

RCGP Position Statement on Palliative and End of Life Care

The RCGP will advocate for the role of the GP in palliative and end of life care delivery, and a consistent approach nationally, by:

- Ensuring that ongoing clinical priorities make due reference to palliative and end of life care.
- Ensuring representation at policy and project meetings that examine and influence aspects of palliative and end of life care provision.
- Supporting professionals with ongoing training at all levels of career development, including the wider agendas of chronic disease management and care and support planning.
- Supporting the call for future investment in primary care to enable the delivery of high quality primary palliative care.
- Supporting the call for future investment and development of the community multi-disciplinary team, including district nurses.
- Supporting the call for national action in palliative and end of life care as a continuum of long term condition management and in cancer.
- Ensuring that palliative and end of life care are covered in the MRCGP curriculum and assessment processes as well as being included as an important part of ongoing postgraduate continuing professional development (CPD).
- Updating current RCGP resources in Palliative and End of Life Care.
- Championing the development of high quality palliative and end of life care for under represented, potentially vulnerable groups of patients, including children and young people, offenders, people with intellectual disabilities and/or autism, the homeless, including the role of the GP in the provision of this care.
- Promoting research into palliative care, particularly in primary care and community settings.
- Developing and supporting a Primary Care Palliative Care Network.
- Working in partnership with other Royal Colleges, particularly with the RCP to ensure that MRCGP remains an entry criteria to specialist palliative care training (advocating for the whole person and family care skills that GPs bring).

RCGP Position Statement on Palliative and End of Life Care

May 2016

The RCGP Position Statement on Palliative and End of Life Care presented here is divided into two sections. Section One provides an overview of current priorities in palliative and end of life care, and overarching priorities for the RCGP. Section Two provides specific considerations for each of the devolved nations of the UK. The Position Statement has been developed through collaboration with representatives from each of the devolved nations, and with a shared vision to provide the best possible palliative and end of life care in primary care.

Section One

Background

500,000 people die in the UK every year; one person every minute, and it is predicted that this number will rise to 590,000 in the next 20 years. There is ongoing variation in the quality of care that people receive as death approaches, raising concerns which have been brought in to sharp focus over the past few years by published reports and high profile media campaigns.

“Care for one another at times of crisis and loss is not simply a task for health and social care services, but it everyone’s responsibility (1).”

As GPs, we have a pivotal role in providing palliative and end of life care for our patients, and their carers and families. GPs are deeply embedded in the community they serve and as such are a focal point for the community, multidisciplinary teams and specialist providers. GPs know the health needs of their local population and are in prime position to engage in public health agendas in palliative and end of life care. The majority of Palliative and End of Life Care services in the UK are provided by generalists.

As patterns of illness change, due to advances in medical treatments and technology, the role of the GP in palliative and end of life care is ever more challenging. Multimorbidity and complexity are rising, and more people, of all ages and with a wide range of conditions, can be considered to have palliative care needs – physical, psychological, social and spiritual (2). Prolonged functional decline results in difficulties identifying the end of life, particularly for those with non-malignant conditions. GPs are more likely to be able to identify patients in the last years of their life, rather than the last year. The RCGP is committed to supporting GPs, through clinical priority programmes in Palliative and End of Life Care, alongside others including Collaborative Care and Support Planning and Mental Health, to develop practical solutions to the clinical, ethical and moral challenges that caring for patients with complex needs and frequent fluctuations in their clinical condition can present. The RCGP recognises local communities as essential partners in providing sustainable palliative and end of life care in the future.

Current pressures in primary care and their effects on the provision of the best quality care to our patients and their families as they deal with the effects of long term illness, death and dying, cannot be ignored (3). The RCGP calls for increased financial and political investment in general practice, and by working in partnership with stakeholders (e.g. other Royal Colleges and voluntary organisations) is highlighting the responsibility of the Government to address the need for improvements in the provision of care for patients with palliative care needs and the dying.

The RCGP will advocate for the role of the GP in palliative and end of life care delivery, and a consistent approach nationally, by:

- Ensuring that ongoing clinical priorities make due reference to palliative and end of life care.
- Ensuring representation at policy and project meetings that examine and influence aspects of palliative and end of life care provision.
- Supporting professionals with ongoing training at all levels of career development, including the wider agendas of chronic disease management and care and support planning.
- Supporting the call for future investment in primary care to enable the delivery of high quality primary palliative care.
- Supporting the call for future investment and development of the community multi-disciplinary team, including district nurses.
- Supporting the call for national action in palliative and end of life care as a continuum of long term condition management and in cancer.
- Ensuring that palliative and end of life care are covered in the MRCGP curriculum and assessment processes as well as being included as an important part of ongoing postgraduate continuing professional development (CPD).
- Updating current RCGP resources in Palliative and End of Life Care.
- Championing the development of high quality palliative and end of life care for under represented, potentially vulnerable groups of patients, including children and young people, offenders, people with intellectual disabilities and/or autism, the homeless, including the role of the GP in the provision of this care.
- Promoting research into palliative care, particularly in primary care and community settings.
- Developing and supporting a Primary Care Palliative Care Network.
- Working in partnership with other Royal Colleges, particularly with the RCP to ensure that MRCGP remains an entry criteria to specialist palliative care training (advocating for the whole person and family care skills that GPs bring).

Definitions -- What is “Palliative and End of Life Care”?

Palliative and end of life care are broad areas of practice, which are applicable across many disease areas. The term “palliative care” is poorly understood by the public, healthcare professionals, and commissioners alike, with frequent associations with cancer and imminent death but not other life limiting conditions (4, 5).

This position statement refers to palliative care as it is defined by the World Health Organisation: “an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual (6).”

The term “palliative care” has become synonymous with end of life care; however the General Medical Council defines people as “approaching the end of life” when they are likely to die within the next 12 months. This includes people whose:

1. death is imminent (expected within a few hours or days)
2. those with advanced, progressive, incurable conditions; general frailty and co-existing conditions; including those where there is a risk of dying from a sudden acute crisis in their condition;
3. and life threatening acute conditions caused by sudden catastrophic events (7).

The WHO definition of palliative care outlines a broad philosophy of care, one that is relevant to all healthcare providers, rather than a particular service offer. “Specialist palliative care services” are defined as those services provided by professionals who have undergone specialist training in palliative care and who are members of a specialist palliative care team, which includes specialists in palliative medicine, palliative nursing and allied health professionals (8).

Assisted Dying

Assisted Dying (deliberately assisting another person to end their life) is illegal in the UK and should not be considered any part of palliative and end of life care.

The RCGP opposes any change in the law in on assisted dying. This is supported by the results of the RCGP 2014 national consultation, which did not provide any evidence of a widespread appetite within the RCGP membership for a shift in the College’s position of opposition to change in the law.

Section Two

This position statement outlines below specific considerations for each of the devolved nations of the UK. Specific developments in palliative and end of life care (2015/16) are described, as well as the commitment of the RCGP to supporting GPs to achieve excellent palliative and end of life care both in practice, and in strategic ambitions.

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England:

The RCGP is committed to palliative and end of life care at the centre of an integrated approach to care and support, and the priorities outlined in Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 (9).

- Each person is seen as an individual
- Each person gets fair access to care
- Comfort and wellbeing is maximised
- Care is co-ordinated
- All staff are prepared to care
- Each community is prepared to help

Each person is seen as an individual

The large majority of deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most recent figures show that 48% of deaths in England occur in NHS hospitals, with around 22% occurring at home, 22% in care homes and 6% in hospices (10-13). Studies continue to suggest however that the preferred place of death for the majority is home.

A proactive approach to care, with the opportunity for individual care planning and open and honest conversations with patients and their families, is necessary. This increasing need is not specific to one disease area or another, or any particular patient group; it is a broad, cross cutting agenda.

Integrating a palliative approach earlier on into chronic disease pathways, rather than just at the end, can improve the quality of the patient experience, and aligns with other RCGP priorities notably Collaborative Care and Support Planning.

Each person gets fair access to care

The RCGP is committed to supporting GPs who care for every member of the population, and to addressing current inequalities in palliative and end of life care provision, particularly in raising the profile for those with non-malignant disease, and for under represented groups of patients with palliative care needs including children and young people, people with intellectual disabilities and/or autism , the homeless, those in prison and those from Black and Minority Ethnic populations.

All staff are prepared to care, and comfort and wellbeing is maximised

GPs and the practice team have the opportunity to identify patients at risk of deterioration towards death earlier on in their illness trajectory, through chronic disease management and the provision of enhanced services to prevent unplanned admissions. The RCGP supports the approach to care for the dying patient described in the Five Priorities for Care (14).

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| IDENTIFY | The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions are made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly. |
| COMMUNICATE | Sensitive communication takes place between staff and the dying person, and those identified as important to them. |
| INVOLVE | The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants. |
| SUPPORT | The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible. |
| PLAN & DO | An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion |

Care is co-ordinated

The RCGP will support GPs as they navigate future information sharing arrangements with other agencies and organisations involved in providing care, such as out-of-hours services, ambulance services and social care organisations, including the implementation of Electronic Palliative Care Co-ordination systems (EPaCCs) as are these developed around the country.

Each community is prepared to help

The RCGP acknowledges local communities as partners in the effective delivery of future palliative and end of life care. Compassionate Communities, Compassionate Cities and the Dying Well Community Charter (15) campaigns call for a paradigm shift within communities to not only normalise death and dying but to also to use empathy and support as a form of health promotion. This will involve closer working with local communities and public health bodies to make end of life care a public health agenda.

What is the role of Clinical Commissioning Groups?

The commissioning and provision of palliative care services is complex. Currently there exists a diverse range of voluntary and statutory providers across sectors, and a complex array of commissioning processes to support these. Services are variable nationally, with a lack of consistent approach and no universal offer of care.

A major challenge for clinical commissioning groups (CCGs) is dealing with the increasing numbers of people with long-term, incurable conditions who are often high users of emergency and unscheduled care services. Developing services and strategies to meet the needs of this heterogeneous, often complex group can be difficult, and requires an integrated approach, to include primary and community care, specialist hospice services and acute trusts, and the interfaces between these services.

CCGs have responsibility, alongside Local Authorities and Health and Wellbeing Boards (HWBs) to develop mechanisms whereby the priorities highlighted in the NHS Five Year Forward View and by Public Health England can be actioned in localities. This will include managing workforce challenges

and the development of new models of care with primary care at the centre, service level agreements (SLAs) between service interfaces.

Local assurance regarding the delivery of high quality palliative and end of life care will be required including:

- Ensuring GPs are aware of local services as well as the referral mechanisms.
- Developing locally relevant EPaCCs systems, linking with the local IT infrastructure.
- 24/7 access to responsive Specialist Palliative Care services when required.
- Ensuring education and training.
- Local clinical leadership and close working partnerships with other engaged professionals (such as Macmillan GPFs) in order that services are developed in a relevant, practical and feasible way.

CCGs have a responsibility to:

- Ensure that palliative care commissioning draws on current best evidence, and to support local research in this area.
- Ensure that palliative care commissioning takes place in partnership with patients and the public who have experience of receiving these services (co-design).
- Share learning from new models of commissioning and integrated care nationally (such as the Vanguard sites).

Northern Ireland:

15,000 people die every year in Northern Ireland; of these 48% currently die in hospital. The number of 85 year olds is set to rise by 50% in the next 10 years, and the number of people dying each year is set to rise by 28% by 2037, the highest rate in the UK (ref). There are large and growing numbers living with complex evolving frailties and co-morbidities.

Strategy in Northern Ireland

Living Matters Dying Matters (16) identified key steps towards achieving planned multidisciplinary palliative care support for all those approaching end of life. Transforming Your Care (17) focussed on the restructuring of services to support those living with medical conditions to receive care and support in the place of their choice and to maximise their independence and integration in community. The development of an integrated approach between patients, carers, statutory services and community voluntary agencies is central to achieving the goals identified by both strategies.

Transforming Your Palliative and End of Life Care (18), led and coordinated by Marie Curie, is a collaborative programme, which has engaged all agencies in agreeing and beginning the implementation of eight key workstreams. These include:

- Improving identification and planning for patients with palliative care needs.
- Enhanced access to palliative care services at home.
- The enhancement of existing Day Hospice Services
- Improved access to Information and support for families and carers.
- Universal access to Palliative Pharmacy
- Training on palliative care and the development of response options for Ambulance Services
- Access to regular training on palliative and end of life care for Healthcare Providers.

Work in Progress

Primary care teams are best placed to identify those with evolving frailties who will benefit from multidisciplinary planned palliative care. They have the opportunity to assess each individual's unique resources and risks and to coordinate individualised care planning with support from specialist colleagues. Use of risk stratification tools, co-morbidity registers and prognostic indicators has improved identification rates, and the use of an Electronic Care Record has greatly enhanced communication at care boundaries. The electronic Key Information Summary, developed in Scotland, was adopted in 2016, and will further facilitate anticipatory planning and coordinated care. Access to 24 hour community nursing services is not yet universal, and is a key goal.

Nursing homes are potential palliative care centres. GAIN regional guidance on palliative care in the Nursing Home setting (19), designed to be used alongside a programme of ongoing education, aims to facilitate the development of a robust culture of generalist palliative care expertise throughout Nursing Homes in NI.

Specialist community palliative care teams provide key guidance, advice and education to all players, including patients, carers and healthcare teams. Access to specialist palliative care advice has improved but gaps remain.

The development of the All Ireland Institute for Palliative and End of Life Care (20) has provided a resource of expertise and innovation which has facilitated creative approaches to deepening awareness, widening public engagement and sharing knowledge.

A draft regional DNACPR policy is currently in consultation. There is no Mental Capacity Act in Northern Ireland. Macmillan's Your Life and Your Choices is a regionally agreed guidance document, which explains the detail of advance care planning and the legal framework within which it exists in NI (21). It is being disseminated as part of regional education initiatives around Advance care planning.

End of Life Care

The LCP is no longer in use in Northern Ireland. The Regional Palliative Medicine Group have developed and widely disseminated Guidance for the Management of Symptoms in Adults in the Last Days of Life. RCGP supports the five priorities for care for the dying as defined in One Chance to Get it Right (14).

Public Health Approaches

For those living at home, the development of supportive and well-informed networks which include families, communities and accessible health and care professionals underpins the successful provision of palliative and end of life care. Access to equipment, practical domiciliary care, information and psychospiritual support are essential components which can only be delivered by a collaborative approach involving statutory services, community voluntary agencies, care providers, and societal groups. RCGP recognises that the vision of a public health approach to palliative care, elucidated by Allan Kellehear and others (1) has been key to inspiring a range of innovative projects to this end. RCGP supports the development of community innovations, such as Compassionate Communities across NI which seek to provide psychospiritual and practical support to those affected by life limiting illnesses.

The role of the RCGP NI in Palliative and End of Life Care in Northern Ireland

RCGP NI recognises the growing importance of palliative and end of life care in current and future health service provision. RCGP has an important role in working with partner organisations to advocate for provision of universal access to generalist palliative care for all those affected by life limiting illness, and for equitable access to well-targeted specialist palliative care.

RCGP NI recognises the integral importance of domiciliary care services to palliative and end of life care at home. RCGP will advocate for the importance of this aspect of care to be recognised valued, and resourced, and supported with appropriate training.

RCGP NI recognises the key role played by acute care services and specialist outpatient services in care planning. RCGP NI will continue to advocate improved communication between secondary and primary care to include:

- Clear identification of those with palliative care needs
- Information on important conversations and care decisions
- Information on patient and carer understanding of diagnosis and prognosis
- Information on current and anticipated problems and suggested management plans
- Individual risks.

RCGP NI will:

- Work to develop a culture of collaborative care planning for those affected by long term conditions and life limiting illness.
- Work to promote Medicines Management among those with palliative care needs, including engaging patients and carers in compliance, encouraging patient activation and education, promoting a key potential collaborative role for pharmacists, and minimising polypharmacy.
- Support campaigns by partner organisations to advocate for improved resourcing of palliative and end of life care.
- Collaborate to provide and promote education programmes on all aspects of supporting those affected by frailty, longterm conditions and life limiting illness.
- Ensure that palliative and end of life care are covered in the MRCGP curriculum and assessment processes as well as being included as an important part of ongoing postgraduate continuing professional development.

- Update current RCGP resources in Palliative and End of Life Care
- Work in partnership with stakeholders (e.g. other Royal Colleges and voluntary organisations) to highlight the responsibility of Government to address the need for improvements in the provision of care for the dying, across health and social care agendas.
- Champion the development of high quality palliative and end of life care for under-represented, potentially vulnerable groups of patients, e.g. children and young people, offenders, the homeless, migrants and those with rare conditions, including the role of the GP in the provision of this care.
- Promote research into palliative care, particularly in primary care and community settings.
- Develop and support a Primary Care Palliative Care Network
- Work in partnership with other Royal Colleges; in particular with RCP to ensure that MRCGP remains an entry criteria to specialist palliative care training (advocating for the whole person and family care skills that GPs bring).

Scotland:

Over 54,000 people die in Scotland every year; one person every minute. It is predicted that this number will rise to 62,000 deaths per year in the next 20 years. Currently it is estimated that 40,000 people per year in Scotland who die will have some palliative care needs. 52% of deaths occur in NHS hospitals in Scotland, with around 25% occurring at home, 22% in care homes and hospices, and the rest elsewhere.

Strategy in Scotland

The Scottish Government published a new strategic framework for action on palliative and end of life care (SFA) in December 2015. This included a vision that everyone who needs palliative care should have access to it by 2021 (37).

The SFA set out 10 commitments to support the delivering of this aim:

1. Support Healthcare Improvement Scotland in providing Health and Social Care Partnerships with expertise on testing and implementing improvements in the identification and care co-ordination of those who can benefit from palliative and end of life care.
2. Provide strategic commissioning guidance on palliative and end of life care to Health and Social Care Partnerships.
3. Support the development of a new palliative and end of life care educational framework.
4. Support and promote the further development of holistic palliative care for the 0-25 years age group.
5. Support the establishment of the Scottish Research Forum for Palliative and End of Life Care.
6. Support greater public and personal discussion of bereavement, death, dying and care at the end of life, partly through commissioning work to facilitate this.
7. Seek to ensure that future requirements of e-Health systems support the effective sharing of individual end of life/Anticipatory Care Planning conversations.
8. Support clinical and health economic evaluations of palliative and end of life care models.

9. Support improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care.
10. Establish a new National Implementation Support Group to support the implementation of improvement actions.

The previous national end of life strategy for Scotland, *Living and Dying Well: A National Action Plan for End of Life Care in Scotland* (22) saw a number of achievements including the development of a national do not attempt resuscitation order (DNACPR) policy (23), which has been implemented across Scotland. It also developed and published *Scottish Palliative Care Guidelines* (24), which are available online to all health and social care practitioners.

The Scottish Government oversaw the phase out of the LCP in 2014 and published new guidance for NHS Boards in December 2014, *Caring for people in the last days and hours of life - National Statement* (25). This National Statement sets out guidance and 4 principles and acts as a framework for further planning and development at a local level across Scotland.

The four principles are:

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| Principle 1 | Informative, timely and sensitive communication is an essential component of each individual person's care |
| Principle 2 | Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion |
| Principle 3 | Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible |
| Principle 4 | Consideration is given to the wellbeing of relatives or carers attending the person. |

In 2010 an Integrated Adult Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and associated Children and Young Persons Acute Deterioration Management (CYPADM) policies were published in Scotland. The purpose of both policies is to provide guidance and clarification regarding the process of making and communicating advance decisions about cardiopulmonary resuscitation treatment and to prevent inappropriate attempts at cardiopulmonary resuscitation which may cause significant harm to patients and their families. Both policies reflect the current legal position following the Tracey Judgement and recent joint guidance published by the British Medical Association, the Royal College of Nursing, and the Resuscitation Council (UK).

The Public Health Agenda and Compassionate Communities

In Scotland the *Good life, Good Death, Good Grief* campaign (26) is working to make Scotland a place where there is more openness about death, dying and bereavement. The campaign aims to make people are aware of ways to live with death, dying and bereavement and make people feel better equipped to support each other through the difficult times. The campaign is a membership organisation made up of individuals and organisations from across Scotland.

Integration joint boards (IJBs) and palliative care in Scotland

Integrating palliative and end of life care earlier on into chronic disease pathways, rather than at the end, can improve the quality of the patient experience, and aligns with the ambitions of the SFA and the new health and wellbeing outcomes published by the Scottish Government that IJBs will need to demonstrate that they are achieving.

Integrating health and social care is one of Scotland's major reform programmes. The 30 IJBs went live in April 2015 alongside the delegated arrangements already in place in NHS Highland and the process of integration was due to was completed in April 2016 IJBs now manage almost £8 billion of health and social care resources, including those associated with 96% of delayed discharge and 83% of unplanned admission for over 75s and palliative care.

Palliative care is one of the functions that has been delegated to the IJBs. IJBs will be responsible for commissioning all palliative care services in their areas, both in acute and community settings. It is possible that across some NHS Board areas, IJBs will pool resources and decision making, so that commissioning decisions are made by one IJB on behalf of one, two or even three IJB. This is still being worked out in a lot of areas and the next 12 months will see discussions taking place between Boards as final arrangements are agreed.

The Scottish Government has published guidance on strategic planning to support the work of integrated joint boards (27). The Government states that strategic plans must deliver better outcomes, particularly for people with multi-morbidities and in terms of improving preventative and anticipatory care, with less inappropriate use of institutional care and better support in communities. IJBs will also be supported by specific strategic commissioning guidance on palliative and end of life care, which is being developed by the Scottish Government and stakeholders following a commitment in the new SFA.

At least one GP must be appointed to serve on each IJB and they are expected to be fully involved in strategic planning and local development plans.

The role of the RCGP in Scottish Palliative and End of Life Care

The RCGP has an important role to support and influence public policy that aims to address more equitable provision of palliative and end of life care. The RCGP will also play a key role in engaging with statutory bodies such as Scottish Government, the Scottish Parliament and independent and third sector bodies to raise palliative and end of life care on the agenda, alongside long term condition management and care planning.

The RCGP should ensure representation at policy and project meetings that examine and influence aspects of palliative and end of life care provision.

- Support the implementation of the Scottish Government’s strategic framework for action on palliative and end of life care
- Ensure that palliative and end of life care are covered in the MRCGP curriculum and assessment processes as well as being included as an important part of ongoing postgraduate continuing professional development.
- Update current RCGP resources in Palliative and End of Life Care, including Commissioning Guidance.
- Work in partnership with stakeholders (e.g. other Royal Colleges and voluntary organisations) to highlight the responsibility of Government to address the need for improvements in the provision of care for the dying, across health and social care agendas.
- Champion the development of high quality palliative and end of life care for under---represented, potentially vulnerable groups of patients, e.g. children and young people, offenders, the homeless, including the role of the GP in the provision of this care.
- Promote research into palliative care, particularly in primary care and community settings.
- Develop and support a Primary Care Palliative Care Network
- Work in partnership with other Royal Colleges in the future development with RCP to ensure that MRCGP remains an entry criteria to specialist palliative care training (advocating for the whole person and family care skills that GPs bring)

Wales:

Over 32,000 people die in Wales every year; equivalent to 82 a day. It is predicted that this number will rise to 35,000 deaths per year by 2037. Currently it is estimated that 6,200 people dying each year in Wales don’t get the palliative care they need. 58% of deaths across Wales occur in hospitals compared to 22% at home. Research tells us that the majority of people would rather die at home surrounded by friends and family, as people grow older however their priorities change and their top priority is to die pain free.

Strategy in Wales

Wales has made considerable progress in the development of palliative care services since the 2008 Sugar report (28), which looked at palliative care services in Wales and made recommendations on how they should be improved. The Palliative Care Implementation Board (now known as the End of Life Care Implementation Board) has overseen important improvements such as increases in the palliative care workforce, better co-ordination of services across the NHS and third sector providers, 24/7 Consultant and nursing services, and improved advice. The most recent National Survey of Patient Activity Data for Specialist Palliative Care Services reflects this progress, finding that Wales has a higher level of specialist palliative care services per 1,000 deaths than England or Northern Ireland (29).

Despite this significant improvement, there are clear indications that palliative care services in Wales are not meeting people’s needs. Equally, people may be spending more time in hospital at the end of their lives than is clinically necessary or desirable.

More than three-quarters of people in their last year of life can expect to be admitted to hospital at least once (13). In Wales in 2012, NWIS data shows that there were a total of 64,305 admissions of people in their last year of life. This is about 8.5% of all admissions (a total of 761,000 in 2011/12) (30). On average a person is admitted to hospital 2.13 times in the 12 months before death. This is similar to the number of admissions per person across England (2.1). NWIS data shows that more than three-quarters of all admissions in the last 12 months of life (76%) were emergencies, compared with 46% of all hospital admissions. Other evidence shows that the number of admissions, and in particular emergency admissions, increases very substantially during the last 3 months and especially the final month of life (31).

In December 2014 The Welsh Government published its first annual report which looked at performance against the 2014 – 2016 End of Life Care delivery plan. A second report has now been published in November 2015 (32), which covers six areas:

- Delivery Theme 1: Supporting Living and Dying Well
- Delivery Theme 2: Detecting and Identifying Patients Early
- Delivery Theme 3: Delivering Fast Effective Care
- Delivery Theme 4: Reducing the Distress of Terminal Illness for Patients and their Families
- Delivery Theme 5: Improving Information
- Delivery Theme 6: Targeting Research

Each Health Board in Wales was required to produce a Plan setting out how it would deliver end of life care services in the context of the Welsh Government's Plan. They are also required to report annually on progress against their plans.

The Welsh Government have extended their Plan to 2020, however it will be subject to a refresh in 2016.

There have been no Health and Social care committee enquiries into Palliative Care or End of life care during the 4th Assembly (2011---2016)

Key developments in Wales

All Wales DNACPR Policy

In 2015, the All Wales DNACPR policy 'Sharing and Involving' was launched (33). The policy was developed by a multi-professional group, and included extensive professional and public consultation. It is applicable to all clinical settings (hospital and community) and all parts of Wales. The aim of the new national policy is to improve the consistency and communication of DNACPR decisions. In particular, the policy introduces the concept of "Natural Anticipated and Accepted Death", with the intention of influencing how professionals approach discussions about resuscitation with individuals. As part of this rollout, a number of videos were produced for NHS Wales by patients, doctors, nurses and healthcare professionals as a co-production between Healthboards and Trusts.

Last Days of Life

Supporting care in the last days of life in Wales is changing to incorporate the recommendations and outcomes of the Neuberger Enquiry 2014 (34) and the NHS Leadership Alliance for Care of Dying people 2015 (14). Although the 'Liverpool Care pathway' (LCP) was not used in Wales, the existing documentation used in Wales (Integrated care Priorities for the Last Days of Life) were reviewed in light of developments in the rest of the UK. As a result new All Wales guidance has been developed that will replace the Last Days of Life Integrated Care Priorities. The Care Decisions guidance represents a patient-centred model of care focussing on communication, comfort and compassionate care for the patient and those important to them wherever possible (35). The new guidance has been developed by a working group set up by the Palliative Care Clinical Implementation Group (on behalf of the End of Life Implementation Board). The work was led by Specialist Palliative Care with support from Primary Care representatives and Third Sector Organisations.

Primary Care Developments

In Wales, a strong emphasis has been placed by Welsh Government on the planning and development of community based services closer to the patient. Part of this process has been the establishment of 'Cluster Groups' made up of GPs, local health care teams, local authority provided services and third sector organisations. Covering population groups of 35,000 to 70,000, the clusters act as local planning groups which mould Healthboard IMTPs to reflect local population needs. Primary Care involvement in this work is supported by the Wales GP contract. The contractual specification requires GP practices to take part in three National Clinical Priority areas (36). One of these is End of Life Care, with all practices being required to carry out reviews of all deaths. The issues and lessons learnt from these reviews are then discussed at cluster peer review meetings, giving individual GPs and practices the opportunity to influence Cluster and Healthboard development plans and services.

The role of the RCGP in Welsh Palliative and End of Life Care

Although recognised as a clinical specialty in its own right, the majority of Palliative and End of Life Care services are provided by generalists. This, and the importance of linking the palliative care and end of life agenda with the role of General Practice in long term condition management and care planning, makes it vital for Primary Care and General Practice to have a strong voice in planning the future of palliative and end of life care service provision. The RCGP in Wales aims to achieve this by

1. Ensuring representation at policy and project meetings that examine and influence aspects of palliative and end of life care provision.
2. Supporting and influencing the Welsh Government's Delivery Plans for Primary Care and End of Life Care.
3. Developing, and encouraging participation by GPs and Primary Care teams in, Primary Care Palliative Care networks (locally, within Wales, and nationally).

4. Supporting professionals with on-going training at all levels of career development, through the provision of educational events and the development of training and educational resources.

Reflecting the RCGP's national priorities in End of Life Care, RCGP Wales will also:

- Ensure that palliative and end of life care are covered in the MRCGP curriculum and assessment processes as well as being included as an important part of ongoing postgraduate continuing professional development.
- Update current RCGP resources in Palliative and End of Life Care, ensuring that relevant areas of divergence between the devolved nations are recognised and highlighted.
- Champion the development of high quality palliative and end of life care for under-represented, potentially vulnerable groups of patients, including children and young people, offenders, the homeless, including the role of the GP in the provision of this care.
- Promote research into palliative care, particularly in primary care and community settings.
- Work in partnership with other Royal Colleges in the future development with RCP to ensure that MRCGP remains an entry criteria to specialist palliative care training (advocating for the whole person and family care skills that GPs bring).

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