

Improving End of Life Care - a Matter of Life and Death

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KEY MESSAGES

- End of Life Care is important - it affects us all
- Most people die of co-morbidity / non-cancer conditions in old age
- Too few people die in their place of choice, usually at home
- Hospital deaths are expensive and often preventable
- Most end of life care is from the usual generalist provider
- There is much that can be done; we are all involved and can play an important part in the delivery of top quality care

Everyone reading this journal will be affected by end of life care in some way, either personally with family and friends or as professionals caring for patients who are nearing the end of their life. We are all involved and we all must play our part. There is a great surge of interest in this area as we come to realise that this is one of the key issues we face as a health service and as a society. It has implications for each one of us, for humanitarian, professional and personal reasons. But also there is recognition that this a key area for cost efficiencies by reducing avoidable admissions and making best use of the scarce resources we have. Planned preventative care given closer to home is more cost effective than managing crises and institutionalising people – and it meets the preferences of most people to spend most time in their own home. End of life care should be firmly on the agenda of everyone commissioning or providing health and social care. Doing nothing is not an option.

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Caring for people nearing the end of their life is part of the core business of primary care – general practice and community services. This role is greatly valued by patients, and is pivotal to effective provision of other care. Care of the dying is considered by many to be a litmus test for the health service. It challenges clinicians to respond with the best that the profession has to offer - clinical expertise, professionalism, personalised care, human compassion. The holistic role of the family doctor and primary care team could come into its own in a way never previously encountered.

This edition of the journal is dedicated to end of life care. We have a number of papers that detail initiatives and developments which reflect the importance of this area. Claire Henry and Anita Hayes describe national developments from the NHS End of Life Care Programme; Paul Thomas describes ways to avoid admissions out of hours, and gives a moving account of a patient that changed his thinking; David Law reflects on the gaps in community provision for the elderly nearing the end of life, the consequences for hospitals and the need to fundamentally rethink cross boundary provision; Gerry McGivern gives an example of a small network of providers that works together to deliver end of life care;

Rachel Addicott describes the benefits and challenges of using a centralised coordination centre for end of life care. Together these papers articulate the passionate commitment many have towards coordinated end of life care, and to finding solutions despite the complexity of our current systems. With these and other insights we must find a flexible, practical and personalised way to provide the kind of care we hope for ourselves and our families.

Box 1

End of Life Care in Numbers

- **1%** of the population dies each year (approx average UK rate)
- **17% - the predicted rise in UK death rate** from 2012
- **40%** of deaths in hospital could have occurred elsewhere (NAO report)
- **50% of hospital deaths of care homes residents could have been prevented**
- **60-70%** people do not die where they choose
- **75%** deaths are from non-cancer conditions
- **85%** of deaths occur in people over 65
- **£19k (non-cancer patient), £14k (cancer patient)** - average NHS expenditure/patient in final year **according to recent NAO Report**
- **Workforce- 2.5 million** generalists - 5,500 Palliative care specialists.

WHAT IS THE URGENCY?

As a society we face a challenge in healthcare that we have never previously encountered. People are living longer with serious illnesses and dying older. Many people will have complex conditions, multi-morbidities and frailty leading to complicated health and social issues. A significant rise in the UK death rate is predicted from 2012 and the current plateau in the death rate for the next three years suggests an urgency to get this right now. Yet health and social care services appear ill-prepared to meet the needs of many approaching the end of their life. Despite recent improvements, patients still often have sub-optimal care at this most crucial stage of their lives.

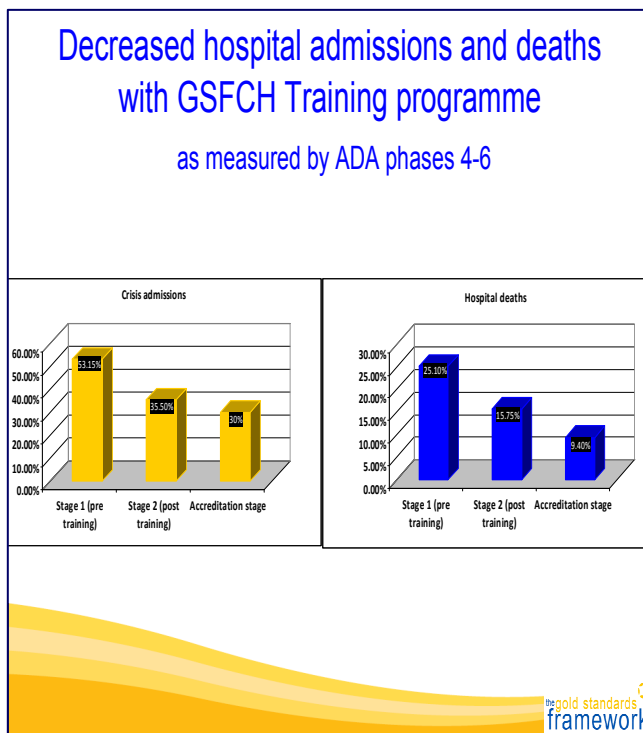
GOLD STANDARDS FRAMEWORK – PART OF THE SOLUTION

Since its development nine years ago, the GSF in Primary Care Programme has helped to improve the coordination and quality of end of life care within primary care. GSF is now extensively used by GP practices across the UK, with over 90% claiming

their palliative care QOF points, and over 60% using GSF in a more depth way. This is a good start, but there is much still to do. ‘GSF Next Stage’ describes a need to build on this good practice in four key areas -to work towards greater consistency and effectiveness in using GSF, greater equity for non-cancer patients and improved quality of care. To meet these challenges as part of Next Stage GSF there are new website resources and tools, a new practice –based ‘Going for Gold’ training programmes and ongoing audit to support quality improvements (i.e After Death Analysis - ADA). GSF has been adapted for other settings including a widely used training programme for care homes, and its adaption for use in hospitals and prisons, other settings and other countries. This use of GSF common principles and tools aims to improve cross boundary working , improve patients experience of care in the different settings and enable more to live and die well, mainly in their home. (visit www.goldstandardsframework.nhs.uk).

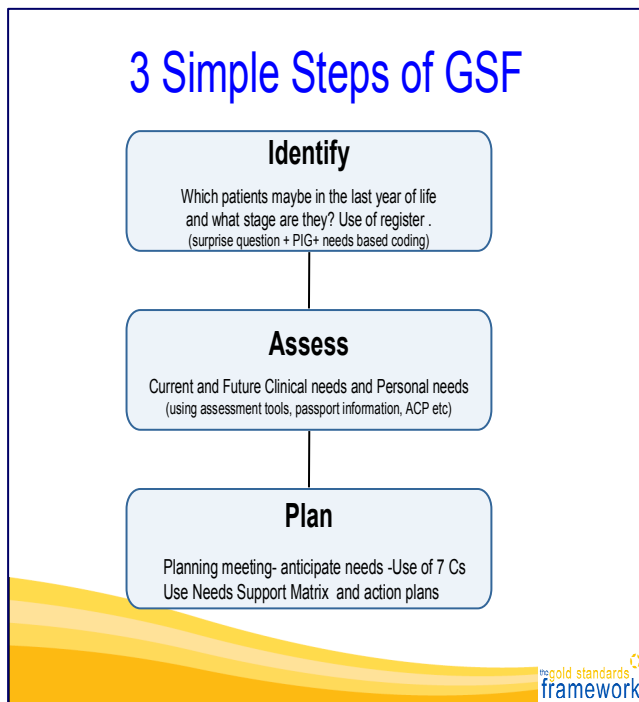
The GSF Care Homes Training Programme for both nursing and residential care homes, mentioned in Gerry McGivern’s article, helps staff to grow in confidence in identifying, assessing, planning and providing good care as a team. The aims are to improve 1) Quality of care, 2) Collaboration between primary care teams and specialists, and 3) Hospital admissions and deaths. Care homes have achieved reduced hospitalisation (many halving hospital deaths and admissions - see Fig 1).

Fig 1.



THREE NEEDS – IDENTIFY, ASSESS, PLAN (see Fig 2)

Fig 2.



In the development of GSF, three key needs were apparent

1. Identify the right patients to be included on the palliative care register (including both cancer and non-cancer patients).
2. Have those difficult discussions (as part of the assessment of patient preferences through Advance Care Planning discussions)
3. Plan for coordinated care by the whole team to ensure that the right things happen at the right time in the right way.

These areas are covered by GSF in more depth through the new training GSF Primary Care Training programme 'Going for Gold', in the work in care homes and the growing work of GSF in Acute Hospitals, to enable better communication and more consistent high quality levels of care for people, wherever they live and die.

SUPPORTING CARERS

The new Caring with Confidence programme funded by the Department of Health supports carers to feel better able to cope through locally run, free support sessions. The roll out of the programme for people nearing the end of life is led by Omega, the National Association for End of Life Care

(visit carers@omega.uk.net and www.omega.uk.net)

RCGP & RCN STRATEGIES

In June 2009, the College approved the RCGP End of Life Care Strategy. This reaffirms the commitment of the College to excellence in end of life care, and agrees to make this a priority for the future. This UK-wide strategy builds on the national developments of the Department of Health End of Life Care Strategy (July 08) and the DH Quality Markers in End of Life Care (July 09) in England and similar developments in the other three nations.

Similarly the Royal College of Nursing supports and endorses this work, and with 'Transforming Community Services', will be helping in practical ways to support nurses, who are often the key deliverers of end of life care. (see also Focus on Nurses on GSF website)

NEXT STEPS

Implementing the above will make a very big difference, but there is much more to be done to attain the high standards we seek End of life care is a touch-stone for 'treating people properly' in all other areas. It is something that affects us all, now or later. As you read this journal, there may be some specific action points for you to put into practice in your area; e.g. to consider advance care planning for yourself and your patients, to use the surprise question to think whether this patient might be in the final year of life and what you should do if they are, to encourage developments of supportive services in your patch and to contribute to the wider debate to improve care for those that are most vulnerable in our society. Extended primary care teams need to learn how to provide excellent coordinated care, despite the difficulties posed by the fragmented nature of primary care these days. Anyone who has experienced it knows that few things are as rewarding as a well handled death. Achieving this means paying attention to the needs of everyone – carers, families and ourselves, as well as patients. We have a responsibility to get it right first time - there is no second chance.