesside – 73 care homes
- Tameside and Glossop – 12 GP practices
- Wirral – 6 GP practices, 5 accredited care homes
- Cumbria – 13 community hospitals

### Central

- Nottingham – 34 care homes, 6 accredited, 30 Foundation Level, 1 acute hospital - 2 wards, 2 Hospices, 12 GP practices, XBC Foundation Site
- Worcester – 63 care homes (Regional Centre) 9 Accredited
- Norfolk – 64 care homes - 8 Accredited
- Suffolk – 41 care homes - 14 Accredited
- Peterborough, Bedford, Luton, Herts – 60 care homes – 8 Accredited
- Shropshire – 28 care homes - 7 Accredited
- Warwickshire – 36 GP practices, 29 care homes
- Wolverhampton – 1 acute hospital, 2 wards, - 3 accredited care homes
- Northampton – 2 hospices

### London / South East

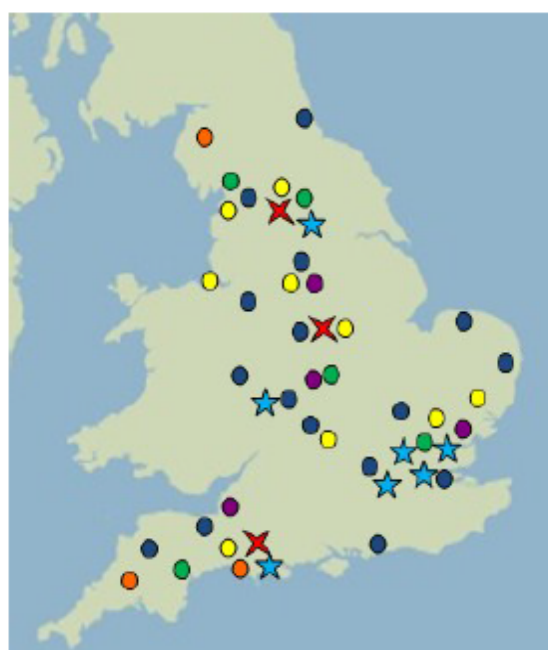
- South East London, St Christopher's (Regional Centre) - 64 care homes
- Barking Havering Redbridge – 90 care homes, 70 GP practices, 76 domiciliary care agencies, 3 hospital wards
- North London (Regional Centre) – 90 care homes
- North East Essex – 42 GP practices
- Esher, Princess Alice (Regional Centre), 26 care homes
- St Francis. Romford (regional Centre)

### South West

- Dorset (Regional Centre) 76 care homes, 34 accredited, 14 community hospitals, acute hospitals 3 wards, 2 GP practices, 1 accredited practice, XBC Site
- Cornwall – All 62 nursing homes and all 14 community hospitals
- Somerset – 90 care homes - 47 Accredited, 15 GP practices, 12 domiciliary care agencies
- Devon – whole hospital Exeter

### Plus international projects and GSF affiliations in:

- Australia – GSF Care Homes + Living and dying well project Tasmania Adelaide etc
  - Holland – Amsterdam Primary Care TADZ study
  - Belgium Flanders GSF Primary Care
  - South Africa – Abundant Life in Cape Town hospitals
  - China, Hong Kong, Singapore, Taiwan and Japan
- GSF strong areas and 8 GSF regional centres
- Dorset
  - Locala
  - North London Hospice
  - St Francis Hospice, Romford
  - St Christopher's
  - Princess Alice Hospice, Surrey
  - South Coast
  - St Richards Hospice, Worcester



- ★ GSF Regional Centres
- ✖ Cross Boundary Care Pilot Sites
- Care Homes Projects
- Domiciliary Care Projects
- Primary Care Projects
- Community Hospital Projects
- Acute Hospital Projects

## How is training delivered?

Our training leading to accreditation or certificates is either through:-

- Delivered Workshops plus homework and coaching, local areas or through one of our GSF Regional Centres (8 in UK).
- Distance Learning filmed programmes on GSF Virtual Learning Zone.
- Blended learning (combination of the above).
- Foundation Level, (Silver) Enhanced level, leading to Accreditation and the GSF Quality Hallmark Award.
- International partnerships - working with other countries to use and adapt GSF Programmes for their needs and context.

## How is impact evaluated?

- Quantitative and qualitative assessments intrinsic in all programmes.
- Key outcome measures showing impact of change before and after.
- Comparative audits – patient level (online After Death Analysis - ADA), staff confidence, organisation questionnaire, patient/carer views.
- Portfolio – evidence of best practice.
- Quality assessment visit/interview.
- Reports and cumulated evidence published in peer reviewed journals.

## How you might like to be involved

- Contact GSF team for a discussion, commission a programme.
- Register on GSF database for the GSF newsletter and other information.
- Feedback on your experience or see patient section of website.
- Let your GP/care home/hospital know about this and ask if they are using GSF/Going for Gold or if they are GSF Accredited!
- Volunteer your services e.g., as a lay visitor.
- Let us know if you think you can help us in any way.

## Meet the GSF team

- Prof. Keri Thomas – Founder, CEO, National Clinical Lead
- Maggie Stobbart-Rowlands – GSF Lead Nurse
- Lucy Giles – Deputy Lead Nurse
- Julie Armstrong-Wilson - Nurse Lead for Acute Hospitals and Primary Care
- Barbara Walker – Nurse Trainer
- Chris Elgar – Clinical Nurse Acute Hospitals and Primary Care
- 32 Clinical Associates and GPs
- Pam Poole – Office Manager
- Aggie Caesar-Homden – Operations Manager
- Mark Thomas – Development Director
- Robyn Handford – PA, Programme Coordinator Primary Care
- Lauren Ford - Programme Coordinator Audit & Evaluation, Acute Hospitals
- Jane Pitchford-Newman – Programme Coordinator for Accreditation
- Alli Sangster-Wall – Training Programme Coordinator
- Sue Richards – Programme Coordinator for Dementia, VLZ, ADA
- Becci Malone – Administrator

## 6. How GSF fits in with other End of Life Care Tools?

### End of Life Care Tools

Since the NHS End of Life Care Programme came to a close in 2014 information was transferred to [www.nhs.uk](http://www.nhs.uk)

**The Gold Standards Framework;** (GSF) for care of patients in the last year of life in the community and other settings. Currently being used by GP practices, care homes, community hospitals, domiciliary care and acute hospitals. GSF is now being implemented internationally.

**The Five Priorities of Care** – Leadership Alliance document ‘More care, Less pathway’ gives guidance on the care that should be incorporated into everyday practice when caring for patients who are in their last hours or days of life.

**Advance Care Planning e.g. Use of the Preferred Priorities of care (PPC)** document - a patient held record to enable patients’ wishes especially about place of care to be discussed and communicated to others.

The GSF Programme has been using Advance Care Planning for many years and the ACP we suggest covers more areas than just preferred place of care, including DNACPR. However, there are many developments in this area and more information and guidance on this can be found at [www.ncpc.org.uk](http://www.ncpc.org.uk)

There are also many variations of these tools but it is easy to see how complementary these tools can be in improving End of Life Care.

### Amber Care Bundle

The Gold Standards Framework Acute Hospital (GSFAH) programme and AMBER care Bundle are two initiatives, with different origins, that are complementary in approach, both aiming to improve care for this most vulnerable group of patients. They can be used separately or increasingly used together and can be seen as a means to support generalist frontline staff care better for this important group of patients in hospital. They are both in line with NICE guidance, national policy and local targets, and both have a growing evidence base to support their success. They should be seen as complementary and not in opposition to each other, and a means of improving care

For more details on the AMBER care bundle [www.ambercarebundle.org](http://www.ambercarebundle.org)

## 7. Dementia Care: Ten Top Tips

Every patient and carer is individual. Barbara Pointon, who cared for her husband Malcolm, offers these ten top tips which worked for them:

- 1) **Feeding** It is the most trustful thing in the world to open your mouth to be fed. Malcolm would refuse food from a new carer, so continuity of staff is vital. Up to one hour may be required to patiently feed pureed food by the teaspoonful; cold thickened drinks may be more easily sensed and controlled than tepid ones. Use metal not plastic teaspoons in case of clamping down.
- 2) **Space** 84% of people with Alzheimer's have visuo-spatial perceptual problems and don't know where they are in space. Rolling a patient on the bed to change an incontinence pad can be alarming and cause resistance for some - we used a standing hoist right to the end. ( Each person will be different in this)The change of position also helped Malcolm to cough productively. A mobile hung from the ceiling helps to give some sense of position.
- 3) **Weight Loss** in severe dementia is inevitable. Relatives of care home residents need to understand that it is not necessarily a sign of neglect.
- 4) **Medication** All of Malcolm's medication had to be reduced to paediatric sized dosages/preparations in line with weight loss and /or severity of dementia. Adult doses became the equivalent of overdosing, with unwanted side effects. Even Malcolm's final syringe driver had only a half dose in it. This is very individual.
- 5) **Loss of Mobility** should not mean confined to bed. Alternate with a recliner chair and wheelchair. Good pressure relief, the right size and absorbency of incontinence pads, scrupulous cleansing and six major changes of position each day ensured that Malcolm's skin remained intact throughout 7 years of immobility and double incontinence.
- 6) **Constipation** It is not your normal constipation; the brain no longer understands the signals from the gut to co-ordinate muscles for consciously bearing down. An assessment by a dementia-aware continence adviser can help as can a special regimen, similar to that for a paraplegic.
- 7) **Sounds** Even if the patient is mute and may have little understanding of speech, continue to talk to them. The sound of a kindly voice is a fundamental human need. Music (of their taste) will still get through.
- 8) **Stimulation** With normal levels of cognition shot to pieces, sensory and emotional needs become more important. Stimulate each of the five senses in an appropriate way – Malcolm loved his aromatherapy sessions – and encourage eye-contact, talking and gentle touch, especially from visitors who are unsure what to do.
- 9) **Familiarity** Most people with dementia become terrified of being anywhere other than in familiar surroundings. Breaks for the carer should be arranged through having replacement care at home, preferably given by the same person each time. For the same reason, at the very end of life, admission to a noisy, busy hospital should be avoided if possible. A calm and tranquil environment is important.
- 10) **Making time** At any stage, time is the greatest gift you can give to people with dementia. Make time just to be alongside as a tangible, comforting presence, especially when life is drawing to a close.

The new GSF Dementia Training Programme is available via the GSF Virtual Learning Zone

The population is increasingly ageing, people aged 85 and over make up the fastest growing group in the UK. With an ageing population there is inevitably an increase in the incidence of dementia. The average life expectancy following diagnosis of a dementia is 4 ½ years and it is predicted that by 2021 over a million people in the UK will have dementia, and be in the last year of life. Many people also suffer from multiple co-morbidity - 29% of people with cancer, circulatory or respiratory disease also have dementia.

Increased confusion and behavioural problems are sometimes attributed to the person's dementia when often the cause is an easily remedied physical problem e.g. infection, constipation, depression, pain or other physical conditions, sometimes it could be caused by change in surroundings or familiar faces or the individual's spiritual, psychological, emotional or social needs not being met.

In addition, a high proportion of people with Alzheimer's have visuo-spatial perceptual problems and miscue their surroundings or other people's actions. Through memory loss, they may also be living in their head in a former time and place. Even mild to moderate dementia complicates the giving of care for other life-threatening conditions (Meisen & Jones 2006).

Over half of people with dementia live in care homes, many of these homes are not specifically registered for dementia care, so it is important that the staff in these homes receive some additional dementia awareness training. Utilise the expertise of your local CPN for older mental health, and seek advice/training opportunities from the Alzheimer's Society and the NCPC. In some areas there are also specialist dementia nurses – Admiral Nurses.

For more information see  
[www.dementiauk.org](http://www.dementiauk.org)  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

#### Some Statistics

- There are currently 800,000 people with dementia in the UK.
- There will be over a million people with dementia by 2021.
- Two thirds of people with dementia are women.
- The proportion of people with dementia doubles for every 5 year age group.
- One third of people over 95 have dementia.
- 60,000 deaths a year are directly attributable to dementia.
- Delaying the onset of dementia by 5 years would reduce deaths directly attributable to dementia by 30,000 a year.
- The financial cost of dementia to the UK is over £23 billion a year.
- Family carers of people with dementia save the UK over £8 billion a year.
- 64% of people living in care homes have a form of dementia. (Alzheimer's Society 2009)
- Only 44% of people with dementia in the UK, receive a diagnosis

#### Challenges in end of life care and dementia;

- Impaired communication of need
- Difficulties in assessing pain/other symptoms
- Aggressive resistance/ 'Challenging behaviour'
- Poor pain management.
- Physical and mental decline
- Behavioural and psychological symptoms
- Prognostic uncertainty
- Ethical and Legal issues
- Nutrition and hydration
- Diagnosing dying
- Discontinuation and conversion of medication
- Drugs / administration (risk assessment)
- Prolonged dying phase
- Bereavement support
- Resources
- Education
- Communication skills training
- Engagement with other Services
- Management of double incontinence and preserving tissue viability
- Positioning
- Enhanced oral hygiene (NB use of community dentist for advice if required)
- Communication through the senses and emotional support

The DH Dementia Strategy addresses some of the end of life care issues for people with dementia and recommends that the person with dementia and their carers/family should be involved in planning end of life care. (DH Living well with dementia: A National Dementia Strategy 2009)

Discussions need to take place on more than one occasion in comfortable unhurried surroundings. People with dementia do not lose all ability to communicate and their ability to engage in discussions can vary from day to day or even during the course of the day. Use words that the individual understands and regularly check their understanding, take cues from their non-verbal responses and involve the resident's NOK or advocate wherever possible – they are likely to have a good knowledge of the person and what their views and wishes were previously. There is evidence to suggest that people with dementia tend to make similar decisions to those without dementia, so we should not avoid asking people with dementia what their views are (Fazel et al 2000). Consider the appropriateness of interventions and the benefits of those interventions to that individual, e.g. the admission to a busy acute hospital ward of a person with dementia in the final stages of their life is very likely to exacerbate confusion and disorientation leading to increased fear, anxiety and agitation.

Guidance on the use of best interest's principles (Mental Capacity Act 2005) is available from;  
[www.opsi.gov.uk/acts/acts2005/en/ukpgaen](http://www.opsi.gov.uk/acts/acts2005/en/ukpgaen).

ACP discussions can be very helpful for people with dementia. Such decisions can take place even though the individual may have quite advanced dementia, as long as they have capacity – the ability to understand and speculate about the decision to be made. Evidence suggests that people with early dementia are interested in participating in ACP discussion, and that they make similar decisions to people without dementia. Therefore, we should not hold back from asking people with dementia their views.

Staff who care for residents with dementia have difficulties in ascertaining wishes and preferences, especially for those residents who had no family. They also spoke of difficulties that arose when GP's were reluctant to make advance decisions. Staff were well aware of unnecessary distress that can be caused by sending a person with dementia out of their environment to the hospital and were in many cases keen to have advanced discussions documented. Staff spoke of their own distress and powerlessness at seeing residents with dementia being sent to hospital in their last 48hrs of life because of lack of documentation relating to resuscitation status.

**A note about Advance Care Planning in dementia - Karen Harrison Denning, Consultant Admiral Nurse**

Many of the best practice points generally applicable to Advance Care Planning (ACP) discussions will apply to people with dementia but there are others that also need to be taken into account in addition:

**Skilled interviewer**

Those undertaking ACP with people with dementia will need to have appropriate knowledge and skills to understand the issues in communication in dementia.

**The right time**

As with all ACP discussions they need to be held at the right time but in dementia these discussions need to be held early on in the illness when the person still has the capacity, cognition and language to hold meaningful discussions and make informed decisions. Ideally the ACP discussions in dementia should be part of supportive post diagnostic counseling processes within e.g. a Memory Clinic.

**The right place**

People with dementia often have visuospatial problems that are associated with their dementia so it is important to hold the discussions in a quiet and unthreatening place with no distractions of noise and interruptions that can hinder their concentration.

**Involvement of family**

Once a person no longer is deemed and assessed to have capacity decisions will need to be made in their 'best interest' and the Mental Capacity Act framework for determining best interest applied. A Lasting Power of Attorney (LPA) with appropriate authority (Personal Welfare) may be empowered to make decisions on the behalf of a person with dementia based on their knowledge of the person and on what they believed the person would or would not have wanted for themselves.

**Take time**

People with dementia will require more time for any ACP discussions; these may need to be done over some period of time with some repetition and clarification.

**Scenarios**

People with dementia may need examples of situations which they need to consider in making an ACP; e.g. Clinical vignettes illustrating cardiac resuscitation or PEG feeding for example for them to conceptualise and apply to their own situation. This has been done using pictures, video clips and narratives.

## 8. Leaflet for Patients

### USEFUL CONTACT NUMBERS:

GP:.....

Tel:.....

District Nurse:.....

Tel:.....

Community Matron:.....

Tel:.....

Palliative Care Team:.....

Tel:.....

Social Worker:.....

Tel:.....

Other:.....

The National GSF Centre is the leading national provider of training for generalists in end of life care. GSF Programmes help to improve the quality of care for all people with advanced life-limiting conditions in a variety of settings.

Contact the GSF Centre for more information.  
Email: [info@gsfcentre.co.uk](mailto:info@gsfcentre.co.uk) / Tel: 01743 291897

*"Every organisation involved in providing end of life care will be expected to adopt a coordination process such as GSF"* Department of Health End of Life Care Strategy 2008



### What are the benefits of the Gold Standards Framework? (GSF)

Providing

**THE RIGHT PERSON**

with

**THE RIGHT CARE**

in

**THE RIGHT PLACE**

at

**THE RIGHT TIME**

GSF helps us to give you the highest standard of care— a gold standard of care, focussing on your own needs, wishes and priorities.

Enquiries or Information:

  
the **gold standards**  
**framework**  
in acute hospitals

**Information for patients,  
families and carers.**



**Planning the right  
care for you and your  
family**



## What is the Gold Standards Framework?



The Gold Standards Framework is a framework to help deliver a 'gold standard' of care for all people as they near the end of their lives. It is widely used in GP practices, care homes, hospitals and other settings. It is recommended as an example of best practice by the NHS, the Government and national policy leaders, and has been found to be of benefit to many thousands of patients in the UK already.

The GSF is very simple. It helps doctors, nurses and others to identify earlier those patients with serious conditions who may be declining, assess their needs and wishes and to plan and better coordinate top quality care in line with their needs, preferences and wishes.

The GSF programme aims to:

- Improve the quality of care for all people with life-limiting conditions.
- Improve co-ordination and collaboration with GPs, primary care teams, specialists and others.
- Improve home care and reduce avoidable hospital stays in the final stage of life.

This hospital is part of the National Gold Standards Framework in Hospital Programme, supported by local facilitators, the National GSF team and other colleagues. Being part of the GSF Programme means that we are working together as a team to ensure that we anticipate possible issues earlier, listen better to you and your family, communicate well to others involved in your care and at all times you and your family are treated with dignity, respect and compassion. We will endeavour to make sure you receive the highest standard of care at all times wherever possible- the 'gold standard' of care .

## How will the Gold Standards Framework affect you?

### HOW WILL I BENEFIT?

As a team, we will work with you to ensure:

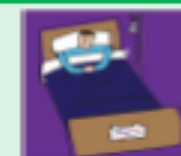
- You are treated at all times with respect and dignity
- Any deterioration in your condition is recognised early, your needs and symptoms are anticipated, assessed and managed as well as possible.
- We will help you identify what is important to you, where you would like to be cared for, what you do and don't want to happen (Advance Care Planning)
- You have the right information you need to support you to make decisions and plan ahead.
- We will support you and your family whilst you are here in hospital or in your transfer home if that is your wish.
- We will ensure other relevant professionals know the important information about you as a 'GSF' or 'gold' patient, and communicate with your GP and community teams when we plan your discharge.
- We will try to ensure that you have well coordinated care wherever you are, and in the final stage of life.



### WHAT ABOUT MY FAMILY?

GSF is here for your family and carers too. It reminds us to support your family throughout your illness. Doctors and nurses can talk with your family about their needs and concerns. They may be entitled to a carer's assessment on their own behalf, and they may be signposted to other sources of help.

## How will GSF improve care?



### WHAT HAPPENS IF MY CONDITION CHANGES?

Your care plan will change if your condition changes. In this way the doctors and nurses can look after you and your family in the best possible way. They will manage any physical problems, but also other things you might like, for example to be able to be at home if possible. Importantly, they will maintain your dignity and respect your wishes.

### WHAT ABOUT WHAT I WANT OR DON'T WANT?:

#### Advance Care Planning

#### Advance Care Planning Discussions

We can help you if you wish to discuss your thoughts about the future, and what you do and do not want to happen. We will go at your own pace, but if you wish to know more, or to discuss specific things, we are ready to do so. This includes three areas :-

- **Advance Statement:** This is a discussion about wishes and preferences, clarifying things that are important to you and ensuring this is written down and communicated so that others are aware of it. It includes preference for place of care.
- **Proxy - Who can speak for me?** You can choose someone to speak on your behalf, in case you cannot, to ensure your wishes are known. This can be a named spokesperson, or a nominated official 'Lasting Power of Attorney'.
- **Advance Decision to Refuse Treatment: What if I don't want a particular treatment?** If you feel strongly that there are treatments that you don't want in the future you can say so formally. This is known as an 'ADRT'. You can also discuss options for resuscitation (known as Do Not Attempt Cardio Pulmonary Resuscitation - DNACPR).

## 9. GP letter



YOUR HOSPITAL HEADED NOTEPAPER

Letter to GPS/Primary Care Teams/Practice Managers re: GSFAH

Dear [name of GP practice]

**Improving coordination of care for patients nearing the end of life in hospital, using the Gold Standards Framework Programme for Acute Hospitals phase 5 (GSFAH) - how this may affect you**

We are writing to inform you that we at [add name of hospital] are taking part in the Gold Standards Framework in Acute Hospitals Training Programme (GSF AH - Phase 5) to improve care for people nearing the end of life. This hospital will be implementing GSFAH initially on [ward/in the whole hospital]. Once we have completed Foundation Level, it is hoped that this might later be spread to include other wards across the hospital, and further embedded to progress towards GSFAH Accreditation and the Quality Hallmark Award for End of Life Care.

**End of Life care** is defined by the GMC as care for any patients considered to be in the final year of life, so includes people in the final months, weeks or days of life (for further information, see the GSF Prognostic Indicator Guidance ([www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk))). Use of **The Gold Standard Framework (GSF) Programmes** is considered to be one of the best ways to improve end of life care, particularly in enabling better coordination, collaboration and cross boundary care for all patients in every setting. Therefore, we are writing to you to indicate the differences you may find and ask for your cooperation in this area.

**The aims of the GSFAH Programme are to:**

- Improve the **quality of care** for all patients in the final year of life receiving hospital care
- Improve **cross boundary coordination of care**, before, during and after hospital admissions
- Reduce **hospitalisation** enabling more to live and die at home and improving cost-effectiveness

**What this may mean to you as a GP/Primary Care Team:**

- **Earlier identification**
  - We plan to identify patients earlier in hospital who are considered to be in the final year/months/weeks of life. We will then notify you, so that they may be included on your practice Palliative Care or GSF Supportive Care Register/**in some areas this may include the Locality Register or EPaCCS**. Patients identified will be given an information leaflet and/or Gold card.
- **Better assessment and communication**
  - We will be improving our assessment of these patients, and developing our discharge letters to include information as to whether patients may be nearing the end of life, what 'needs-based coding' we consider them to be, and any advance care planning discussion we may have had with them. This will include discussion of their preferred place of care, a proxy advocate to speak for them (or Lasting Power of Attorney), resuscitation discussion or DNACPR, and maybe some further information. We ask that you might continue this discussion with them following discharge **e.g. using the ACP record your area is using**. We also ask that you pass on any such information back to us if they are readmitted to hospital or attend outpatients.
- **Better planning**
  - Armed with this information, we hope that you are better able to proactively plan their care, they will be regularly reviewed at your team meetings, you can continue the important discussions of preferences and needs, continue to support the family and carers and enable their wishes of place of care to be attained wherever possible.

We hope that this is helpful - please see additional notes overleaf. We welcome your feedback and suggestions on ways to further improve our care for this important group of patients. Do contact us if you require any further information and we look forward to working with you.

Yours sincerely

[Name], GSF Hospital Facilitator

*GSF - the right care, for the right person, in the right place, at the right time, every-time*

### **What is GSF and where is it used?**

GSF is a systematic common-sense approach to formalising best practice, so that quality end of life care becomes the standard for every patient. It embodies an approach that centres on the needs of patients and families, and encourages inter-professional teams to work together.

GSF was originally developed in 2000, developed *by* primary care and *for* primary care teams, as a means to improve the quality and organisation of care for all people nearing the end of life. Most GP Practices use Foundation Level GSF (QOF, plus having a register and meeting) with many others having progressed to Next Stage GSF/Enhanced Level through the GSF 'Going for Gold' training programme, with some now receiving Quality Recognition/Accreditation. This GSF Acute Hospital programme was developed in 2008, with a group of grass roots hospital clinicians and is now used in about 40 hospitals. It is a similar framework, adapted for hospitals, and is used for inpatient stay and as part of a means to improve cross boundary care and collaboration.

If you would like to know more about moving on with GSF to the Going for Gold Programme please see the GSF website [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk) or contact [info@gsfcentre.co.uk](mailto:info@gsfcentre.co.uk).

### **Benefits and means of improving Cross Boundary Care**

GSF in Hospitals is sometimes called the 'missing link' - one of the main focuses must be to improve cross boundary communication. Often communication breakdown is a barrier to effective and seamless end of life care. The main areas to be aware of are:-

- GSF helps to put patients at the centre of care, no matter where they are
- Using a common language for all involved in end of life care
- Use of commonly accepted needs based coding - ABCD or Blue, Green, Amber, Red
- Using needs support matrices as checklists to trigger the right care, at the right time
- Preventing inappropriate admissions, reducing length of stay, improving community care
- Use of passport information including offering ACP discussion during admission, advocacy, awareness and use of ACP, DNACPR, Lasting Power of Attorney and others
- Hospitals recommend to GPs that their patients should be on a palliative care register - either whilst an inpatient or on discharge (e.g. a default sentence at end of discharge letter). If they are readmitted they are already flagged on the hospital system as GSF registered

(All these areas are covered in more detail in the GSF Going for Gold Primary Care Programme)

GSF in hospitals should provide a stable framework on which to continue to build a high standard of care, allowing hospital trusts to work in conjunction with all other health care professions to improve integrated care for people nearing the end of life in all settings. Without the important piece of the jigsaw of hospital care, this is unlikely to happen.

This hospital team is raising awareness across the organisation, communicating with others and linking with GPs, Specialist Palliative Care teams and Care Homes. The hospital team have prepared the ground and the next stage is to commence the training sessions for staff and improve this cross boundary coordination. The programme will be independently evaluated at various stages.

For more information about the range of training and quality improvement programmes see the GSF website [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk), email [info@gsfcentre.co.uk](mailto:info@gsfcentre.co.uk), or phone 01743 291 897.

## 10. Target exercise

### Self-Reflection Target Exercise

On the target there are eight statements. As a team, go round every statement and get each person to make a dot on the target with the marker pen to 'score' how much you agree with each statement. If you strongly agree you should put a dot in the middle circle. If you disagree your mark goes in the outer circle. It's a snapshot. Go with your initial feelings and do not reflect at huge length. Do not discuss anything or challenge each other while dots are being placed on the target. When every person has marked all the segments of the target, discuss the results. Where you are a high achieving ward—identify your top 3 priorities 1, 2, 3 next to those statements

### Target Practice - Introduction

**1. Family test**—If a close family member was dying and was a patient on the ward, we would feel happy with their care.

**2. Identifying patients** — We identify patients in the last year of life and have a clear ideas of where they might be on their illness trajectory

**3. Assessing clinical care**—We use assessment tools to ensure good control of symptoms and clinical care and give anticipatory medications

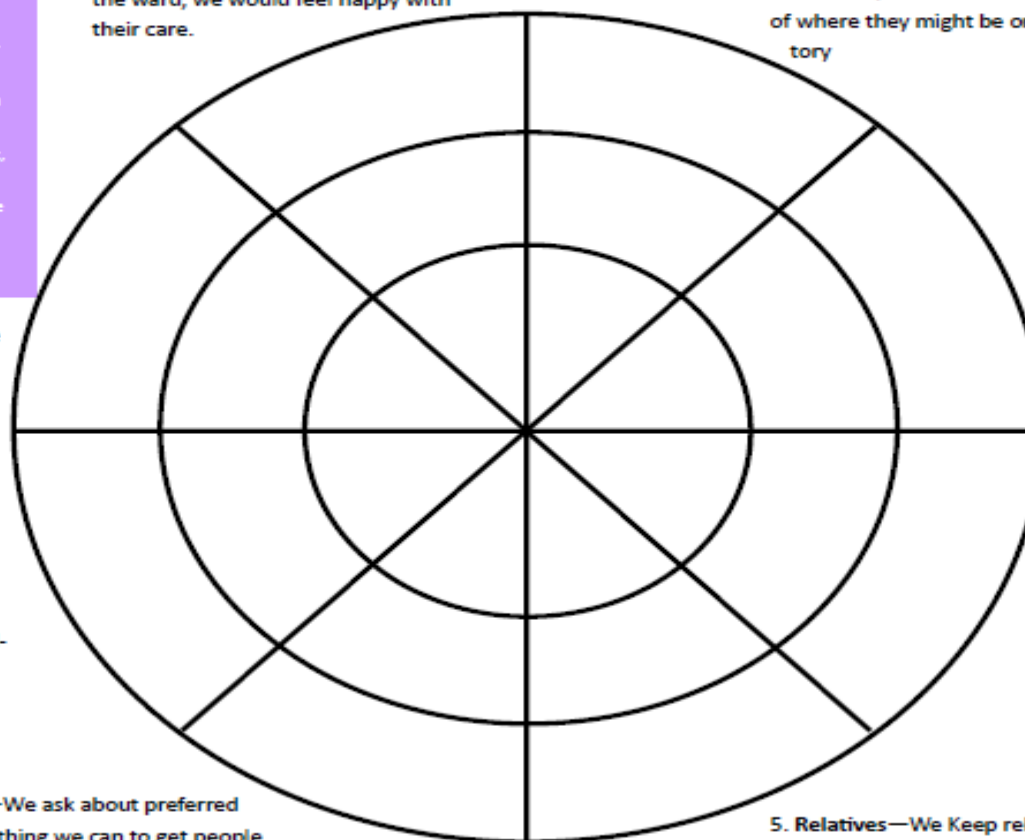
**4. ACP**—We enquire as to whether patients have recorded their wishes and preferences , and we feel comfortable having advance care planning discussions with patients about their future care and preferences

**5. Relatives**—We Keep relatives well informed and updated to enable them to be well prepared if the patient dies

**6. Dying where they choose**—We ask about preferred place of care and we do everything we can to get people home quickly if that is their place of choice in the final stage of life

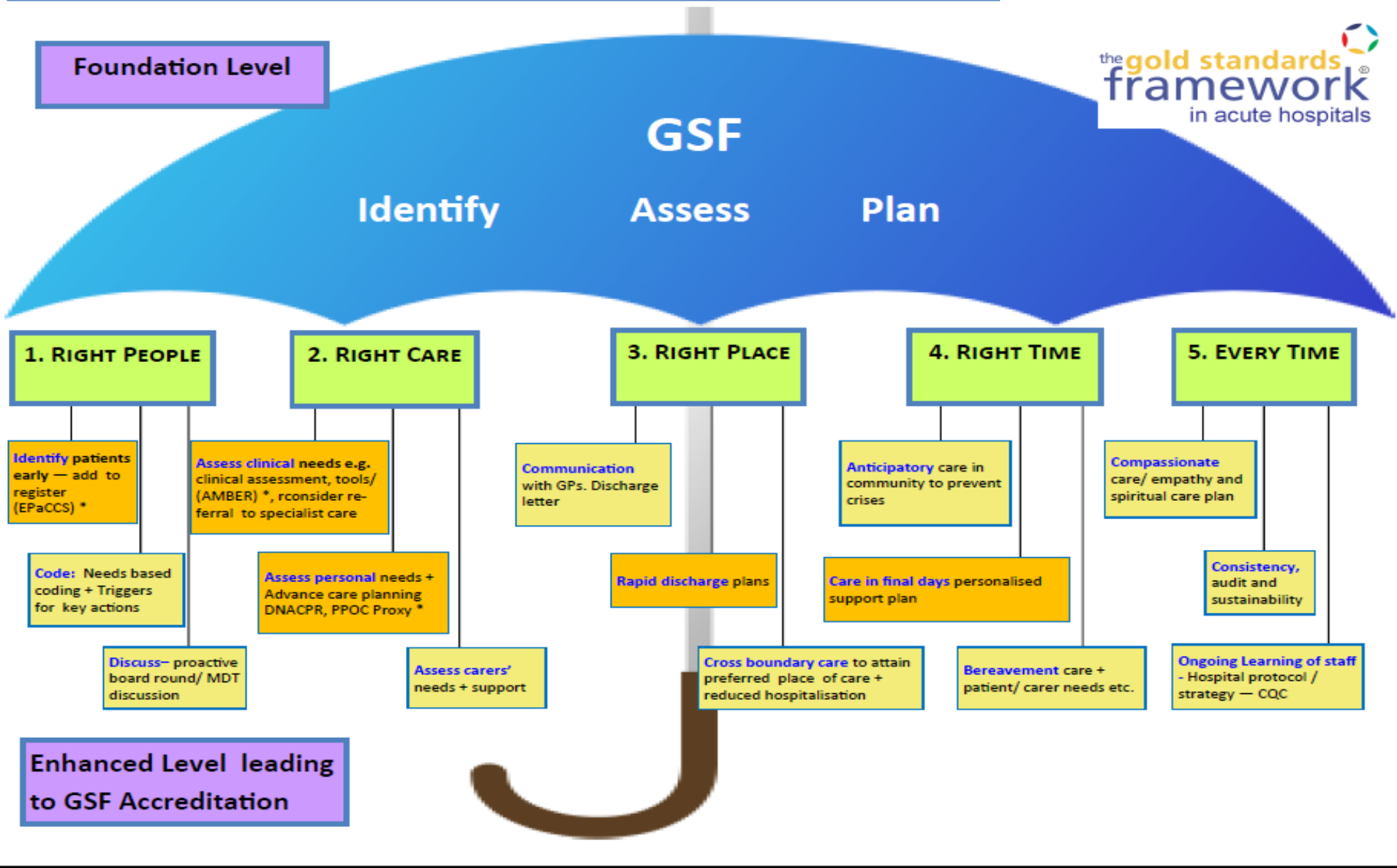
**8. Dying**—We feel we give best quality care for all dying patients with a personalised support plan. No one ever dies badly or on their own on our ward

**7. Cross Boundary**— we plan good cross boundary care for our patients and communicate well with other healthcare providers , eg GPs, DNs, care home staff





# 11. Umbrella





## 12. Prognostic Indicator Guidance (PIG)

### The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life

#### Why is it important to identify people nearing the end of life?

**'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)

About 1% of the population die each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, and include them on a register, there is good evidence that they are more likely to receive well-co-ordinated, high quality care.

This updated fourth edition of the GSF Prognostic Indicator Guidance, supported by the RCGP, aims to help GPs, clinicians and other professionals in earlier identification of those adult patients nearing the end of their life who may need additional support. Once identified, they can be placed on a register such as the GP's QOF / GSF palliative care, hospital flagging system or locality register. This in turn can trigger specific support, such as clarifying their particular needs, offering advance care planning discussions, prevention of crises admissions and pro-active support to ensure they 'live well until they die'.

**Predicting needs rather than exact prognostication.** This is more about meeting needs than giving defined timescales. The focus is on anticipating patients' likely needs so that 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 preferences.

#### Definition of End of Life Care General Medical Council, UK 2010

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.

#### Three triggers that suggest that patients are nearing the end of life are:

1. The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days?'
2. General indicators of decline - deterioration, increasing need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.

#### Average GP's workload – average 20 deaths/GP/year approx. proportions

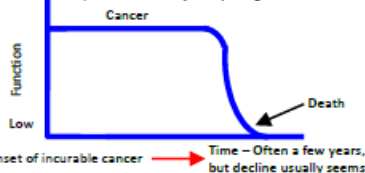
Sudden Unexpected Death  
1-2

Frailty / Co-morbidity / Dementia  
8

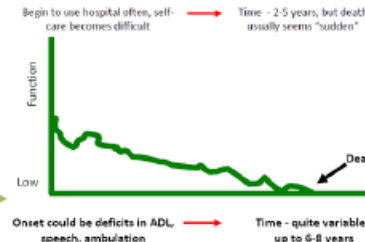
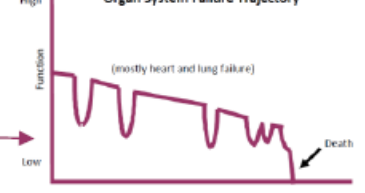
Cancer  
5

Organ Failure  
5-6

#### Rapid "Cancer" Trajectory, Diagnosis to Death



#### Organ System Failure Trajectory



#### Typical Case Histories

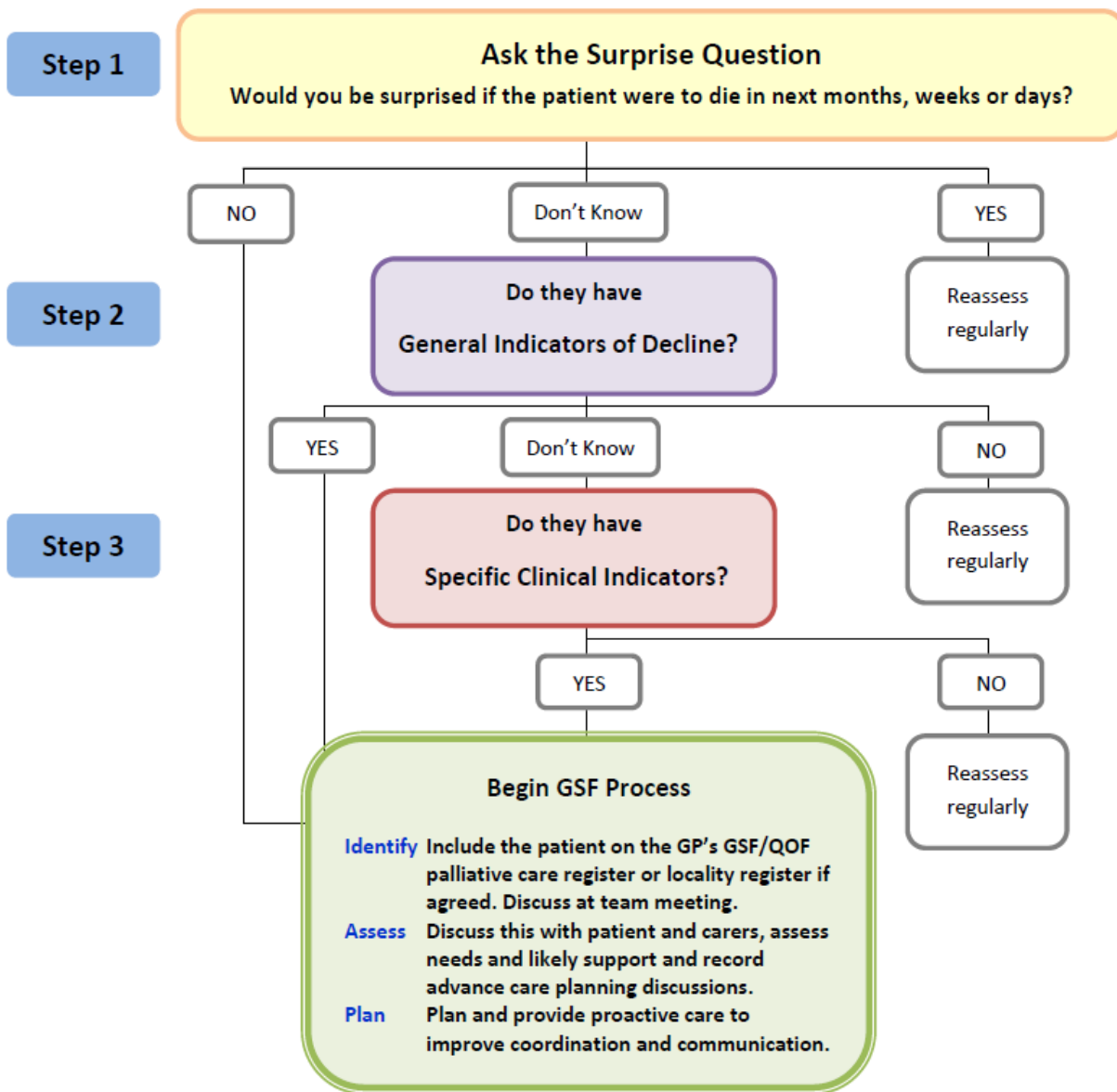
1) Mrs A - A 69 year old woman with cancer of the lung and known liver secondaries, with increasing breathlessness, fatigue and decreasing mobility. Concern about other metastases. Likely rapid decline

2) Mr B - An 84 year old man with heart failure and increasing breathlessness who finds activity increasingly difficult. He had 2 recent crisis hospital admissions and is worried about further admissions and coping alone in future. Decreasing recovery and likely erratic decline

3) Mrs C - A 91 year old lady with COPD, heart failure, osteoarthritis, and increasing signs of dementia, who lives in a care home. Following a fall, she grows less active, eats less, becomes easily confused and has repeated infections. She appears to be 'skating on thin ice'. Difficult to predict but likely slow decline



Summary of suggested three steps for earlier identification

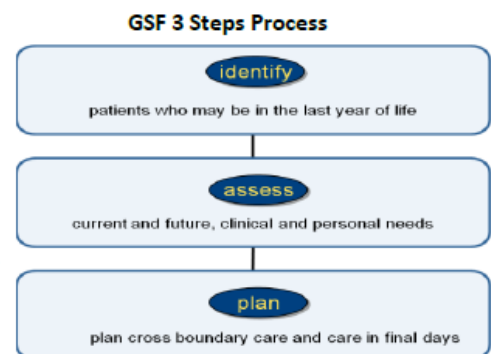


How to use this guidance – what next?

GSF Needs Based Coding



This guidance aims to clarify the triggers that help to identify patients who might be eligible for inclusion on the register (supportive/palliative care/ GSF/ locality registers). Once identified and included on the register, such patients may be able to receive additional proactive support, leading to better co-ordinated care that also reflects people's preferences. This is in line with thinking on shared decision-making processes and the importance of integrating advance care planning discussions into delivery of care. It is based on consideration of people's needs rather than exact timescales, acknowledging that people need different things at different times. Earlier recognition of possible illness trajectories means their needs can be better anticipated and addressed. Specific tasks for each stage are part of the GSF Programmes in different settings, to enable better proactive coordinated care.



## 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 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?

## Step 2 General Indicators

### Are there general indicators of decline and 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 and 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).

**Karnofsky 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 and other co-morbidities.

#### a) Cancer – rapid or predictable decline

##### Cancer

- 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'
- 'The single most important predictive factor in cancer is performance status and 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

##### Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- 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 of 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 two of the indicators below:

- 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.

### Renal Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- 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.

### 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. Plus the following:

#### 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% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

#### 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.

#### 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.

### c) Frailty / Dementia – gradual decline

#### Frailty

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

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofsky
- Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression.

#### Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

#### Dementia

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

It is 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.

Use of needs based coding	Use of this guidance by different teams
<p><b>Prognostication or prediction of need.</b></p> <p>Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators. Most people tend to give undue weight to prognosis and too little to the importance of planning for possible need, especially for those with non-cancer illnesses, frailty and co-morbidities. In order to identify more accurately those patients who need additional pro-active supportive care, the focus should be on a pragmatic, even instinctive, prediction of the rate and course of decline. Some specific tools can help to predict accurately the time remaining for cancer patients but they should be used with caution (BMJ .2011; 343:d5171)</p> <p>We suggest a move towards earlier consideration and more ‘rainy day thinking’ – bringing an umbrella just in case it rains. This instinctive, anticipatory and ‘insurance-type’ thinking relates more to meeting likely needs and planning ahead, rather than focusing on trying to predict likely timescales, and should ensure appropriate support and care can be mobilised.</p> <p>If you can anticipate possible deterioration, then you can begin discussions about preferences and needs at an earlier stage. The aim of such advance care planning discussions is to establish patients’ sometimes unvoiced concerns, needs and preferences, enabling more people to live out the final stage of life as they choose (see ACP Guidance on GSF/ EOLC websites). This also means you can introduce practical measures to prevent crises and make referrals for extra help or advice.</p> <p><b>Needs Based Coding - the right care at the right time</b></p> <p>Patients have differing requirements at varying stages of their illness. The use of needs-based or colour coding can be very helpful in prioritising need. Some clinicians in care homes, GP practices and hospitals use this system to identify their patients’ stage of decline and so predict at an earlier stage their future needs. Although only a rough guide, this helps us focus on giving the right care at the right time, with regular reviews built in to trigger actions at each stage. As a result a needs/support care plan can be developed for each individual.</p>	<p><b>Primary care teams.</b> Identifying patients, the first step of GSF, is key to developing a Palliative Care Register, which forms part of the QOF palliative care points in the GMS contract.</p> <p><b>The National Primary Care Snapshot Audit (2010)</b> in England demonstrated 3 key findings:</p> <ul style="list-style-type: none"> <li>• Only about <b>25%</b> of patients who died were included on the GP’s Palliative Care/ GSF register</li> <li>• Only <b>25%</b> of these had non-cancer conditions</li> <li>• Most importantly, those patients identified early and included on the register received <b>better quality coordinated care</b></li> </ul> <p>Therefore this affirms the need for earlier recognition and identification of people nearing the end of life where possible, i.e. the 1% of the population who die each year, greater representation of patients with non-cancer, organ failure, and those with frailty and dementia is recommended, including those from care homes.</p> <p><b>Two helpful questions for practice teams to ask:</b></p> <ol style="list-style-type: none"> <li>1. <b>What is your register ratio?</b> The number of patients on your palliative care register over the number who died in your practice (using the 1% rule as an approximation e.g. 5000 population = about 50 deaths/ year).</li> <li>2. <b>What is your non-cancer/cancer ratio on register?</b> What percentage of patients on the register has cancer or non-cancer conditions as their main cause of death?</li> </ol> <p>For more details on the QOF points and guidance on Next Stage GSF in Primary care, see the GSF website.</p>
<p><b>Needs Based Coding and Needs Support Matrices</b></p> <p>Identifying the stage of illness and anticipating needs and support– to deliver the right care at the right time for the right patient</p> <ul style="list-style-type: none"> <li>• <b>A – All – stable from diagnosis</b>      <b>years</b></li> <li>• <b>B – Unstable, advanced disease</b>      <b>months</b></li> <li>• <b>C – Deteriorating, exacerbations</b>      <b>weeks</b></li> <li>• <b>D – Last days of life pathway</b>      <b>days</b></li> </ul> <p>For further details of use of Needs / Support Coding and Matrices as part of the GSF Programmes contact the GSF Centre.</p>	<p><b>Care homes.</b> Use of the surprise question and this guidance has been found to help identify residents who are most in need in care homes. This can help focus care and trigger key pro-active support, thereby leading to reduced hospital deaths (e.g. halving of death rate in care homes using GSF in Care Homes Programme).</p> <p><b>Acute hospital teams.</b> About 25% of all hospital beds are occupied by someone who is dying. The National Audit Office estimates that at least 40% of those people have no medical need to be there. Improved early identification of people in the final year of life helps reduce hospitalisation and accessing supportive and palliative care services. It is extremely helpful if hospital teams notify GPs that a particular patient has advanced disease and might be included on their register.</p> <p><b>Specialist teams.</b> Specialist palliative care teams play a vital role especially with cancer patients, but there is a need for collaboration with other specialist teams for non-cancer patients to provide optimal care. These include those with dementia, care of the elderly, heart failure, etc. and this guidance may help clarify referrals.</p> <p><b>Commissioners/managers.</b> This guidance could be used as part of an end of life care strategic plan, with improved provision of services for all patients nearing the end of life and introduction of a locality register.</p>
<p><b>Long term conditions.</b> There is a strong correlation between care for patients with long-term conditions and those with advanced disease nearing the end of life. This is especially true for patients with organ failure (heart failure, COPD). Close collaboration with case managers can reduce unplanned admissions and support good end of life care.</p>	

"It should be possible therefore to predict the majority of deaths, however, this is difficult and errors occur 30 per cent of the time... However, the considerable benefits of identifying these patients include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need. **Identifying** patients in need of palliative care, **assessing** their needs and preferences and proactively **planning** their care, are the key steps in the provision of high quality care at the end of life in general practice."  
(Quality and Outcomes Framework (QOF Guidance) 2011/12 Guidance)

'It is recommended that people approaching the end of life are identified in a timely way.'  
(Draft Recommendation NICE Guidance in End of Life Care 2001)

This is not attempting to answer the question that doctors often hear - 'how long have I got?' Rather, it responds to the underlying sometimes unspoken questions from people facing a new reality 'If I haven't got long, then what should I do and how can you help?'  
(Thomas K GSF Centre 2008)

"For many people suffering from a chronic illness, a point is reached where it is clear that the person will die from their condition. Despite this, for many conditions it may be difficult, if not impossible and potentially unhelpful, to estimate prognosis accurately. The Prognostic Indicator Guidance developed as part of the Gold Standards Framework (GSF) provides useful prompts or triggers to a healthcare professional that discussions about the end of life should be initiated, if this has not already happened". (DH End of Life care Strategy 2008 England)

Identification of people with a life-limiting illness when they are starting to need a change in their goals of care contributes to end of life care planning and can aid communication with patients and families. It depends on clinical judgement and weighing up a complex mix of pathology, clinical findings, therapeutic response, co-morbidities, psychosocial factors, and rate of decline. (Glare P J Palliat Med 2008)

"Using the GSF 'PIG' has helped us to identify these patients earlier than we previously did, especially those with non-cancer, thereby giving them earlier support as they face the end of their lives, leading to fewer crises and hospital admissions." (GP using Next Stage GSF Training Programme 'Going for Gold')

**Development of this guidance paper.** This guidance was originally commissioned from the GSF Centre in June 2006 to support GPs include appropriate patients on their QOF Palliative Care Registers i.e. those considered to be in the final 12 months of life. It is regularly revised following extensive consultation with clinical and disease specialist groups, palliative care specialists and GPs in the Royal College of General Practitioners. Particular thanks go to the NHS End of Life Care Programme and University of Edinburgh team for their help. Since publication, this Guidance has been widely used by clinicians in many sectors in the UK and internationally. A list of detailed references is available on request. This is one of several tools available to support improvements in End of Life Care, and further details on best use, IT support and further developments can be obtained from the GSF Centre.

#### Resources and Further Reading :

National Gold Standards Framework Centre for End of Life Care- Primary care, care homes and other areas [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)  
National Primary care Snapshot Audit (2009/2010) DH report + Next Stage GSF Primary Care Training [www.goldstandardsframework.org.uk/GSFInPrimary+Care](http://www.goldstandardsframework.org.uk/GSFInPrimary+Care)  
NHS End of life care Programme [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)  
NHS Department of Health. End of Life Care Strategy (2008) P51, 3.22 <http://www.endoflifecareforadults.nhs.uk/strategy/strategy>  
GMC End of Life Care [www.gmc-uk.org/static/documents/content/End\\_of\\_life.pdf3](http://www.gmc-uk.org/static/documents/content/End_of_life.pdf3)  
QOF Palliative Care - [www.nhsemployers.org/SiteCollectionDocuments/QOFguidanceGMScontract\\_2011\\_12\\_F1%2013042011.pdf](http://www.nhsemployers.org/SiteCollectionDocuments/QOFguidanceGMScontract_2011_12_F1%2013042011.pdf)  
NICE Draft Quality standards in End of Life Care (for consultation- due Nov 2011) [www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp](http://www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp)  
National Audit Office End of Life care Report Nov 08 [www.nao.org.uk/publications/0708/end\\_of\\_life\\_care.aspx](http://www.nao.org.uk/publications/0708/end_of_life_care.aspx)  
British Geriatrics Society. [www.bgs.org.uk/index.php?option=com\\_content...id](http://www.bgs.org.uk/index.php?option=com_content...id)  
The 'Surprise question': Lynn J. 2005. Alarum Institute Center for Elder Care and Advanced Illness [www.thehastingscenter.org/pdf/living-long-in-fragile-health.pdf](http://www.thehastingscenter.org/pdf/living-long-in-fragile-health.pdf)  
Dying Matters- and the QIPP Find the 1% campaign - [www.dyingmatters.org.uk](http://www.dyingmatters.org.uk) or National Council for Palliative Care [www.ncpc.org.uk](http://www.ncpc.org.uk)  
Liverpool Care Pathway for the Dying Patient. <http://www.mcpcil.org.uk/liverpool-care-pathway/>  
QIPP Department of Health [www.endoflifecareforadults.nhs.uk/strategy/policy/quality-innovation-productivity-prevention](http://www.endoflifecareforadults.nhs.uk/strategy/policy/quality-innovation-productivity-prevention)  
Frameworks for Implementation (2010) from the End of Life Care Programmes - [www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework](http://www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework), [www.kidneycare.nhs.uk/Library/EndofLifeCareFINAL.pdf](http://www.kidneycare.nhs.uk/Library/EndofLifeCareFINAL.pdf), [www.endoflifecareforadults.nhs.uk/publications/care-towards-the-end-of-life-for-people-with-dementia](http://www.endoflifecareforadults.nhs.uk/publications/care-towards-the-end-of-life-for-people-with-dementia), [www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework](http://www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework)  
Renal advisory group of the NSF, British Renal Society, and British Transplant Society. [www.britishrenal.org](http://www.britishrenal.org)  
Barthel Score: Barthel's index of activities of daily living (BAI), [www.patient.co.uk/showdoc/40001654/](http://www.patient.co.uk/showdoc/40001654/)  
Glare P (2011). Predicting and communicating prognosis in palliative care. *BMJ*;343:d5171  
Glare P, Sinclair CT (2008). Palliative medicine review: prognostication. *J Palliat Med*;11:84-103  
William B, Keeley V, Todd C, Gittins M, Roberts C, Kelly L (2011) Development of prognosis in palliative care study (PIPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *BMJ*;343:d4920  
McDaid P (2011) Quick Guide to Identifying Patients , Islington PCT, (personal communication)  
Quinn TJ, McArthur K, Ellis G, Stott DJ (2011). Functional assessment in older people. *BMJ* ;343:d4681  
Quinn TJ, Langhorne P, Stott DJ (2011). Barthel index for stroke trials: development, properties and application. *Stroke*; 42:1146-51  
SPICIT Guidance University of Edinburgh (2010). Supportive and Palliative Care Indicators tool (SPICIT) [www.palliativecareguidelines.scot.nhs.uk/careplanning/](http://www.palliativecareguidelines.scot.nhs.uk/careplanning/)  
SPOTLIGHT: Palliative care beyond cancer: Recognising and managing key transitions in end of life care: Boyd K , Murray S *BMJ* 341  
Watson M, Lucas C, Hoy A, Back I (2005) Oxford Handbook of Palliative Care. *Oxford University Press*

[info@gsfcentre.co.uk](mailto:info@gsfcentre.co.uk)

The Gold Standards Framework Centre CIC

[www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

+44 (0) 1743 291 891 / 367 066

## 13. The GSF Needs Support Matrices

Needs Support Matrices for End of Life Care in Care Homes – used with the needs based prognostic coding to predict and achieve the right care at the right time every time.

### i. Elderly Care Needs Support Matrix

	Needs	Support
<b>Underpinning Plans</b>	Planned framework of care e.g. -Attitude -Patterns of working -Outcomes e.g. dying at home	<input type="checkbox"/> Agreed ethos/ 'culture of home and priority for end of life care <input type="checkbox"/> Systems in place e.g. GSF, LCP, accessing equipment, working with GP and specialists etc <input type="checkbox"/> Ongoing education for staff and at induction <input type="checkbox"/> Ongoing addressing of spiritual needs <input type="checkbox"/> Other.....
<b>A Years</b>	Adjustment to living well in a new home, with regular review of care	<input type="checkbox"/> Introduction and preparation for GSF <input type="checkbox"/> Assessment of needs, level of dependency and level of care <input type="checkbox"/> Advance Care plan including preferred place of care and DNAR discussion <input type="checkbox"/> Spiritual and social needs assessed –'what is important to you?' <input type="checkbox"/> Other.....
<b>B Months</b>	Regular proactive review of patient needs and care.	<input type="checkbox"/> Communication with GP, primary care team, CNS <input type="checkbox"/> Advance care plan reviewed <input type="checkbox"/> Assessment of family needs, level of care involvement etc <input type="checkbox"/> Assessment and/or Continuing Care Funding review of care. <input type="checkbox"/> Other.....
<b>C Weeks</b>	Preparing for final stage – seeing family	<input type="checkbox"/> Regular Assessment of needs and symptoms at each stage and agreed management <input type="checkbox"/> Regular discussion within team and increased proactive review by GP, CNS etc <input type="checkbox"/> Increased contact with family <input type="checkbox"/> Advance care plan rechecked and preference for place of care reassessed and enabled <input type="checkbox"/> Continuing Care Funding review if needed <input type="checkbox"/> Sending of OOH Handover Form if not already sent <input type="checkbox"/> Anticipatory prescribing <input type="checkbox"/> Other.....
<b>D Days</b>	Preparation for death in preferred place – resisting transfers	<input type="checkbox"/> Diagnosing Dying <input type="checkbox"/> Use of an individualised plan of care <input type="checkbox"/> Close contact with GP (+OOH Handover form sent and DNACPR status) <input type="checkbox"/> Contact with family increased, discuss prognosis and provide some pre-bereavement care. <input type="checkbox"/> Follow symptom control guidance <input type="checkbox"/> Spiritual and/or religious care according to needs <input type="checkbox"/> Other.....
<b>Aftercare</b>		<input type="checkbox"/> Verification of death procedure clarified <input type="checkbox"/> Staff protocol for after death care <input type="checkbox"/> Bereavement care for family <input type="checkbox"/> Bereavement care for other residents e.g. remembrance service <input type="checkbox"/> Staff support, debriefing <input type="checkbox"/> Audit of care provision e.g. After death analysis <input type="checkbox"/> Other.....

## ii. Dementia Care Needs Support Matrix for End of Life Care in Care Homes

According to Needs Assessment

	Needs	Support	Checklist
<b>Underpinning Plans</b>	Planned framework of care e.g. -Attitude -Patterns of working -Outcomes e.g. dying in the home	<input type="checkbox"/> Agreed ethos/ 'culture of home and priority for end of life care for residents with dementia <input type="checkbox"/> Develop an ethos of 'understanding why the resident is behaving in the way they are' don't assume due to dementia. <input type="checkbox"/> Systems in place e.g. GSF, LCP, accessing equipment, working with GP and specialists e.g. Psychologists, Geriatrician and Psychiatrist <input type="checkbox"/> Ongoing education for staff and at induction on the specific needs of residents with dementia. <input type="checkbox"/> Ongoing addressing of spiritual needs of resident and family. <input type="checkbox"/> A 'life' book of resident – photos, stories etc – the life they had before dementia – better understanding for staff.	
<b>A Years</b>	Adjustment to living well in a new home, with regular review of care. Assessment of disease progression, to optimise care.	<input type="checkbox"/> Assessment and map out residents needs to be addressed – co morbidity, high dependency, frailty. <input type="checkbox"/> Address 'loss' of the individual with the family and staff <input type="checkbox"/> Introduction and preparation for GSF, by staff and relatives. <input type="checkbox"/> Assessment of needs, person centred- level of dependency and level of care (loss of brain function) <input type="checkbox"/> Advance Care plan including preferred place of care and DNAR discussion with resident, family or advocate (MCA) ethical/legal issues. <input type="checkbox"/> Communication challenges 'windows of opportunity' to discuss issues. <input type="checkbox"/> Nutrition, hydration, mobility, continence, ADL, SALT –swallowing assessment. <input type="checkbox"/> Pain assessment – Abbey scale, ADD, CNPI, Doloplus 2 scale, DS-Dat etc. <input type="checkbox"/> Assessment of speech and language, dysphasia, Aphasia. <input type="checkbox"/> Spiritual and social needs assessed –'what is important to you?'	
<b>B Months</b>	Regular proactive review of patient needs and care.	<input type="checkbox"/> Communication with GP, primary care team, CNS, Psychologist <input type="checkbox"/> Advance care plan reviewed with MDT. <input type="checkbox"/> Assessment of family needs, level of care involvement etc <input type="checkbox"/> Assessment /or Continuing Care Funding review of care.	
<b>C Weeks</b>	Preparing for final stage- seeing family regularly, focus of comfort care.	<input type="checkbox"/> Regular Assessment of needs and symptoms at each stage and agreed management by MDT.. <input type="checkbox"/> Regular discussion within team and increased proactive review by GP, CNSCPN'S Admiral Nurses etc <input type="checkbox"/> Increased contact with family <input type="checkbox"/> Advance care plan rechecked and preference for place of care reassessed and enabled <input type="checkbox"/> Continuing Care Funding review if needed <input type="checkbox"/> Sending of OOH Handover Form if not already sent <input type="checkbox"/> Anticipatory prescribing.	
<b>D Days</b>	Preparation for death in preferred place-resisting transfers	<input type="checkbox"/> Diagnosing Dying <input type="checkbox"/> Use of an individualised plan of care <input type="checkbox"/> Close contact with GP (+OOH Handover form sent DNACPR status) <input type="checkbox"/> Contact with family increased, discuss prognosis and provide some pre-bereavement care. <input type="checkbox"/> Follow symptom control guidance <input type="checkbox"/> Spiritual and/or religious care according to needs	
<b>Aftercare</b>		<input type="checkbox"/> Verification of death procedure clarified <input type="checkbox"/> Staff protocol for after death care <input type="checkbox"/> Bereavement care for family, additional loss, guilt issues, <input type="checkbox"/> Bereavement care for other residents eg remembrance service <input type="checkbox"/> Staff support, debriefing <input type="checkbox"/> Audit of care provision e.g. After death analysis	

### iii. Learning Disabilities Needs Support Matrix for End of Life Care in Care Homes

	Needs	Support	Checklist
<b>Underpinning Plans</b>	Planned framework of care e.g. – Attitude - Patterns of working - Outcomes	<input type="checkbox"/> Agreed ethos of care for clients with L.D – Statement of purpose and philosophy of care –‘culture of home and priority of care <input type="checkbox"/> Systems in place within the speciality e.g. GSF, LCP, accessing equipment, working with GP and specialists – including psychologists <input type="checkbox"/> Ongoing education for staff and at induction. <input type="checkbox"/> Regular Clinical Supervision of staff sessions- one to one/, group work <input type="checkbox"/> Ongoing addressing of spiritual needs of clients and staff <input type="checkbox"/> Communication – e.g. Maketon language Pictures or large text etc <input type="checkbox"/> Other.....	
<b>A Years</b>	Adjustment to living well in a new home, with regular review of care – involving Social Services, Family, Advocate (at least yearly)	<input type="checkbox"/> Introduction and preparation for GSF client, family and staff <input type="checkbox"/> Advance Care plan including preferred place of care and DNAR discussion constant review. <input type="checkbox"/> Knowledge of level of understanding from previous placement or family members – record how they express themselves, what they are saying with their behaviour patterns. <input type="checkbox"/> Review of future care needs – complex – related to posture, abdominal organs misplaced due to gravity issues etc. <input type="checkbox"/> Involvement of family in decision making – of child with older parents <input type="checkbox"/> Assessment of needs – person centred – level of dependency and care <input type="checkbox"/> Swallowing and reflux issues assessed by SALT’s service, ACP – in place in case of sudden episode choking, fitting. <input type="checkbox"/> Spiritual and social needs assessed –‘what is important to you?’ – simplified – where they are in the world – ‘a walk in the sunshine’ <input type="checkbox"/> Assess symptoms- body language, changed behaviour ‘gut’ feeling <input type="checkbox"/> Other.....	
<b>B Months</b>	Regular proactive review of client/service user needs and care.	<input type="checkbox"/> Communication with extended MDT, GP, LDN, psychologist, S/W. <input type="checkbox"/> Advance care plan constantly reviewed. <input type="checkbox"/> Assessment of family needs, level of care –Ongoing support to family <input type="checkbox"/> Assessment and/or Continuing Care Funding review of care paid for by a variety of funding streams. <input type="checkbox"/> On GSF database at surgery – now flagged as GSF palliative care pt <input type="checkbox"/> Review of proactive treatment e.g. antibiotics for aspiration situations <input type="checkbox"/> Other.....	
<b>C Weeks</b>	Preparing for final stage – seeing family, communicating all aspects of care	<input type="checkbox"/> Regular Assessment of needs and symptoms at each stage and agreed management, using adapted tools for assessment for people with L.D <input type="checkbox"/> Regular discussion within team and increased proactive review by GP, LD Nurse, Psychologist etc <input type="checkbox"/> Increased contact with family, allowing them to ‘let go’ <input type="checkbox"/> Advance care plan rechecked and preference for place of care reassessed and enabled <input type="checkbox"/> Continuing Care Funding review if needed <input type="checkbox"/> Sending of OOH Handover Form (+DnaR) and Anticipatory prescribing <input type="checkbox"/> Other.....	
<b>D Days</b>	Preparation for death in preferred place – resisting transfers	<input type="checkbox"/> Diagnosing Dying- recognising signs <input type="checkbox"/> Use of an individualised plan of care <input type="checkbox"/> Close contact with GP (+ OOH Handover form sent DNACPR status) <input type="checkbox"/> Contact with family increased, discuss prognosis and provide some pre-bereavement care. <input type="checkbox"/> Follow symptom control guidance <input type="checkbox"/> Spiritual and/or religious care according to needs <input type="checkbox"/> Preparing other residents –careful use of words, pictures, body language. <input type="checkbox"/> Other.....	
<b>Aftercare</b>	Understanding by other residents of loss. Support of parents who have lost a child.	<input type="checkbox"/> Verification of death procedure, Staff protocol for after death care <input type="checkbox"/> Bereavement care for family and other residents e.g. memorial – open communication, remembrance service, flowers, music – focus for understanding. <input type="checkbox"/> Staff support, debriefing <input type="checkbox"/> Audit of care provision e.g. SEA, ADA Other.....	



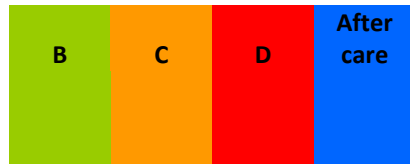
### Example of modified GSF Needs Support Matrix

Name: ..... D.O.B: .....

B	C	D	After care
Regular team monthly review at meeting and needs assessed <input type="checkbox"/>	Regular team review at least weekly and assessment of symptoms and needs <input type="checkbox"/>	Recognition of dying phase by team and commencing Care of the Dying Individualised plan of care / minimum protocol checklist <input type="checkbox"/>	Verification of death and protocol for after death care <input type="checkbox"/>
Communication with GP practice team <input type="checkbox"/>	Communication and proactive review with GP practice team, and others <input type="checkbox"/>	Increased communication and proactive review with GP practice team and others eg specialists <input type="checkbox"/>	Support for relatives and early bereavement care <input type="checkbox"/>
Support from District Nurses/ specialist nurses as required <input type="checkbox"/>	Complete GSF Out of Hours Handover Form with DNAR status <input type="checkbox"/>	Complete GSF Out of Hours Handover Form with DNACPR status <input type="checkbox"/>	Clearing of room and giving family belongings <input type="checkbox"/>
Assessment of needs of relatives and support provided <input type="checkbox"/>	Assessment of needs of relatives and support provided – increased contact <input type="checkbox"/>	Increased contact with relatives and support provided – discussed deterioration and given other relevant information <input type="checkbox"/>	Offer Bereavement Leaflet/What to do After a Death Booklet/ other leaflet <input type="checkbox"/>
Advance Care Plan reviewed or leaflet to help planning discussion <input type="checkbox"/>	Advance Care Plan reviewed and care provided as requested <input type="checkbox"/>	Advance Care Plan reviewed and care provided in alignment with wishes <input type="checkbox"/>	Support for other residents and means of commemoration <input type="checkbox"/>
DNAR / AND / ADRT status reviewed <input type="checkbox"/>	DNAR / AND / ADRT status reviewed <input type="checkbox"/> Spiritual or religious care according to wishes considered <input type="checkbox"/>	DNACPR / AND / ADRT status reviewed <input type="checkbox"/> Spiritual or religious care according to wishes considered <input type="checkbox"/>	Support and debriefing for other staff <input type="checkbox"/>
Complete DS1500 / continuing care or other benefits <input type="checkbox"/>	Complete DS1500 / continuing care or other benefits <input type="checkbox"/>	Follow symptom control guidance where appropriate <input type="checkbox"/>	Significant Event Analysis <input type="checkbox"/>
Reduce chance of avoidable hospital admission <input type="checkbox"/>	Consider anticipatory prescribing of required and suggested PRN drugs <input type="checkbox"/>	Consider anticipatory prescribing of required and suggested PRN drugs <input type="checkbox"/>	Audit – After Death Analysis ADA audit <input type="checkbox"/>
	Reduce chance of avoidable hospital admission <input type="checkbox"/>	Reduce chance of avoidable hospital admission <input type="checkbox"/>	

Sample sheet for each resident Name: ..... D.O.B: ..... Diagnosis:.....

DATE



Comments

Sign

## Selection of options for Needs Support Matrices related to Needs Based Coding

### Hospital Needs Support Matrix Example 3 (from Karen Groves, Southport)

		On Admission	In Patient	Discharge
<p><b>B – Months (6 to 12 months)</b> Advancing Disease</p> <p>Advanced</p>	<ul style="list-style-type: none"> <li>■ HP awareness of patient</li> <li>■ co-ordination of care</li> <li>■ Proactive monitoring</li> <li>■ May need Spiritual/religious support</li> </ul>	<ul style="list-style-type: none"> <li>■ Check GSF status (GP surgery/GP letter/patient documentation/locality based register)</li> <li>■ Check PPC</li> <li>■ ? ACP/AD in existence</li> <li>■ Eligible for free prescriptions</li> <li>■ Document current care being received</li> </ul>	<ul style="list-style-type: none"> <li>■ Put alert in IT system for GSF / ACP /AD if in place</li> <li>■ Undertake holistic assessment (physical / psychological /spiritual / social)</li> <li>■ Undertake carer assessment</li> <li>■ Explain current disease status &amp; expected progress</li> <li>■ Discuss keyworker</li> <li>■ Conversation about ACP/ AD as required</li> <li>■ Discuss DNACPR /AND as appropriate</li> <li>■ Link with SPC service as required</li> <li>■ MDT working to produce treatment plan</li> <li>■ Clear documentation of all discussions &amp; decisions</li> </ul>	<ul style="list-style-type: none"> <li>■ Let GP know GSF eligible if not already on register</li> <li>■ Enter on locality based GSF register if available</li> <li>■ Include on discharge summary &amp; discharge letter details of:-                             <ul style="list-style-type: none"> <li>○ GSF eligibility</li> <li>○ PPC</li> <li>○ ACP</li> <li>○ AD</li> <li>○ Ongoing treatment plan</li> <li>○ All significant patient &amp; family discussions</li> <li>○ Ensure information to DNs even if nursing intervention not immediately required</li> <li>○ Info to out of hours services as appropriate</li> </ul> </li> </ul>
<p><b>C – Weeks to 6 months (DS1500)</b></p> <p>Deteriorating</p>	<ul style="list-style-type: none"> <li>■ Increased frequency of MDT discussions</li> <li>■ Need to understand</li> <li>■ Need clear plan of care</li> <li>■ Need opportunity to express emotion &amp; concerns</li> <li>■ May need spiritual/religious support</li> <li>■ Need good symptom control</li> </ul>	<p>Check whether receiving DLA under special rules</p>	<p>Arrange DS1500 if not applied for</p> <ul style="list-style-type: none"> <li>■ Clear senior clinical decision making</li> <li>■ Clear action plan in notes for ceiling treatment</li> <li>■ Ensure family kept apprised of situation &amp; all possible outcomes</li> <li>■ Ensure hospital at night team or equivalent receive thorough handover of all details</li> <li>■ If deterioration is recognised/ expected:-</li> <li>■ Anticipatory prescribing of required and prn drugs</li> <li>■ If PPC is home be prepared to enact rapid discharge plan</li> </ul>	<p>Update all the above information for discharge</p> <ul style="list-style-type: none"> <li>■ Inform GP re DS1500</li> <li>■ Inform DN service</li> <li>■ Inform out of hours GP &amp; DN services</li> <li>■ If imminent deterioration predicted</li> <li>■ Prescribe TTO- anticipatory prn drugs</li> <li>■ Sign DN administration form</li> <li>■ Inform GP/DN/OOH by telephone</li> </ul>
<p><b>D – Last Days</b></p> <p>Dying</p>		<ul style="list-style-type: none"> <li>■ Diagnose &amp; acknowledge dying</li> <li>■ Clear discussion with team, patient (if possible) &amp; family that dying is likely to be imminent / soon</li> <li>■ Check ACP/AD/PPC – if home, prepare for rapid discharge i.e. turnaround</li> <li>■ Ensure DNACPR/AND status clinical decision (futility) made &amp; documented</li> <li>■ Individualised plan of care</li> <li>■ Anticipatory prescribing of prn drugs</li> </ul>	<p>Holistic assessment of patient and family needs (physical / spiritual / psychological / social)</p> <ul style="list-style-type: none"> <li>■ Ensure dignity &amp; privacy for patient &amp; family</li> <li>■ Family needs to be anticipated &amp; attended to</li> <li>■ Ensure family understand that they both need &amp; are welcome to stay if they wish to be present</li> <li>■ Ensure spiritual care offered to family as well as patient</li> <li>■ If PPC is, or becomes, home – implement rapid discharge pathway</li> </ul>	<ul style="list-style-type: none"> <li>■ Order TLC ambulance within 2 hrs</li> <li>■ DNACPR/AND order for transfer</li> <li>■ Order required equipment to be delivered on same day</li> <li>■ TTO for terminal care / prn drugs within 2 hrs</li> <li>■ DN administration form signed</li> <li>■ Urgent funding for care e.g. CHC</li> <li>■ Individualised plan of care to go with patient to inform other providers</li> <li>■ Inform GP/DN/OOH by telephone &amp; fax</li> <li>■ Clearly advise GP that early visit may be required to ensure patient has been seen prior to death to avoid coroners/police involvement for family</li> </ul>

<p>E – Immediate After Care and Bereavement</p>	<ul style="list-style-type: none"> <li>▪ Need time</li> <li>▪ Need to tell story</li> <li>▪ May need spiritual/religious support</li> </ul>	<ul style="list-style-type: none"> <li>▪ Ensure family understand clearly that patient has died</li> <li>▪ Answer any immediate questions</li> <li>▪ Allow opportunity to vent emotion and express concerns</li> <li>▪ Arrange for verification / certification to occur promptly</li> <li>▪ Allow any religious rites / cultural needs to be met</li> <li>▪ Ensure GP/DN aware that death has taken place</li> </ul>		
---	---	---	--	--

# 14. SCR1 – GSF ACUTE HOSPITAL SUPPORTIVE CARE REGISTER SHEET

(Optional)

Identified as Needing End of Life Care				Assessment										Planning							
Patient Name	NHS No	Consultant	Needs Based Code	Clinical Information				Advance Care Planning						Coordination & Communication							
				Primary Diagnosis	Reason for admission/Main Problem	Trigger for GSF	Anticipated Issues	On Admission				During Admission		Preferred Place of Care	Discharge information sent to others e.g. OOH, DNs, GP	Cross Boundary e.g. Passport Information	GP & Community Support Planned	Suggest to GP inclusion on Register	Other involvement e.g. SPC, Social Care	Other/ Comments	
								AS	ADRT	DNAR	LPA/Proxy	AS	ADRT	DNAR	LPA/Proxy						

**GUIDANCE NOTE: Use as Checklist**

## 15. SCR2 – Supportive Care Register – Acute Hospitals Summary sheet ( Optional)

<u>Name</u>  <u>DOB</u>  <u>Address</u>   <u>Tel No</u>	<u>NHS Number</u> <u>GP/Keyworker</u>  <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left;">Current Code A-D</th> <th style="text-align: right;">Date</th> </tr> </thead> <tbody> <tr> <td>A=Years – <span style="color: blue;">Blue</span></td> <td style="text-align: right;">A</td> </tr> <tr> <td>B=Months - <span style="color: green;">Green</span></td> <td style="text-align: right;">B</td> </tr> <tr> <td>C= Weeks - <span style="color: orange;">Amber</span></td> <td style="text-align: right;">C</td> </tr> <tr> <td>D=Days - <span style="color: red;">Red</span></td> <td style="text-align: right;">D</td> </tr> </tbody> </table>	Current Code A-D	Date	A=Years – <span style="color: blue;">Blue</span>	A	B=Months - <span style="color: green;">Green</span>	B	C= Weeks - <span style="color: orange;">Amber</span>	C	D=Days - <span style="color: red;">Red</span>	D
Current Code A-D	Date										
A=Years – <span style="color: blue;">Blue</span>	A										
B=Months - <span style="color: green;">Green</span>	B										
C= Weeks - <span style="color: orange;">Amber</span>	C										
D=Days - <span style="color: red;">Red</span>	D										
<u>Main Diagnosis</u>   <u>Other Conditions</u>	<u>Family/carer contacts + Tel No</u>  <u>Contact at night Y/N</u> <u>Comments</u>										
<u>Personnel involved Health/Social Professionals</u> <b>Hospital Specialists</b>  <b>Others (OT, Physio, Priest)</b>  <b>Macmillan/Nurse/SPC <input type="checkbox"/></b> <b>Hospice <input type="checkbox"/></b> <b>Social Services <input type="checkbox"/></b>	<u>Advance Care Plan Discussion</u>  1. AS <b>Advance Statement of Wishes</b> Date:  2. ADRT <b>Advance Decision To Refuse Treatment</b> Date:  3. DNAR <b>Do Not Attempt Resuscitation</b> Date:  4. LPOA <b>Lasting Power of Attorney</b> Date:										
<u>Past Treatment &amp; Current Medication</u>   											
<u>Priorities (Problems and concerns – physical, psychological, social spiritual)</u>   <u>Other issues (incl. care plan, out of hours information, anticipatory drugs left in home, before considering admission try etc)</u>											
<i>Preferred Place of Care:</i>  Date:	<i>Comments</i>										





## 17. SCR4: PEPSI COLA Aide Memoir – Palliative Care Monthly Checklist

## Assessment Tool

	Date	Date	Date	Date	Date	Date
<b>P – Physical</b> Symptom control Medication – regular & PRN Compliance / stopping non-essentials Complementary therapies						
<b>E – Emotional</b> Understanding expectations Depression and adjustment Fears /Security Relationships						
<b>P – Personal</b> Spiritual / religious needs Inner journey Quality of life Pt/carer's agenda						
<b>S – Social Support</b> Benefits/Financial Care for carers Practical support						
<b>I – Information/ Communication</b> Within PHCT Between professionals To and from patient To and from carers						
<b>C – Control</b> Choice, dignity Treatment options/ Management Plan Advanced directive Place of death						
<b>O – Out of Hours/ Emergency</b> Continuity Communication to out of hours/pts/carers Carer support Medical support Drugs and equipment						
<b>L – Late</b> End of life/Terminal care Stopped non-urgent Rx Patient and family aware Comfort measure Spiritual care Rattle, agitation						
<b>A – Afterwards</b> Bereavement Follow-up/others informed Family support Assessment/Audit Support team						



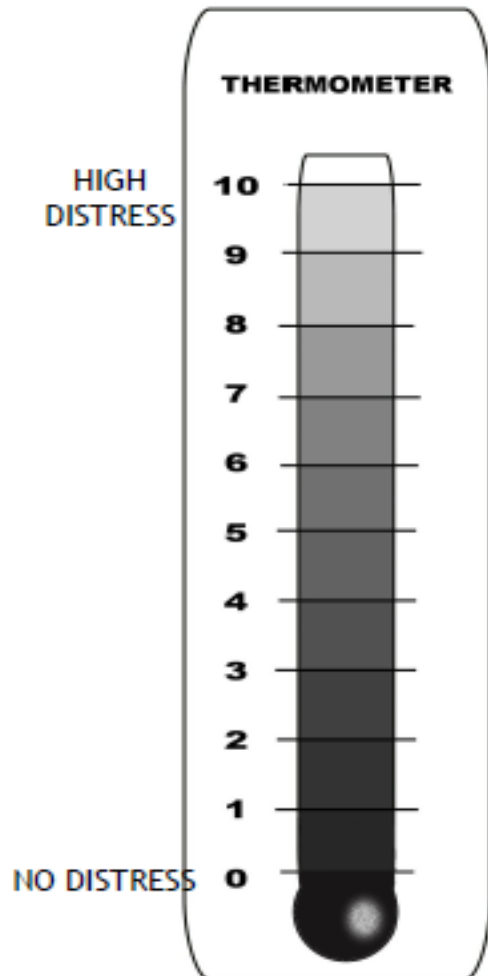
## 18. Distress Thermometer

**Distress Thermometer For The Elderly- adapted by GSF Programme Patient's name:**

First please circle the number (0-10) that best describes how much distress in general you have been experiencing over the past week, including today.

Second, if any of the following has been a problem for you over the past week, including today, please tick the box next to it. Leave it blank if it does not apply to you. Then rank your top 4 difficulties (1 would be the biggest problem, 4 would be your fourth biggest concern)

**Date of Review:**



**RANKING**

### Practical Issues

- Environment – in the home / your room
- Independence
- Bathing / dressing
- Caring for yourself
- Money
- Activities in home
- Other concerns

### Social / Relationship Issues

- with family / partner
- with children / grandchildren
- with other s
- with friends outside the home
- with staff

### Emotional Concerns

- Anxiety / worry
- 'Bad nerves' / nervousness
- Fears
- Sadness
- Undecided about future plans
- Lack of self worth
- Bereavement
- Depression
- Other feelings or concerns:

### Spiritual / Religious Concerns

- Loss of religious faith
- Difficulty relating to God
- Loss of meaning or purposes of life

**RANKING**

### Physical Problems

- General appearance
- Fatigue / tiredness
- Pain
- Skin – dry / itchy / discoloured
- Broken skin / pressure sores
- Hearing / sight
- Circulatory problems
- Forgetfulness / memory
- Appetite / eating
- Weight loss or gain
- Swallowing difficulties
- Breathing / breathlessness
- Continence – passing water
- Bowels – constipation / diarrhoea
- Joint problems
- Mobility – getting around
- Ankle swelling
- Mouth sores / denture problems
- Nausea / sickness / indigestion
- Nose dry / congested
- Cough
- Sleep
- Other, please state:

Patient  
details

Signed by staff member:	Today's Date:	
	<b>DURATION OF INTERVIEW:</b> (in minutes)	
Diagnosis:		

Highest ranked concerns	RATING	Description and history of problem	Plan of action
1.			
2.			
3.			
4.			

## 19. Advance Care Planning

### 'Thinking Ahead' – GSF Advance Care Planning Discussion



*We wish to be able to provide the best care possible for all patients and their families, but to do this we need to know more about what is important to them and what are their needs and preferences for the future.*

The aim of any discussion about thinking ahead, often called an Advance Care Planning Discussion, is to develop a better understanding and recording of peoples' priorities, needs and preferences and those of their families and carers. This should support planning and provision of care, and enable better planning ahead to best meet these needs. This philosophy of 'hoping for the best but preparing for the worst' enables a more proactive approach, and ensures that it is more likely that the right thing happens at the right time.

This example of an Advance Statement should be used as a guide, to record what the patient DOES WISH to happen, to inform planning of care. In line with the Mental Capacity Act (2005), this is different from a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, which is called an Advance Decision (to refuse treatment) (ADRT).

Ideally an Advance Care Plan should be discussed to inform future care at an early stage. Due to the sensitivity of some of these issues, some may not wish to answer them all, or may quite rightly wish to review and reconsider their decisions later. This is a 'dynamic' planning document to be adapted and reviewed as needed and is in addition to Advanced Directives, Do Not Resuscitate plan, or other legal document.

Name:	Date completed:
Address:	GP Details
DOB:                      Hosp / NHS no:	Hospital contact:
Family members involved in Advance Care Planning discussions:	
Name:	Contact tel:
Name of healthcare professional involved in Advance Care Planning discussions:	
Role:	Contact tel:

Patient signature	Date
Next of kin / carer signature (if present)	Date
Healthcare professional signature	Date
Review date:	

Thinking ahead....

1. At this time in your life what is it that makes you happy or you feel is important to you?
  
2. What elements of care are important to you and what would you like to happen in future?
  
3. What would you **NOT** want to happen? Is there anything that you worry about or fear happening?

**4. Do you have a Legal Advance Decision to Refuse Treatment document? (This is in keeping with the Mental Capacity Act (2005) and enables people to make decisions that will be useful if at some future stage they can no longer express their views themselves) No / Yes**

*If yes please give details (eg who has a copy?)*

**5. Proxy / next of kin**

Who else would you like to be involved if it ever becomes difficult for you to make decisions or if there was an emergency? Do they have official Lasting Power of Attorney (LPoA)?

Contact 1 .....	Tel.....	LPoA Y / N
Contact 2 .....	Tel.....	LPoA Y / N

**6. Preferred place of care**

If your condition deteriorates where would you most like to be cared for?

1<sup>st</sup> choice

2<sup>nd</sup> choice

Comments

**7. Do you have any special requests, preferences, or other comments?**

**8. Are there any comments or additions from other people you are close to? (Please name)**

**NB See also any separate DNACPR/AND or ADRT documents.**

*Advance Care planning (ACP) is essentially a process of discussion between an individual and their care providers, which may include family/friends, about the kind of care they would like to receive now and in the future.*

DH Guidance on Advance Care Planning. End of Life Care Programme 2008

**The aim is to increase the number of people who are offered advance care planning discussions within acute hospitals, especially those with dementia or who have declining capacity to make decisions in future.**

Introducing advance care planning as routine practice for every resident of a care home with the GSF Care Homes Training Programme is one of the most significant elements of the work, and has made a huge difference to care. By having this discussion, a **shared understanding** can be reached, so that current and future care can be tailored to the person's individual needs and preferences, some difficult situations or crisis events can be averted and communication with others is made easier. The process of holding advance care planning discussions to ascertain wishes is strongly recommended as it enables the decision-making process to be initiated, recorded, and communicated to others involved in care. This then ensures that the person's wishes are more likely to be met, and they receive a higher quality of end of life care.

In summary:

It is recommended good practice that recording of ACP should be routinely offered to all patients.

The opportunity to discuss ACP should be *offered* to everyone as normal practice, with the appropriate degree of respect and sensitivity, though everyone has the

option to decline. Some may decline or defer to another time, and staff should always be sensitive to this.

- With the individual's agreement this discussion should be documented, regularly reviewed and communicated to key persons involved in their care.
- Advance care planning discussions are different from resuscitation/ DNACPR forms and policies. You might need to be involved in the resuscitation discussions.
- This is more than just a paper exercise as it involves holding sensitive conversations, discussing issues that are rarely discussed and deeply felt.
- The patient's wishes are paramount, but it is also helpful to confirm who else might be involved in the decision-making process, and might be consulted in case of lack of capacity of the person in future
- The benefit of ACP is that others caring for the patient in differing situations e.g. in care homes, community etc should refer to the ACP to produce a consistent approach to care – to know what the person wants and or who to ask if they are unable to express their views

The Mental Capacity Act (Oct 07) requires staff to support people so that they can make decisions for themselves as far as they are able. The process of ACP is important here as it relates to the possibility of future lack of capacity of the patient. If they can make a decision they should – if they cannot, it ensures that their wishes are already noted through the earlier ACP discussion, and are thereby more likely to be respected.

## Guidance Notes on completing the GSF Advance Care Plan 'Thinking Ahead' as an example of an ACP Tool

Adapted from Deborah Holman, Palliative Care Clinical Nurse Specialist, St Christopher's Hospice, London

### 1. At this time in your life what is it that makes you happy?

- What do you hope for? What do you enjoy doing?
- What or who is really important to you?
- Is there anyone you're especially worried about?
- Has your illness changed the ways you can get close to people you care about?

### 2. What elements of care are important to you and what would you like to happen in the future?

- Statements of wishes and preferences can include personal preferences, such as where one would wish to live, having a shower rather than a bath, or wanting to sleep with the light on. Such statements may also include requests and /or types of medical treatment they would or would not want to receive
- Sometimes people may have views about treatments they do not wish to receive but do not want to formalise these views as an advance decision.
- Discussion should focus on the views of the individual, although they may wish to invite their carer or another close family member or friend to participate
- Some families are likely to have discussed preferences and would welcome an approach to share this discussion.

### 3. Is there anything that you worry about or fear happening? What would you not want to happen?

- What worries you most about your illness?
- Can you help me understand a bit better?
- What else would help you cope?
- What is helping most at the moment?
- Has being ill made any difference to what you believe in?
- Do you find yourself thinking about what is going to happen to you?
- Are there things that bother you that you find yourself dwelling on?
- Know when you have reached the limits of your knowledge

### 4. Ending difficult conversations but enabling ongoing discussion later

- Acknowledge emotional intensity of conversation – "We've talked about a lot of important things today".
- Help person to rehearse what they need to do, who to talk to?
- Try and close the conversation on a positive note.
- End conversation in a safe place for them – refer to everyday, practical topics.
- "What you have said is very important, can we continue this tomorrow?"
- "Unfortunately I have to leave in five minutes and this is a very important conversation; is there anything else you want to say?"
- "I'm sorry but I think we've got as far as we can at the moment and we will have to leave it there for now"

## Communication Skills Guidance 1 – Advance Care Planning discussions

Jackie Beavan, Honorary Teaching Fellow: Advanced Communication Skills University of Birmingham

Talking with patients about their views on how they would like to be cared for towards the end of their lives is rarely an easy task. What follows is a basic structure which might help you to engage in such conversations. It is important to remember, though, that no two discussions on this topic will be the same and that you need to take your cue from the patient and to be flexible in responding to their needs.

### Preparing the ground

- Speak to the patient beforehand to explain what it's all about. This might also be a good time to check their understanding of their situation and get a feel of the language they use to talk about it.

*NB If the patient has specific communication needs, e.g. they have limited English or they are hearing impaired, you should check whether an interpreter or signer is needed, both for this interaction and the main meeting.*

- Set up a time to meet and ask who (if anyone) they would like to be present. This might include family, friends or even an advocate.
- Make sure that you can meet in a private and comfortable room and that you have set aside enough time for the meeting.

### Using the Plan

- Start with general greetings and by introducing yourself, if necessary, to any family, friends or others who have attended. Find out who they are, too! Remind all present of the purpose of the meeting. Let them know that you will be making some notes in the meeting so that you can be sure you have an accurate record of what is said.
- Ask the patient whether s/he has given any thought to how s/he would like to be cared for in the future. This will give you some idea of their priorities.

- Address the issues outlined in the Advance Care Plan. You might want to work through systematically, or you might prefer the patient to talk for a while and then to bring up any aspects that have not been touched on. Adjust the language used in the Advance Care Plan as appropriate for the patient's understanding. You might need to check that they understand terms like Advance Directive and Lasting Power of Attorney or you might need to explain what resuscitation involves.
- Check that you understand what the patient says, e.g. if they use the term 'dying with dignity' you might need them to explain what that means to them.
- Make notes as appropriate, but try not to do this while the patient or others are speaking. Ensure that your notes are legible and unambiguous to others who might need to refer to them.

### Wrapping up

- Summarise the main points of what has been said and check that you have understood them correctly.
- Ask if there are any questions.
- Make it clear that you know that the patient's views might change over time and they should let you know if this should happen, so that the Plan can be amended.
- Either read aloud what you have written or, if they prefer, let the patient and one other person present read it themselves before asking them to sign the Advance Care Plan.

*"We have to learn how to feel 'with' patients without feeling 'like' them if we are to give them a kind of listening and steady support that they need to find their own way through"*

Cicely Saunders (2003)

## Communication Skills Guidance 2 - Being PREPARED

From 'Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers' Josephine M Clayton, Karen M Hancock, Phyllis N Butow, Martin HN Tattersall and David C Currow, **MJA** • Volume 186 Number 12 • 18 June 2007

### Summary

Prognostic and end-of-life communication is a vital skill for health care professionals caring for patients with progressive life-limiting illnesses, and their families. Expert opinion varies, and high quality evidence on how best to discuss these issues with such patients and their caregivers is limited. These guidelines were developed by a team in Australia to address these issues. The guidelines were developed through the following methods: • Systematic literature review of the best available evidence on discussion of prognosis and end-of-life issues; • Review of previous relevant guidelines and expert opinions in the literature; and • Refining of draft guidelines by an expert advisory panel. The key recommendations of these guidelines are for health professionals to consider the recommendations conveyed by the acronym PREPARED.

<b>P</b>	<p><b>Prepare for the discussion</b>, where possible:</p> <ul style="list-style-type: none"> <li>▪ Confirm pathological diagnosis and investigation results before initiating discussion.</li> <li>▪ Try to ensure privacy and uninterrupted time for discussion.</li> <li>▪ Negotiate who should be present during the discussion.</li> </ul>
<b>R</b>	<p><b>Relate to the person</b>:</p> <ul style="list-style-type: none"> <li>▪ Develop rapport.</li> <li>▪ Show empathy, care and compassion during the entire consultation.</li> </ul>
<b>E</b>	<p><b>Elicit patient and caregiver preferences</b>:</p> <ul style="list-style-type: none"> <li>▪ Identify the reason for this consultation and elicit the patient's expectations.</li> <li>▪ Clarify the patient's or caregiver's understanding of their situation, and establish how much detail and what they want to know.</li> <li>▪ Consider cultural and contextual factors influencing information preferences.</li> </ul>
<b>P</b>	<p><b>Provide information</b>, tailored to the individual needs of both patients and their families:</p> <ul style="list-style-type: none"> <li>▪ Offer to discuss what to expect, in a sensitive manner, giving the patient the option not to discuss it.</li> <li>▪ Pace information to the patient's information preferences, understanding and circumstances.</li> <li>▪ Use clear, jargon-free, understandable language.</li> <li>▪ Explain the uncertainty, limitations and unreliability of prognostic and end-of-life information.</li> <li>▪ Avoid being too exact with timeframes unless in the last few days.</li> <li>▪ Consider the caregiver's distinct information needs, which may require a separate meeting with the caregiver (provided the patient, if mentally competent, gives consent).</li> <li>▪ Try to ensure consistency of information and approach provided to different family members and the patient and from different clinical team members.</li> </ul>
<b>A</b>	<p><b>Acknowledge emotions and concerns</b>:</p> <ul style="list-style-type: none"> <li>▪ Explore and acknowledge the patient's and caregiver's fears and concerns and their emotional reaction to the discussion.</li> <li>▪ Respond to the patient's or caregiver's distress regarding the discussion, where applicable.</li> </ul>
<b>R</b>	<p><b>(Foster) Realistic hope</b>:</p> <ul style="list-style-type: none"> <li>▪ Be honest without being blunt or giving more detailed information than desired by the patient.</li> <li>▪ Do not give misleading or false information to try to positively influence a patient's hope.</li> <li>▪ Reassure that support, treatments and resources are available to control pain and other symptoms, but avoid premature reassurance.</li> <li>▪ Explore and facilitate realistic goals and wishes, and ways of coping on a day-to-day basis, where appropriate.</li> </ul>
<b>E</b>	<p><b>Encourage questions</b> and further discussions:</p> <ul style="list-style-type: none"> <li>▪ Encourage questions and information clarification; be prepared to repeat explanations.</li> <li>▪ Check understanding of what has been discussed and if the information provided meets the patient's and caregiver's needs.</li> <li>▪ Leave the door open for topics to be discussed again in the future.</li> </ul>
<b>D</b>	<p><b>Document</b>:</p> <ul style="list-style-type: none"> <li>▪ Write a summary of what has been discussed in the medical record.</li> <li>▪ Speak or write to other key health care providers involved in the patient's care. As a minimum, this should include the patient's general practitioner.</li> </ul>



## Advance care planning with people with dementia

The DH Dementia Strategy addresses some of the end of life care issues for people with dementia and recommends that the person with dementia and their carers/family should be involved in planning end of life care. (DH Living well with dementia: A National Dementia Strategy 2009)

Discussions need to take place on more than one occasion in comfortable unhurried surroundings. People with dementia do not lose all ability to communicate and their ability to engage in discussions can vary from day to day or even during the course of the day. Use words that the individual understands and regularly check their understanding, take cues from their non-verbal responses and involve the resident's NOK or advocate wherever possible – they are likely to have a good knowledge of the person and what their views and wishes were previously. There is evidence to suggest that people with dementia tend to make similar decisions to those without dementia, so we should not avoid asking people with dementia what their views are (Fazel et al 2000). Consider the appropriateness of interventions and the benefits of those interventions to that individual, e.g. the admission to a busy acute hospital ward of a person with dementia in the final stages of their life is very likely to exacerbate confusion and disorientation leading to increased fear, anxiety and agitation.

Guidance on the use of best interest's principles (Mental Capacity Act 2005) is available from; [www.opsi.gov.uk/acts/acts2005/en/ukpgaen](http://www.opsi.gov.uk/acts/acts2005/en/ukpgaen).

ACP discussions can be very helpful for people with dementia. Such decisions can take place even though the individual may have quite advanced dementia, as long as they have capacity – the ability to understand and speculate about the decision to be made. Evidence suggests that people with early dementia are interested in participating in ACP discussion, and that they make similar decisions to people without dementia. Therefore we should not hold back from asking people with dementia their views.

Staff who care for residents with dementia have difficulties in ascertaining wishes and preferences especially for those residents who had no family. They also spoke of difficulties that arose when GP's were reluctant to make advance decisions. Staff were well aware of unnecessary distress that can be caused by sending a person with dementia out of their environment to the hospital and were in many cases keen to have advanced discussions documented. Staff spoke of their own distress and powerlessness at seeing residents with dementia being sent to hospital in their last 48hrs of life because of lack of documentation relating to resuscitation status.

**A note about Advance Care Planning in dementia - Karen Harrison Dening, Consultant Admiral Nurse**

Many of the best practice points generally applicable to Advance Care Planning (ACP) discussions will apply to people with dementia but there are others that also need to be taken into account in addition:

**Skilled interviewer**

Those undertaking ACP with people with dementia will need to have appropriate knowledge and skills to understand the issues in communication in dementia

**The right time**

As with all ACP discussions they need to be held at the right time but in dementia these discussions need to be held early on in the illness when the person still has the capacity, cognition and language to hold meaningful discussions and make informed decisions. Ideally the ACP discussions in dementia should be part of supportive post diagnostic counseling processes within e.g. a Memory Clinic.

**The right place**

People with dementia often have visuospatial problems that are associated with their dementia so it is important to hold the discussions in a quiet and unthreatening place with no distractions of noise and interruptions that can hinder their concentration

**Involvement of family**

Once a person no longer is deemed and assessed to have capacity decisions will need to be made in their 'best interest' and the Mental Capacity Act framework for determining best interest applied (see page #). A Lasting Power of Attorney (LPA) with appropriate authority (Personal Welfare) may be empowered to make decisions on the behalf of a person with dementia based on their knowledge of the person and on what they believed the person would or would not have wanted for themselves

**Take time**

People with dementia will require more time for any ACP discussions; these may need to be done over some period of time with some repetition and clarification

**Scenarios**

People with dementia may need examples of situations which they need to consider in making an ACP; e.g. Clinical vignettes illustrating cardiac resuscitation or PEG feeding for example for them to conceptualise and apply to their own situation. This has been done using pictures, video clips and narratives.



## 26.Dignity

**How using GSF helps improve the dignity of residents**

Dignity symbolises many things inherent in good end of life care e.g. respect, autonomy, choice, humanity of each person.

- Breakdown in dignity comes in;
  - Crises / Crisis admissions
  - Ambulance deaths
  - Trolley deaths
  - Out of hours inadequate care e.g. nursing home / locum etc.
  - Inappropriate physical symptom control e.g. over medicalisation of tubes investigations etc.
  - Symptoms e.g. terminal agitation leading to under use of sedative drugs
  - Not respecting patient wishes - not asking them or not communicating effectively.
  
- GSF enables improved dignity of resident by;
  - General ethos as above - respect etc.
  - Enhancing choice, control, self-determination etc.
  - Earlier identification of residents facing end stage illness
  - Advance care planning with team at board rounds/ MDT meeting
  - Advance Care planning discussion with patient (and family)
  - Needs based appropriate care provided
  - Assessment of needs and concerns (+ soon dignity thermometer)
  - Resident choice at centre e.g. in preferred place of death
  - Reduction in crisis admissions
  - Reduction in TROLLEY DEATHS (ultimate in undignified care)
  - Use of minimum protocol in dying stage to stop non-essential interventions etc.
  - Use of enhanced advocacy role of nurses and GPs
  
- GSF enables improved dignity of family by;
  - Earlier discussion, pre-planning and involvement
  - Carer's needs assessed and carer support specified
  - Bereavement support of families
  - Advance care planning discussion can help communication with family members
  
- GSF enables dignity of staff members by;
  - Enhancing skills and confidence
  - Giving permission to discuss deep issues
  - Providing tools to support more open communication

**Dignity Conserving Care** Kindness, humanity, and respect - the core values of medical professionalism - are too often being overlooked in the time pressured culture of modern health care, says **Harvey Chochinov**, and the A, B, C, and D of dignity conserving care can reinstate them **Harvey Max Chochinov** professor, department of psychiatry, University of Manitoba. CancerCare Manitoba, Winnipeg, MB, Canada R3E 0V9 [harvey.chochinov@cancercare.mb.ca](mailto:harvey.chochinov@cancercare.mb.ca) (BMJ | 28 July 2007 | VoluMe 335)

The best way to understand what dignity means for an individual is to ask each resident and family what are the most important factors for him/her in regard to dying with dignity.

<b>Dignity-Conserving Interventions at End of Life</b>		
<b>Factors and Themes</b>	<b>Dignity-related questions</b>	<b>Therapeutic Interventions</b>
<b>Symptom Distress</b>		
Physical distress	<i>"How comfortable are you?" "Is there anything we can do to make you more comfortable?"</i>	Vigilance to symptom management Frequent assessment Application of comfort care
Psychological distress	<i>"How are you coping with what is happening to you?"</i>	Assume a supportive stance Empathetic listening Referral to counselling
Medical uncertainty	<i>"Is there anything further about your illness that you would like to know?" "Are you getting the information you need?"</i>	Upon request, provide accurate, understandable information and strategies to deal with future crises.
Death anxiety	<i>"Are there things about the later stages of your illness that you would like to discuss?"</i>	
<b>Level of Independence</b>		
Independence	<i>"Has your illness made you more dependent on others?"</i>	Have residents participate in decision making, regarding both medical and personal issues
Cognitive acuity	<i>"Are you having any difficulty with your thinking?"</i>	Treat delirium When possible, avoid sedating medication
Functional capacity	<i>"How much are you able to do yourself?"</i>	Use orthotics, physical and occupational therapy
<b>Dignity Perspectives</b>		
Continuity of Self	<i>"Are there things about you that this disease does not affect?"</i>	Acknowledge and take interest in those aspects of the resident's life that he/she most values See the resident as worthy of honour, respect, and esteem
Role preservation	<i>"What things did you do before you were sick that were most important to you?"</i>	
Maintenance of Pride	<i>"What about yourself or your life are you most proud of?"</i>	Encourage & enable the resident to participate in meaningful or purposeful activities
Hopefulness	<i>"What is still possible?"</i>	
Autonomy / control	<i>"How in control do you feel?"</i>	Involve resident in treatment and care decisions
Legacy	<i>"How do you want to be remembered?"</i>	Life Project (making video, audio, writing letters) Dignity psychotherapy
Acceptance	<i>"How at peace are you with what is happening to you?"</i>	Support the resident in his/her outlook Encourage doing things that enhance his/her sense of well-being (meditation, light exercise, listening to music, prayer, etc...)
Resilience	<i>"What part of you is strongest right now?"</i>	
<b>Dignity Practices</b>		
Living in the moment	<i>"Are there things that take your mind away from illness and offer you comfort?"</i>	Allow the resident to participate in normal routines or take comfort in momentary distractions (daily outings, exercise, music etc)
Maintaining normalcy	<i>"Are there things you still enjoy doing on a regular basis?"</i>	
Finding spiritual comfort	<i>"Is there a religious or spiritual community that you are, or would like to be involved with?"</i>	Make referral to chaplain or spiritual leader Enable participation in spiritual practices
<b>Social Dignity</b>		
Privacy boundaries	<i>"What about your privacy or your body is important to you?"</i>	Ask permission to examine resident Proper draping to safeguard privacy
Social Support	<i>"Who are the people most important to you?" "Who is your closest confidant?"</i>	Liberal policies about visitation and rooming-in Enlist involvement of wide support network
Care tenor	<i>"Is there anything in the way you are treated that is undermining your sense of dignity?"</i>	Treat the resident as worthy of honour, esteem, and respect. Adopt a stance conveying this
Burden to others	<i>"Do you worry about being a burden to others?"</i>	Encourage explicit discussion about these concerns with those they fear they are burdening
Aftermath concerns	<i>"What are your biggest concerns for the people you leave behind?"</i>	Encourage the settling of affairs, preparation of an advanced directive, making a will, funeral plans.

## 21. Passport Information

### GSF PASSPORT INFORMATION



Name: \_\_\_\_\_

Contact Details: \_\_\_\_\_

Date Issued: \_\_\_\_\_ NHS Number: \_\_\_\_\_

<b>Nme:</b> Comp No: DoB: Hosp No:	<b>Main Diagnosis:</b> <b>Other:</b> <hr/> Date of diagnosis: DS 1500 date
<b>Address:</b>  Tel No:	<b>Family/Carer Contacts:</b>
<b>Personnel Involved</b> Specialists CNS SPC Team                  Hospice Social services          Other	<b>Key GP</b> <b>Key DN</b>  Other Conditions:
<b>Treatment</b>  <b>Current Medication</b>	
Priorities (Problems and concerns – physical, psychological, social, spiritual)  Other Issues (incl, care plan, out of hours, drugs left at home, before considering admission try etc)	
Preferred place of care:  Date:	Comments:

**Thinking ahead... (Advance Care Planning Discussion)**

1. At this time in your life what is it that makes you happy?
2. What elements of care are important to you and what would you like to happen in future?
3. What would you **NOT** want to happen? Is there anything that you worry about or fear happening?

---

**Do you have a Living Will or Legal Advance Decision to Refuse Treatment (ADRT) document?**  
 (This is in keeping with the new Mental Capacity Act and enables people to make decisions that will be useful if at some future stage they can no longer express their views themselves) *No / Yes*

**If yes please give details (e.g. who has a copy?)**  
**Proxy / next of kin**  
 Who else would you like to be involved if it ever becomes difficult for you to make decisions or if there was an emergency? Do they have official Lasting Power of Attorney (LPOA)?

**Contact 1** ..... **Tel**.....                      **LPoA Y / N**

**Contact 2** ..... **Tel**.....                      **LPoA Y / N**

**Preferred place of care**  
 If your condition deteriorates where would you most like to be cared for?

**1<sup>st</sup> choice**

**2<sup>nd</sup> choice**

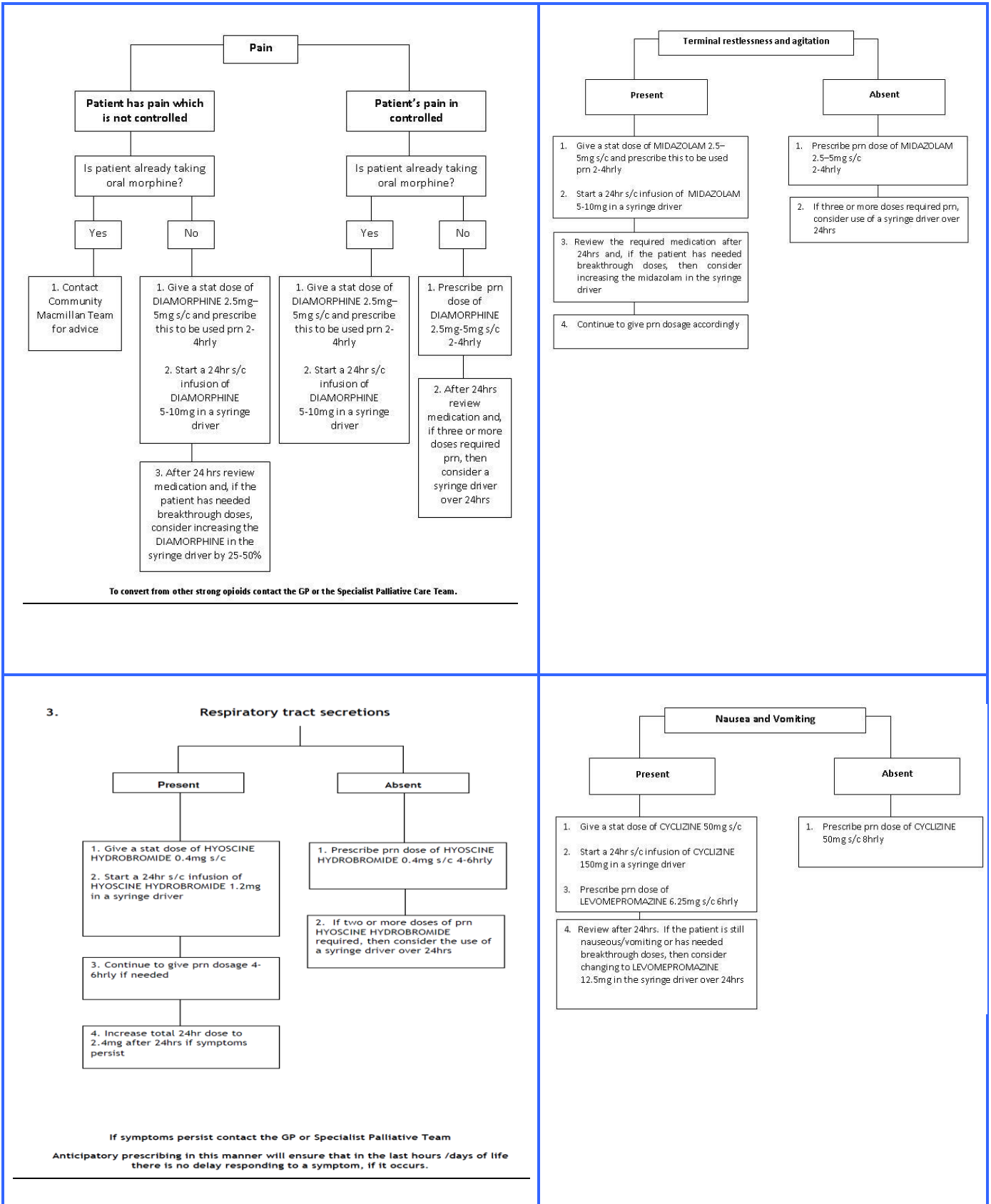
Comments

1. **Do you have any special requests, preferences, or other comments?**
2. **Are there any comments or additions from other people you are close to? (please name)**

**NB See also any separate DNAR/AND or ADRT documents.**

## 22. Suggested Clinical flow diagrams of four main symptoms

These flow charts are an example of guidelines for anticipatory prescribing in the dying phase - many areas have local guidance for the management of symptoms and may be referenced accordingly.



If symptoms persist contact the GP or Specialist Palliative Care Team

Anticipatory prescribing in this manner will ensure that in the last hours/days of life there is no delay responding to a symptom, if it occurs.





## 23. Minimum Protocol

### GSF C7 Care in the Dying Phase - Minimum Protocol for Care in the Final Days

Name of patient ..... Date ..... completed by.....

Check list	Achieved Date/signature	To do	Not appropriate
<b>1. Diagnosis and recognition of dying –awareness of signs of terminal phase</b> <ul style="list-style-type: none"> <li>▪ Agreement by clinical team</li> <li>▪ Bed bound / increasing sleepiness, semi-conscious / only taking sips of fluids / not taking oral medicines/ other factors</li> </ul>			
<b>2. Advance Care Planning</b> <ul style="list-style-type: none"> <li>▪ Use of an Advance Care Plan / Statement with preferences/statements noted and respected</li> <li>▪ DNACPR discussed, noted and communicated to others</li> <li>▪ Other refusal of treatment / Advance Decision if appropriate</li> </ul>			
<b>3. Medication re-assessed</b> <ul style="list-style-type: none"> <li>▪ Non-essential medication discontinued</li> <li>▪ Essential treatment converted as appropriate to subcutaneous (e.g. syringe driver) /transdermal/sublingual /rectal route</li> </ul>			
<b>4. Nutrition and Hydration</b> <ul style="list-style-type: none"> <li>▪ Assess the individual's ability to swallow, if safe and appropriate offer regular fluids; ice creams, jellies, smoothies etc. if wanted. If there is a risk of aspirating, just give water to moisten the mouth.</li> </ul>			
<b>5. Anticipatory medication - PRN</b> <ul style="list-style-type: none"> <li>▪ Standard protocol for 'as required' medication in anticipation for the dying phase written up and available, including pain, agitation, respiratory secretions, nausea and vomiting and breathlessness.</li> </ul>			
<b>6. Spiritual, religious needs</b> <ul style="list-style-type: none"> <li>▪ Spiritual and religious needs assessed and met regarding patient and carers</li> <li>▪ Support from clergy or other spiritual advisors</li> </ul>			
<b>7. On-going assessment</b> <ul style="list-style-type: none"> <li>▪ Regular assessment of pain, agitation, respiratory tract secretions, mouth-care, pressure areas, psychosocial support</li> <li>▪ Evaluate care plans for all care including mouth-care, pressure relieving for comfort, urinary management etc.</li> </ul>			
<b>8. Family awareness</b> <ul style="list-style-type: none"> <li>▪ Family / carers are aware that the patient is dying</li> <li>▪ Family to be enabled to be involved in some patient care, if appropriate</li> <li>▪ Family contact increased - arrangements for contact before / at time of death confirmed and practical arrangements arranged e.g. staying overnight</li> <li>▪ Ensure information provided e.g. pre-bereavement care, advice sheet</li> </ul>			
<b>9. Communication</b> <ul style="list-style-type: none"> <li>▪ GP aware patient is dying and handover form for out-of-hours providers sent</li> <li>▪ Other patients prepared</li> <li>▪ 'Expected death' form: Code 'D' - expected death discussion - recorded and signed. Local policies / guidelines followed</li> </ul>			
<b>10. After care and bereavement</b> <ul style="list-style-type: none"> <li>▪ Verification of death procedure and funeral director notified</li> <li>▪ Staff protocol for after-death care - religious / cultural rituals</li> <li>▪ Follow up care for family - leaflet / information for relatives, access to bereavement support services</li> <li>▪ Support for patients e.g. Memorial Service / acknowledgement</li> <li>▪ Secondary / specialist services informed and hospital appointments cancelled after a death</li> <li>▪ Support and debriefing for staff</li> </ul>			



## 24. SEA (Significant Event Analysis)

It is good practice to complete an SEA as a team and or individually following the death of a patient.

<b>What went well?</b>
<b>What didn't go so well?</b>
<b>What could be improved?</b>
<b>Action Plan</b>



## 25. Useful Website Links

- [NICE Guidance on Neuropathic pain](http://www.nice.org.uk/guidance/index.jsp?action=byID&o=12948): the pharmacological management of neuropathic pain in adults in non-specialist settings (<http://www.nice.org.uk/guidance/index.jsp?action=byID&o=12948>)
- One of the key objectives of implementation of the [Department of Health's End of Life Care Strategy for England](#) is, 'To improve the quality of care at the end of life for all patients and enable more patients to live and die in the place of their choice' <http://www.nhs.uk>
- The associated [DH Quality Markers and Measures for End of Life Care](#) is a key development in improving care. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_1\\_01681](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_1_01681)
- The English [Cancer Services Collaborative 'Improvement Partnership'](#) (CSC'IP') is a national NHS Programme that supports local service improvements <http://www.cancerimprovement.nhs.uk/>
- The [Macmillan Cancer Relief](#) is a UK charity that works to improve the quality of life for people living with cancer. <http://www.macmillan.org.uk/Home.aspx>
- The NHS Cancer Plan (DH 2000) acknowledged that support for patients living at home with advanced cancer is sometimes poorly coordinated and may not be available 24 hours a day. Moreover, it acknowledged that cancer patients should be able to live and die in the place of their choice wherever possible. [www.cancerlancashire.org.uk/ppc.html](http://www.cancerlancashire.org.uk/ppc.html)
- The [CancerHelp UK](#) is a free information service about cancer and cancer care for people with cancer and their families. <http://www.cancerhelp.org.uk/>
- Europe's leading cancer information service, with over 4,500 pages of up-to-date cancer information, practical advice and support for cancer patients, their families and carers. <http://www.cancerbacup.org.uk/Home>
- This site provides essential, comprehensive and independent information for health professionals about the use of drugs in palliative care. <http://www.palliativedrugs.com/>
- [NICE](#) is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. <http://www.nice.org.uk/>
- The [MAP Foundation](#) uses the creative arts to express and communicate complex and painful issues relating to serious illness and dying. <http://www.mapfoundation.org/>
- The [World Health Organization](#) is the United Nations specialized agency for health. It was established on 7 April 1948. WHO's objective, as set out in its Constitution, is the attainment by all peoples of the highest possible level of health. <http://www.euro.who.int/>
- The [King's Fund](#) is an independent charitable foundation working for better health, especially in London. We carry out research, policy analysis and development activities, working on our own, in partnerships, and through funding. <http://www.kingsfund.org.uk/>
- Help the Hospices [Carers Guide resource](#).
- The National Council for Palliative Care - [users and families information](#).
- [Hospice Information](#) provides information for healthcare professionals and the public on UK and international hospice and palliative care. <http://www.kingsfund.org.uk/>
- Cancer is the UK's biggest killer. Every year it claims the lives of more than 150,000 people, with a further one million living with the disease at any one time. [Marie Curie Cancer Care](#) is working tirelessly for you and your loved-ones by challenging the disease through its work in cancer care and research. <http://www.mariecurie.org.uk/>

- [Crossroads](http://www.carers.org.uk/) is the largest charity in the world, providing 'in the home care' for Carers. <http://www.carers.org.uk/>
- The [Princess Royal Trust for Carers](#) website for unpaid carers.
- [The Carer](#) was formed to offer a unique reference point on advice to carers of all ages and professions. Tips and advice to all carers on getting help, everyday practicalities, accommodation, health issues, money matters and bereavement. <http://www.carers.org/>
- [Bereavement Advice Centre](#) supports bereaved people on a range of practical issues via a single Freephone number. It offers advice on all aspects of bereavement from registering the death and finding a funeral director through to probate, tax and benefit queries.
- Call the helpline 0800 634 9494 (Mon-Fri 9am-5pm, answer-machine at all other times) or visit <http://www.bereavementadvice.org/>
- [Mesothelioma](#) - The Mesothelioma Centre is an up-to-date resource for all mesothelioma ([What is Mesothelioma?](#)) issues ranging from mesothelioma statistics to diagnosis options. The daily tasks of caring for someone who has been diagnosed with malignant mesothelioma can be overwhelming. Besides dealing with your own emotions, fears, and uncertainties, you will find yourself responsible for many daily tasks, managing appointment schedules, remembering medications and treatments, dealing with both medical and legal professionals, bathing and feeding your loved one, and managing their financial affairs <http://www.asbestos.com/>