

Dear Colleague,

Ref. The RCGP End of Life Care Strategy Document (EOLC Strategy)

The recently launched RCGP End of Life Care Strategy Document (attached) was approved by College Council in June 2009 and presented at the RCGP Annual Conference in November 2009, when the UK-wide RCGP End of Life Care Working Group was officially launched.

The purpose of the Strategy is to affirm that end of life care is **now a matter of priority** for the College and will be integrated into many areas of future work. The Strategy followed extensive consultation and contains ten specific recommendations, as part of a three year plan, including the formation of an RCGP EOLC UK Wide Working Party with individual working groups in each of the four nations.

The remit of the national and local groups over the next 12 to 18 months is to develop guidance and further resources which will support the implementation of best practice in end of life care by GPs both regionally and nationally. The work of the RCGP in End of Life Care is only just beginning and the Strategy is an important first step. It sets out the College's vision for the future and the direction of travel, but there is considerably more work to do to attain the goals, including further consultation, development of best practice guidance, creation of resources and tools and adaptations for local implementation.

The College welcomes your views on the Strategy and any suggestions on how we can best support future development of End of Life Care within primary care. If you would like to take part in the consultation meetings or conference calls, please do let us know. For details of the next consultation event see below. Please respond via email to circ@rcgp.org.uk.

We look forward to hearing from you and to working together to bring about real and practical improvements in care for all people nearing the end of life.



Professor Keri Thomas MB.BS MRCGP DRCOG MSC (Pall Med)
RCGP Clinical Champion in End of Life Care
National Clinical Lead Gold Standards Framework Centre,
Hon Professor End of Life Care University of Birmingham

N.B. You are welcome to attend the next consultation event to share your views on the strategy at the forthcoming **Clinical Evening Update on End of Life Care event on 19 January 2010** at RCGP Headquarters Princes Gate. The presenters will include Professor Mike Richards CBE, National Clinical Director for Cancer, Professor Mayur Lakhani (National Council for Palliative Care) and Lynne Young (Royal College of Nursing) as well as myself. For more information please visit RCGP events: http://www.rcgp.org.uk/news_and_events.aspx

RCGP End of Life Care Strategy 2009

- 1. Executive Summary + Recommendations**
- 2. Introduction**
 - a. Aim of this strategy
 - b. Development of the strategy
 - c. Underlying principles and values
 - d. End of Life Care definition
 - e. Support and Endorsements
- 3. Background and context**
 1. Context and demographics
 2. National Policy drivers and College policy
 3. Where are we now? Culture and public awareness
 4. Key issues in improving home care
- 4. Moving towards the vision**
 1. Statement of vision - what would best practice will look like
 2. Affirmation within College activity
 3. Building on the Gold Standards Framework in Primary Care
 4. Developing and piloting new initiatives
- 5. Detailed Recommendations +Action plan**
 - a. Recommendations, action plan and timescale
 - b. Conclusion and Next Steps
- 6. References**

**Author: Professor Keri Thomas,
RCGP Clinical Champion in End of Life Care, CIRC**

1. Executive Summary

The adoption of this RCGP End of Life Care Strategy will lead the way in defining, enabling and pioneering good practice in end of life care, reflecting the crucial role that GPs play now and in future. The development and support of high quality end of life care aligns with the principles and vision of the College. To do this it is recommended that the College affirms the importance of end of life care as a priority throughout its work, establishes a collaborative End of Life Care Working Group, and supports ten specific recommendations (see below). This includes recommendations, detailed later, that the College will recognise achievement, enhance and update accessible educational resources, build on current good practice such as the Gold Standards Framework in Primary Care, support and pioneer new ideas, audit tools and models, focus on improving weaker areas such as care homes, out of hours care, and help to raise awareness of this important issue to meet the needs of this and future generations.

Caring for people nearing the end of their lives is part of the core business of General Practice.

The GP and the primary care team occupy a central role in the delivery of end of life care in the community. This role is greatly valued by patients and remains pivotal to the effective provision of all other care. Care of the dying is a litmus test for the health service, and challenges general practice to respond with the best that the profession has to offer - clinical expertise, considered professionalism, personalised care and human compassion. The importance of the holistic role of the family doctor is poised to come into its own in a way never previously encountered.

As a society we face a challenge in healthcare needs never previously encountered.

Dramatically changing demographic profiles mean more people are living longer with serious illnesses, with more protracted end of life and dying stages. Current health and social care services are ill prepared and unready to fully meet the needs of the majority of those approaching the end of their life.

Despite recent developments and many areas of good practice, patients still face a lottery of inconsistent, sometimes sub-optimal care. As illness patterns change with increasing multiple morbidities, and as patients and their families seek trusted 'companions on the journey', no-one is better suited to provide excellence of care than the GP and the primary care team. GPs are ideally placed to meet this challenge, but must be supported to do this.

End of Life Care is a matter of life and death. While other demands on the GPs time and energy will come and go, the stark fact of our mortality will remain the same. End of Life Care is a complex area, fraught with practical difficulties and beset by ethical dilemmas. We have a responsibility to our patients to get it right first time - there are no second chances. Our aim is that high quality care for people nearing the end of their life becomes the legacy of this, the baby boom generation, a legacy that we will all benefit from personally and with our patients.

This strategy affirms the College's commitment to promote excellence in end of life care.

Key Strategy Recommendations for Endorsement by Council

1. That Council, on behalf of the College, recognises the significance of the challenge of improving end of life care and affirms the importance of this work and continues to make improving end of life care a matter of priority within the work of the College.
2. That Council recommends the establishment of a three year RCGP End of Life Care Working Group in collaboration with other stakeholders such as the RCN, to further develop College policy, thinking and practical implementation of the Strategy. Annual reports will be produced for Council, and a comprehensive College Report on best practice in End of Life Care will be published at the end of the first year. A commitment to support the implementation of its findings and to assess further progress is also recommended.
3. That Council will actively support and integrate the recommendations made below, as a first stage of the three year plan, and will allocate appropriate funding support to the working group when finances allow. Support is also requested for the publication of the report which is designed to enable wider communication and raise the profile of the College.

Summary of Recommended Actions	
1. Establish an End of Life Care Working Group	<ul style="list-style-type: none"> a. Collaborative working with the College Patient Partnership group, Royal College of Nursing, Association of Palliative Medicine, Children's Palliative Care Groups, Government End of Life Care programme and other stakeholders to develop local implementation guidance relevant to each nation. b. The development and publication of joint UK wide best practice guidance to improve practitioner skills and raise public awareness, with local implementation plans.
2. Build on current good practice	<ul style="list-style-type: none"> a. To build on the Gold Standards Framework in Primary Care, though GSF Primary Care Next Stage working group to further develop a consistent systematic approach. b. To further influence QOF to recognise the importance of end of life care through integrating GSF principles and activity. c. Build on other models of excellence such as Advance Care Planning, the Liverpool Care Pathway for the Dying and cross boundary strategic plans and pathways.
3. Recognise and reward best practice	<ul style="list-style-type: none"> a. Recognition and reward examples of excellence e.g. Beacon GSF practices b. Integrate end of life care into accreditation process e.g. RCGP Provider Accreditation c. Specific awards established for End of Life Care e.g. RCGP GP Enterprise Awards d. Inclusion of end of life care in Annual Practice Reports
4. Review and refine existing educational resources to better meet needs	<ul style="list-style-type: none"> a. RCGP E-learning modules b. Integrate end of life care into curricula at all levels c. Update and link with other college educational initiatives
5. Support research and development of innovative best practice models	<ul style="list-style-type: none"> a. Support research into means of best practice, with CIRC and the DH Intelligence Unit b. Pilot use of co-morbidity indices and other innovations. c. Pilot extended 'early warning model', earlier recognition in line with QOF registers, incorporating long term conditions
6. Develop and promote use of audit tools to improve practice	<ul style="list-style-type: none"> a. Refine the ADA audit tool (After Death Analysis) for GP use b. Develop new audit tools for primary care assessment to support improvement
7. Strengthen team-working with nurses, as part of the primary healthcare team	<ul style="list-style-type: none"> a. Improve means of collaboration with community nurses at practice level b. Highlight areas of good nursing practice e.g. supportive care in community pathway c. Continue collaboration with the Royal College of Nursing
8. Promote and recognise good practice for GPs working in care homes	<ul style="list-style-type: none"> a. Working with others, to recommend better ways of supporting residents in care homes b. Encouraging more pro-active GP involvement in care homes, e.g. allocated GP sessions for care homes, development of new roles such as GPwSI in care homes c. Use of best practice models such as the Gold Standards Framework in Care Homes Programme to improve collaboration with GPs and reduce avoidable hospitalisation.
9. Endorse the use of Advance Care Planning for those patients on the palliative and supportive care registers	<ul style="list-style-type: none"> a. Provide further training and enablement for GPs and primary care teams to integrate Advance Care Planning into routine practice
10. Improve Out of Hours Palliative Care	<ul style="list-style-type: none"> a. Collaborate with CIRC Clinical Champions and Macmillan Cancer Support to improve out of hours palliative care b. To promote proactive care e.g. anticipatory prescribing to prevent crises

2. Introduction

a. Aim of this Strategy

This RCGP End of Life Care (EOLC) Strategy has been developed in line with and in response to the DH End of Life Care Strategy, to address the current issues relevant to primary care. It presents a vision, recommendations and means of implementing the plan to address the emerging challenge.

To implement the recommendations of the strategy, a working group will be established for 3 years in England and similar processes in Wales, Scotland and Northern Ireland. This will focus on the primary care team's practical response to implementing the shared vision of this strategy in improving end of life care in the community.

This strategy was commissioned and written for the UK wide College, but the implementation will vary between the four nations. Scotland has an independent End of Life Care Group and strategic plans, and others are developing these for their nations, so this strategy aims to affirm the principles and shared vision but encourage local national implementation and developments.

b. Development of the Strategy

Timeline of development of RCGP End of Life Care Strategy and recommendations

- Proposed July 07 by Prof Mayur Lakarni, then RCGP Chairman
- Planning through CIRC and Clinical Champion role commenced Autumn 07
- GP half day think tank meeting with Clare Gerada Jan 08
- Further consultation by email and phone with RCGP members summer 08
- Further development in line with DH EOLC Strategy launched July 08
- Meeting with Steve Field RCGP Chair July 08
- Consultation conference call with RCN and Children's Alliance Sept 08
- RCGP member Consultations – Sep - November 08
- Meeting with RCN to develop draft manifesto – Nov 08
- 2 Meetings of GSF Next Stage Working Group (GPs) Sept and November 08
- Discussions with others - Association Palliative Medicine, Help the Hospices 08
- Consultation by conference call with other RCGP members (Clare Gerada, Ben Riley) and others (Nigel Sparrow) by email November 08
- National Audit Office Report launched Nov 08
- Final document to RCGP CEC Board for 23rd Jan 09
- Proposal for approval by Council June 09
- Funding proposals approved by CEC July 09
- Further discussions with other College areas e.g. education, accreditation, media Consultation with national leads in End of Life Care in Wales Scotland and Northern Ireland and with Regional Faculties
- Development of College EOLC Groups in each of the 4 nations
- Formal launch of the UK wide EOLC Working Group, Nov 09 at RCGP Annual conference.

Plan for RCGP End of Life Care Working Group

- Meetings to commence 2010 with representatives of all 4 nations EOLC Groups and interested stakeholders
- Review of implementation plan and next steps –report back to CIRC and council annually

c. Underlying principles and values

Palliative and End of Life Care reflects key principles enshrined in college ethos and are part of the core business of General Practice. Providing high quality end of life care aligns with the principles and vision of the College of coordinated, accessible, comprehensive care, tailored to meet the specific needs of patients, based on maintaining the continuity of long-term relationships. Much of good palliative care uses transferable skills which are of benefit in other areas of general practice.

d. End of Life Care and Palliative Care - working definitions

There can be some ambiguity in definitions which needs clarification. In general, Palliative Care is based on principles of holistic, person-centered care that are intrinsic to general practice and are now familiar to most people. As the specialty of Palliative Medicine developed, increasingly in this country the term of generalist palliative care has been used to mean the care provided by generalists rather than specialists, i.e. those who care for other patients than dying patients such as GPs, community nurses etc. Of the 1.2 million working in the NHS, there are currently about 5,500 in specialist palliative care. It is only by everyone becoming engaged in fulfilling their roles in end of life care that we will achieve our goal of reliable comprehensive high quality care.

Over recent years other terms have been used to describe this area of care, and there is growing recognition that all health and social care professionals are involved in care for people nearing the end of life to some degree. Since the development of the NHS End of Life Care Programme and Strategy in England, the term is used increasingly to include patients months and years before death, not just those in the final days, and focus on the work of all professionals involved in end of life care, rather than just palliative care specialists.

This is the definition of End of Life Care we are using here - to include care for all patients with life-limiting conditions in the final stage of life, (with cancer and non-cancer illnesses), to include care in the final years and months of life, as well as the dying stage and to focus on care provided by generalists working with specialists.

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
World Health Organisation 2005

Department of Health England Definition of End of Life Care

A working definition of End of Life Care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. *DH End of Life Care Strategy England July 08*

“Mission Impossible? Palliative care embraces what is most noble in medicine: sometimes curing, always relieving, supporting right to the end.” (Gomas, 1993)

In summary

- **End of Life care**
 - 'Care that helps all those with advanced progressive incurable illness to live as well as possible until they die'. Patients living with the condition they may die from- weeks/months/ years –includes all types of deaths (cancer, organ failure ,frail elderly /dementia/co-morbidity, etc.)
- **Supportive Care**
 - 'Helping the patient and family cope better with their illness' (NICE definition)- not disease or time specific, 'less end- stage', often provided by generalists
- **Palliative care**
 - WHO definition of holistic care (physical psychological, social, spiritual)-specialist and generalist palliative care
- **Terminal care/ Final days**
 - Care in final hours and days of life- requires diagnosis of dying (as in Liverpool Care Pathway for the Dying)

e. Support and Endorsements

Royal College of Nursing

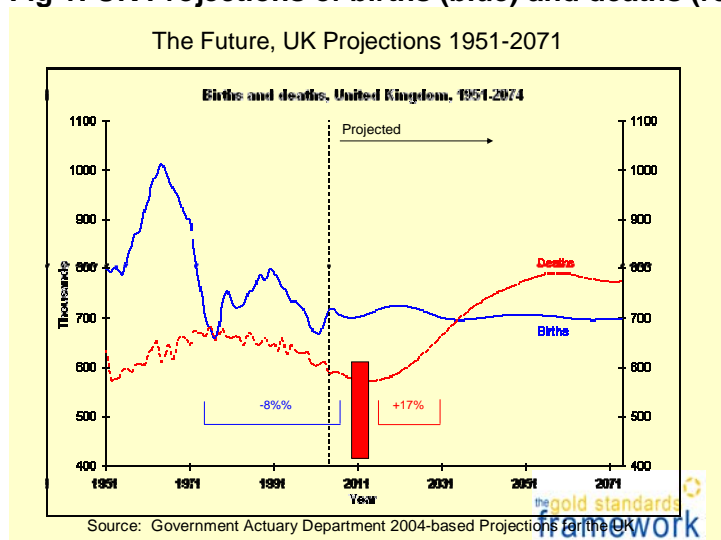
"The RCN wishes to give its wholehearted support to the RCGP's end of life strategy. General practice is well placed to significantly improve the end of life care for its patients and by working closely with local community nurses effective changes can be made to services which would bring huge benefits to patients and their carers. GPs and community nurses have always been committed to providing the best possible care to patients who choose to die at home and the RCGP strategy has the potential for ensuring that exemplary standards of care become the norm.

We look forward to continuing to work with the College as part of the proposed End of Life Care Working Group to improve this vitally important aspect of primary care"

Lynn Young, Primary Care Adviser, Royal College of Nursing

Other support for the development of this strategy and interest in further collaboration comes from the Alliance of Children's Palliative Care services, Association of Palliative Medicine, Department of Health End of life Care Programme; Macmillan and others. Further interest will be sought from Help the Aged, Help the Hospices, Marie Curie, Kings Fund and others involved in end of life care.

Fig 1: UK Projections of births (blue) and deaths (red) 1951- 2071



3. Background and context

a. Context and Demographics

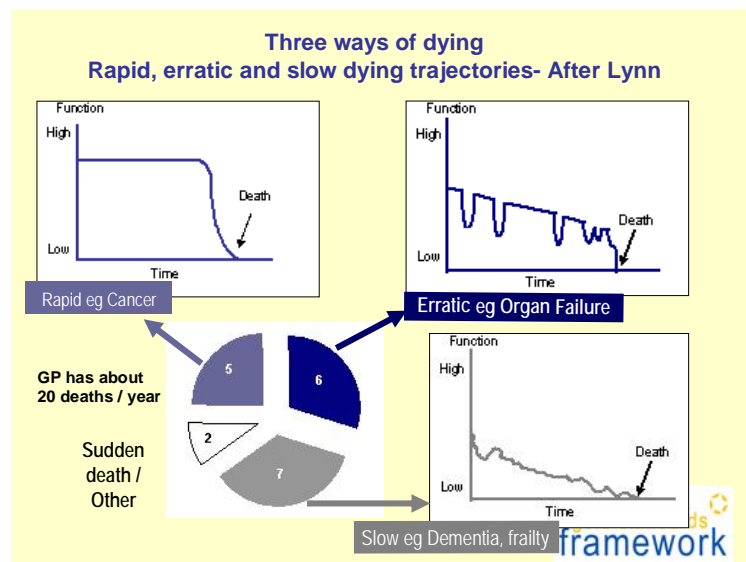
The context of this strategy is the change in the predicted demographics of dying (see Fig 1). As a society we now face an unprecedented challenge in healthcare needs. The way we care for all people nearing the end of life in the coming years is regarded by many as being one of the greatest challenges of the future, both as a health service and as a society. Preparation must commence now, in anticipation of the predicted surge in numbers dying from 2012. The next three years are crucial.

The conclusion is that we have a short time to plan and prepare before the predicted rapid increase in demand for end of life care services. As a College we therefore need to clarify, anticipate and lead the way in responding to this challenge from the perspective of community care delivered by GPs and primary care teams.

Key points

- Dramatic rise in deaths from 2012 - three key years before death curve rises
- Deaths outnumber births by about 2030
- People dying older - over 85s (32% in 2004, 44% in 2030)
- Decreasing home deaths – now **18%** - less than 10% by 2030 - trend to hospitalisation (Higginson Gomes Palliative Medicine 2008)
- Care Homes deaths **17%** - totalling **35%** of all deaths are under the care of GPs
- About 1% population die/ year- i.e. 18-20/GP/year
- Three trajectories of dying in addition to sudden death (see Fig 2)
- Societal change in communities - increase single occupancy households

Fig 2: The three Dying Trajectories



b. Where are we now?

'Around half a million people die in England each year, of whom almost two thirds are aged over 75. The large majority of deaths at the start of the 21st century follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere'

DH End of Life Care Strategy July 08

There are radical changes within primary care, both nationally and locally such as contractual changes, the Quality Outcomes Framework (QOF), strategic and operational restructuring, changes in provision of out of hours services, the introduction of new ways of working such as federated models, local commissioning (e.g. Practice Based Commissioning in England) and other developments. With further devolution, all four nations of the UK also face equally challenging restructuring changes and developments, some welcomed and some less so.

The specialty of Palliative Care was pioneered in this country, with the development of the modern hospice movement, and there is increasing understanding of the complementary and collaborative roles that specialists and generalists must play in this area for effective care. There is good evidence (Mitchell 2003 systematic review) that GPs can provide excellent palliative care that is much appreciated by patients, but is best when formally collaborating with specialists.

Community end of life care. There has been a growing focus on increasing care closer to home (e.g. *Our Health Our Care Our Say* DH White Paper England Jan 2007) and reducing avoidable hospitalisation. In England, the NHS End of Life Care Programme led on to the publication of the EOLC Strategy, with some similar activity and developments in Scotland, Wales and Northern Ireland. Also, the Darzi Next Stage Review in England included a work stream specifically on End of Life Care, ensuring now that improving end of life care is firmly on the agenda of all Strategic Health Authorities and Primary care trusts, with some recurrent funding.

The Gold Standards Framework in Primary Care Programme was first piloted in 2001 and is now used by over two thirds of GP practices, with 99% claiming their palliative care QOF points, equating to GSF Level 1 i.e. they have a palliative/supportive care register and hold a planning meeting to discuss these patients. (Note - probably not all practices fully meet this standard, but the fact that they claim to have a register is considered a good foundation from which to build). The GSF was supported and endorsed by College on 12th Feb 2005 (reference Report C/71 Item 18) and Council agreed that the College may explore involvement in the continuing development of this work. College endorsed and supported the development of certain tools such as the GSF Prognostic Indicator Guidance, and the After Death Analysis (see references). Further collaboration is currently being explored. Building on the success of GSF in Primary Care to now reflect, further develop and constructively re-launch it with the GSF Primary Care Next Stage Review, is therefore an integral part of the development and implementation of this strategy. Other End of Life Care models are also integrated into this strategy i.e. the Liverpool Care Pathway for the Dying and the Preferred Priority of care tool as part of Advance Care Planning.

c. National Policy Drivers

End of Life Care is increasingly regarded as an important area for improvement, and featured in several policy initiatives over recent years (see references). There is recognition of some improvements but still current inadequacies i.e. in the variable quality, inequity of provision, unmet needs of patients and families, about half not dying where they would choose, overuse of hospitals leading to poor cost effectiveness, and significant number of complaints. In response to this, the Department of Health in England developed the **NHS End of Life Care Programme** (04-07) and **DH End of Life Care Strategy** (July 08) and **Quality Markers** in End of Life Care (July 09).

The National Audit Office End of Life Care Report (November 2008) produced a strong economic argument for the importance of seeing end of life care within the wider health and social care context. It claimed that failings in the commissioning and provision of end of life care services are costing the NHS more than £100m every year. The service variations of more than £1,500 per death between the highest and lowest Primary Care Trusts confirmed the influence on the NHS of poor end of life care services and the importance of measures of cost effectiveness and improved commissioning. It predicted that £104 m a year could be

saved and reinvested in community provision if emergency admissions were cut by 10% and average length of stay for terminally ill patients reduced by 3 days. Along with the policy driver in England of **World Class Commissioning**, several areas therefore set targets for reduced hospitalisation in their area, with concomitant impact on community and primary care services.

DH End of Life Care Strategy (England) - extracts related to primary care.

What the EOLC Strategy means for patients and carers (p17). You will have access to:

- The opportunity to discuss your personal needs and preferences with professionals who can support you
- Coordinated care and support - **every organization involved in providing end of life care will be expected to adopt a coordination process such as the Gold Standards Framework**
- Rapid specialist advice and clinical assessment wherever you are etc....

6.56 (p128) Good PCTs, working with local authorities, will wish to give high priority to development of the local workforce through initiatives such as GSF, PPC and LCP and ensure that differing funding processes are not a barrier to integrated workforce developments

- Community - The importance of 24/7 rapid response community nursing services for end of life is emphasised. GSF or the equivalent is recommended for use in general practice
- Care homes - Major scope for improvement of end of life care in care homes. The NHS End of Life Care Programme (2004-2007) has shown what can be achieved, using GSF, LCP, PPC, etc. These approaches now need to be spread
Importance of good medical cover is emphasised

8.35 Primary care teams will wish to ensure that they can identify, assess and plan care for people approaching the end of life. They will also wish to document decisions taken with the person and have mechanisms to ensure good communication both within the primary care team and with other care providers, for example, out of hour's services. Where they do not already exist, processes need to be put in place to ensure that patients approaching the end of life are reviewed regularly. (Page 158)

8.36 Primary care teams will wish to ensure that relevant staff has the necessary competences to communicate effectively and assess the needs of people approaching the end of life and their carers.

Coordination - 3.52 Good commissioners of end of life care will wish to ensure that effective mechanisms are in place to facilitate coordination of care, both within individual organisations and across organisational boundaries.

Care Homes - There is appropriate access to GP, district nursing and specialist palliative care advice.

Education and training and continuing professional development.

20. Ensuring that health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care for the dying will be critical to the success of improving end of life care. For this to happen, end of life care needs to be embedded in training curricula at all levels and for all staff groups. End of life care should be included in induction programmes, in continuing professional development and in appraisal systems.

d. Changing culture - death seen as failure

There is an inherent reticence in addressing issues around death and dying within the human psyche, reflected by responses in public opinion, from many healthcare professionals, and national policy and funding requests. But this is now changing, and increasingly the issues around end of life care are being raised on the agendas of health and social care providers and other public bodies, in response to the challenge already discussed. However, the natural and human antipathy to this subject within our 'death denying society' is a factor that regularly re-emerges in our contact with patients, hospital services and other areas. It is one we have to face honestly and with sensitivity if we are to make progress in this area.

Talking about death and dying with patients is one of the most difficult discussions GPs will face (Heath 2008), and requires considerable sensitivity and skill. And yet it is incumbent on us as professionals to support patients in this way, in honest yet compassionate, developing both realistic hope and internal resilience, and guiding people towards making the best choices for them.

We need to help them see the road ahead and to plan for the future, whilst maintaining optimism and hope. Such advance care planning discussions are a crucial part of this process and GPs and primary care teams can play a central role in this.

e. Key issues in improving community care

Care in the community is one very crucial part of the jigsaw with the emphasis of reducing hospital admissions meaning increased provision of community services. Several factors play a role here including strategic planning and commissioning, public awareness and changing of cultures and ethos, providing Individualised patient-orientated care, pre-planning of care and advance care planning discussions, reliable delivery of high quality care at home 24 hours a day, coordination across boundaries of care and in emergencies and out of hours etc. This requires an emphasis and enablement of the role of GPs, District Nurses, primary care teams, care homes and other community services, requiring adequate funding for staff, enablement of good care provision and meeting training needs.

Other areas such as community hospitals, private hospitals, prisons, and care for the homeless also need to be included. Empowering patients and enabling greater supportive self care and support for carers is crucial, including care for children as patients and carers. This requires strategic planning and local commissioning of services underpinned by national drivers. To assess and mainstream progress, and to analyse and address gaps, there need to be adequate audit or measurement tools, simple to use and focused in their constructive feedback, supported by development of a strong research evidence base of effective solutions. And finally and importantly, realistic funding must be provided by local and national commissioning, redistribution of services, incentivising best practice and enabling improvements if we are to make inroads in this area.

f. Care Homes

Currently, the provision of end of life care by GPs for residents in care homes is considered to be of inconsistent and sometimes inadequate standard, both in the varying amount of secured time allocated to GPs, and in the quality of care provided. However GP cover for care homes is recognised to be of great significance in improving care for residents throughout their entire stay at a care home. Some care homes and PCT fund specific GP sessions to improve consistency and standards of care, but this is not widespread. Discussion about improved consistency and evolving roles of GPs caring for care homes e.g. allocated GP sessions, GPwSI for care homes, should be examined along with others from health and social care.

One of the aims of the **GSF Care Homes Training Programme**, now widely used by over 1000 care homes, is to improve the collaboration and team working with GPs, and many examples of best practice have emerged from this work. Care homes that have undertaken the GSFCH training programme can progress to accreditation, with successful accredited homes receiving Quality Hallmark Awards. Such examples of best practice should be encouraged.

4. Moving towards the vision

1. Statement of vision- what would best practice will look like?

“How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social services.” (DH EOLC Strategy)

We are moving towards a vision in which patients and their families are enabled to live well and die well in the place and manner of their choosing, are treated with respect and dignity at all times, receive high quality reliable home care, and their families and carers are supported throughout and into bereavement.

There needs to be further clarity about what best practice looks like in primary care, and how to practically attain it, building on the examples of excellence already available through such work as the Gold Standards Framework. We need to recognise and reward success, whether this is part of formal accreditation or local recognition, thereby developing integration of high standard of best practice through peer example.

The strategy affirms the need to:-

- Reward and recognise good practice
- Build on GSF in Primary care as part of the Next Stage Review
- Develop implementation plan through the RCGP EOLC Working Group
- Use current levers for change e.g. Practice Based Commissioning etc
- Develop plans that relate appropriately to the context of each nation within the UK

b Affirmation and integration within College

Success criteria for affirmation and integration within the college should include:-

- Inclusion of aspects of end of life care in college policy,
- Inclusion of end of life care principles in the educational programmes of the college such as MRCGP, communication skills and e-learning,
- Development of criteria and processes in end of life care for accreditation of practices,
- Rapid response by college to issues raised in the media about end of life care involving the expertise of the RCGP EOLC Working Group
- Involvement in national clinical audits, service development and end of life care research project activity as appropriate through circ
- Inclusion of en of life care issues within college publications if appropriate

c Building on good practice of the Gold Standards Framework in Primary care

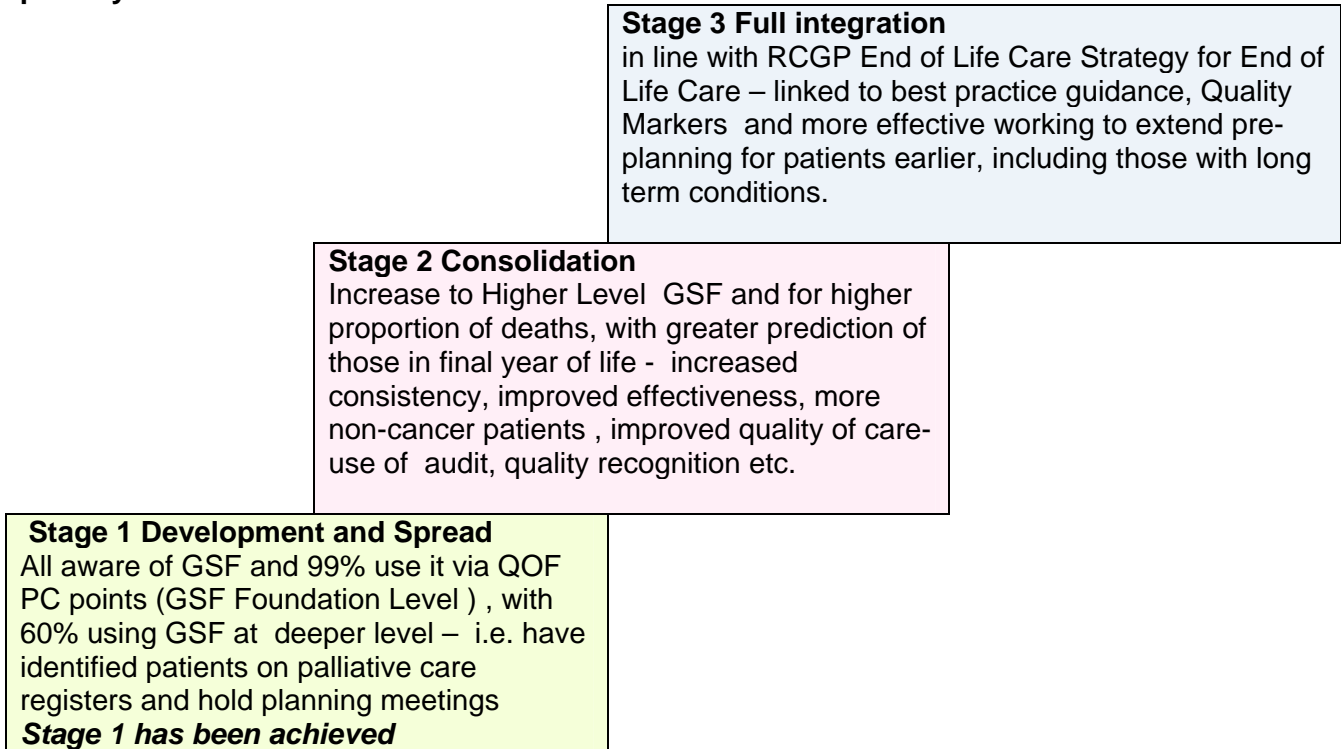
The GSF- Next Stage Working Group (see Fig 3)

The GSF Primary Care Next Stage group undertook an extensive review, literature review and consultation with a number of working groups, including that through the RCGP which led to the launching of Next Stage GSF in June 09. The assessment affirmed that, though much good progress has been made in the UK over the last 9 years of implementing GSF and other end of life care initiatives, there are still significant gaps in four areas:-

1. Consistency of use of GSF in Primary Care
2. Effectiveness of use of GSF across boundaries of care
3. Equity for non cancer patients Inclusion of more non cancer patients
4. Quality of care provided

Most practices have integrated at least ‘foundation level’ GSF as recommended in QOF, but there needs to be a further drive to improve these key areas and update and integrate other improvements. For a review of Next Stage GSF for primary care and examples of tools, resources and new training programme please see website www.goldstandardsframework.nhs.uk

Fig 3 Three Stage Plan of the National GSF Centre towards the future vision of use of GSF in primary care end of life care



d. Developing and piloting new ideas

This presents a good opportunity to pilot and integrate the used of co-morbidity indices in predicting patients with deteriorating illnesses, which is already underway within CIRC’s plans for the coming years.

Plan- to seek funding to

- develop the practical co-morbidity indices
- develop audit measures
- pilot in 2009 to develop learning and evidence base
- Increase use of advance care planning in primary care
- modify and suggest integration into QOF/ NICE recommendations

1) Co-morbidity / Multi- morbidity

Within College, CIRC has already begun work in this area and is committed to taking this forward in future. Though recognised by all as an increasingly important factor, primary care is seen as the best area to consider the effects of co-morbidities in care for patients. The use of a co-morbidity index will support other areas of work undertaken by CIRC and others.

2) Proposed Early Warning Model pilot

A research study to pilot an ‘early warning’ model for pre-planning of supportive care for patients with advancing illness is being proposed, to integrate supportive care thinking and planning earlier in the illness trajectory for the 6 ‘killer diseases’ on the QOF long term conditions registers. Better identification of those approaching the final year of life, building on the GSF Prognostic Indicator guidance, the Needs Support Matrix, and multi-morbidity indices.

3) Development of further audit tools for primary care

Building on the work of the GSF After Death Analysis Tool (ADA), a further tool needs to be developed to anticipate the needs of patients before death, and to trigger appropriate actions.

4) Use of Advance Care Planning etc.

Further integration of advance care planning and use of integrated pathways should be considered by the Working Group over the next year.

5. Detailed Recommendations + Action plan- to be confirmed

6. Conclusion and Next Steps

In conclusion, the College affirms its approval of the RCGP End of Life care Strategy and the development of a working group to take further the implementation plans within the wider context with further consultation and stakeholder involvement.

Key Strategy Recommendations for Endorsement by Council

1. That Council, on behalf of the College, recognises the significance of the challenge of improving end of life care and affirms the importance of this work and continues to make improving end of life care a matter of priority within the work of the College.
2. That Council recommends the establishment of a three year RCGP End of Life Care Working Group in collaboration with other stakeholders such as the RCN, to further develop College policy, thinking and practical implementation of the Strategy. Annual reports will be produced for Council, and a comprehensive College Report on best practice in End of Life Care will be published at the end of the first year. A commitment to support the implementation of its findings and to assess further progress is also recommended.
3. That Council will actively support and integrate the recommendations made below, as a first stage of the three year plan, and will allocate appropriate funding support to the working group when finances allow. Support is also requested for the publication of the report which is designed to enable wider communication and raise the profile of the College.

6. References

DH End of Life Care Strategy - promoting high quality care for all adults at the end of life Published 16 July 2008
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

The DH End of Life Care Programme England
www.endoflifecareforadults.nhs.uk/eolc

RCGP – CIRC End of Life Care Clinical Champion
http://www.rcgp.org.uk/clinical_and_research/circ/clinical_priorities_and_ccs/end_of_life_care.aspx

National Audit Office, End of life care Publication 26 November 2008 HC: 1043 2007-2008 ISBN: 9780102954432
http://www.nao.org.uk/publications/0708/end_of_life_care.aspx

Gold Standards Framework - Thomas K 'Caring for the Dying at Home Radcliffe Medical press 2004
www.goldstandardsframework.nhs.uk

GSF After Death Analysis tool Briefing Paper
<http://www.goldstandardsframework.nhs.uk/images/cmsdocs/ADA%20Briefing%20Paper%20July%202008%20FINAL.pdf>

GSF Prognostic Indicator Guidance Paper
www.goldstandardsframework.nhs.uk/content/gp_contract/PIG%20Paper%20Final%20revised%20v5%20Sept08.pdf

Scotland End of Life Care Strategy www.scotland.gov.uk/Publications/2008/10/01091608/8
www.palliativecarescotland.org.uk/publications/Palliative%20and%20End%20of%20Life%20Care%20in%20

Wales End of Life Care www.rcgp.org.uk/default.aspx?page=5450

Northern Ireland www.allirelandnci.org/programs/palliative_care.shtml

World Health Organization definition of Palliative Care, 2004.
<http://www.who.int/cancer/palliative/definition/en/>

Liverpool Care Pathway for the Dying Patient (LCP)
http://www.mcpcil.org.uk/liverpool_care_pathway

House of Commons Health select Committee
www.publications.parliament.uk/pa/cm200304/cmselect/cmhealth/cmhealth.htm

Darzi Next Stage review End of Life Care
www.ournhs.nhs.uk/ - 22k

Gomas JM (1993) Palliative care at home: a reality or mission impossible? *Pall Med* 7:45-59

Heath I *Matters of life and Death: key writings* Radcliffe Medical Press 2008

Mitchell G (2003) How well do General practitioners deliver palliative care? A systematic review. *Pall Med* 16. 457-464

Thorpe G Enabling more dying people to remain at home *BMJ* 307:915-8

Thomas K 'Caring for the Dying at Home Radcliffe Medical press 2004