

**National Council
for Hospice
and Specialist
Palliative Care
Services**



The **ROYAL**
SOCIETY of
MEDICINE

The Essence of Palliative Care

**A Personal Perspective
by Derek Doyle**

The National Council for Hospice and Specialist Palliative Care Services is the umbrella body for hospice and specialist palliative care in England, Wales and Northern Ireland. Council promotes the extension and improvement of palliative care services. Over the past 13 years Council has done much to encourage and promote good practice across palliative care both nationally and internationally. As a result of this, government, clinical, professional and public understanding has been enhanced. Palliative care is now positioned high on the Government's health agenda, and Council's publications and information on good practice have been disseminated widely.

The Royal Society of Medicine is an independent, apolitical organisation, founded nearly 200 years ago. The Section of Palliative Care aims to promote a scientific approach to, and understanding of, the palliative management of patients, their families and carers. Objectives of the Section include:

- to stimulate research collaboration between Section members
- serve as a link between disciplines in palliative care
- disseminate good practice and establish standards
- to stimulate collaboration with other health disciplines.

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A Personal Perspective
by Dr Derek Doyle



The text of a speech delivered to a Day Conference organised
by The Royal Society of Medicine

Foreword by Eve Richardson, Chief Executive of the
National Council for Hospice and Specialist Palliative Care Services,
and Adrian Tookman, President of the Section of Palliative Care,
Royal Society of Medicine

Foreword

By Eve Richardson

Chief Executive, National Council for Hospice and Specialist Palliative Care Services
and Adrian Tookman

President of the Section of Palliative Care, Royal Society of Medicine

On 13 November 2003 The Palliative Care Section of the Royal Society of Medicine (RSM) organised 'The History of Palliative Care – Looking Back, Taking Stock, Looking Forwards'. This was part of the bicentennial celebrations of the RSM. The eminent speakers included Sir Kenneth Calman, Dr Mary Baines, Professor Geoffrey Hanks and Dr Derek Doyle. These are people who are well known to the palliative care community. They were able to give the audience a unique insight into the birth and development of palliative care. They have made an invaluable contribution to palliative care and we were privileged to share their experiences and their wisdom. The success of palliative care is due to pioneers such as these who had a belief that care for the dying could and should be improved.

The audience heard about the important role of the voluntary sector, the Association of Palliative Medicine and the National Council. The recognition of palliative medicine by the Royal College of Physicians was hailed as a key milestone. The success of palliative care is reflected by the fact that palliative medicine has now become the UK's fastest growing medical specialty.

The opportunity to share the expertise of the speakers was capitalised upon. Each was asked to define the essence of palliative care. This was a challenging task, but the resultant statements may be of value to those who have chosen to be a part of this invaluable, exciting and expanding area of care.

Finally Derek Doyle concluded the day with a personal reflection, his valedictory address, published here in full. Derek has always been a man of enormous wisdom and integrity and this was amply demonstrated in his speech. Derek, we thank you on behalf of us all in palliative care. We owe you a great deal for your contribution to our specialty.

The essence of palliative care:

- Putting the patient first
- Care, compassion and quality of life
- Meeting the needs of patients with advanced disease, and their carers
- The pursuit of the irreducible by the efforts of the unstoppable
- Making people matter
- A model to understand the complex nature of health care
- Relieving total suffering
- Science and compassion, communication and partnership
- Supersensitivity
- Total approach to improving quality of life – particularly in the last phase
- Receiving commitment – for the patient and family
- Having the courage to be inspired and act – for the professional
- Attention to detail.

Speakers: Professor Sir Kenneth Calman, Professor Mike Richards, Professor David Clark, Professor Irene Higginson, Professor Geoff Hanks, Dr Elizabeth Thompson, Professor Baroness Ilora Finlay, Dr Derek Doyle.

Chairpersons: Dr Adrian Tookman, Dr Gillian Ford, Dr Mary Baines, Ms Eve Richardson

Organised by Dr Andrew Davies, past President, Section of Palliative Care, Royal Society of Medicine.

The Essence of Palliative Care – A Personal Perspective

By Derek Doyle

'When any of us are tempted to wonder whatever will happen to palliative care it is worth remembering that our specialty is based on a noble tradition of comforting and caring as much as on scientific evidence.'

Thank you for inviting me. It is a genuine pleasure to be here even if it is a *déjà vu* experience. I feel as though my life has come full circle.

In 1968 when I first became involved in what was then *terminal care* or *hospice care*, I was always the last speaker of any conference or meeting. I got used to the chairman glancing anxiously at his watch and then saying those immortal words. '...and now finally, our last speaker of the day...' (at which point he checked his notes to recall my name.). As the years passed I graduated to become the first speaker of the afternoon '...I know our next speaker will manage to keep us all awake after that excellent lunch' (I didn't). In the past 10 to 15 years I have graduated to opening keynote speaker, which I regarded as an honour until I realised I was the speaker who first discovered that the audio-visual facilities were not all they might be. More recently, in my retirement and anecdotage, I have become a professional chairman. Today, not only will I be your final speaker, probably with nothing new to say, but this will also be my final talk on palliative care.

So as we chairmen always say, 'and now finally...'

Some weeks ago I was indulging my love of history and, on this occasion, the history of Gothic cathedrals. My guide in one of the great cathedrals on the Continent was as enthusiastic and knowledgeable as anyone could be and I had him to myself. For the first time I realised the

parallels between those cathedrals and palliative care.

'Cathedrals were not built on green field sites,' said my guide. *'There had usually been churches there for hundreds of years, falling down and another built in its place, each a little larger and grander than its predecessor until at last the cathedral was built, using much of the stone from the earlier churches as a strong foundation.'*

Yes, palliative care (or terminal care) was not as new as some of us made it out to be in the late 1960s and 70s.

It was built on the foundations of generations of caring, a tradition we sometimes forget. The care being given when we started this work was not always as pharmacologically appropriate as you and I would want today, but nevertheless there was a genuine desire to care better.

I wish I could put back the clock and apologise to those whose professional concern and commitment I doubted when, like many others, I spoke as though terminal/hospice care was a discovery, something we had just invented. When any of us are tempted to wonder whatever will happen to palliative care it is worth remembering that our specialty is based on a noble tradition of comforting and caring as much as on scientific evidence. In fact in those early days there was remarkably little robust evidence. The need was obvious (but not well researched) and we had Twycross's work on

'There was no co-ordination of research, no attempt to explain to politicians and health planners what we were doing.'

morphine and diamorphine but little else in the 1960s.

Palliative care is built on the foundations of:

- A tradition of caring and deep concern that was there long before we came on the scene
- Charismatic leadership – in my view a prerequisite for the development of palliative care anywhere in the world
- Acquired immunity to the professional disappointment, disillusionment and low morale all around us
- A spirit of adventure, discovery and curiosity (of which research is but one manifestation).

Strong foundations, yet, as we all know, even strong foundations can be weakened. In the case of palliative care that will happen if we lose any of the components I have listed or permit boredom or complacency to seep in.

My guide went on: *'It surprises people that though there was a master plan – overall size on the ground, shape and so on – when the work started on any cathedral there was never a detailed blueprint. The precise shape, decoration, type of roof vaulting, type of buttresses, etc – they were worked out as the building went up. Since it took between 150 and 300 years to build such a place, most of the people working on it never knew what it would eventually look like. Generations of builders had worked and died even before they reached roof height!'*

That sounds familiar! Does anyone really think our pioneers knew what the future held or the directions they should take? Few of us who were in this work 25 to 30 years ago ever imagined that today there would be more than 8,000 services in 100 countries, more than 20 professorial chairs, countless journals and a great

textbook. None of us thought there would be so many models of care provision or that palliative care would be included in government strategic plans in so many countries.

It was in 1983 that Robert Twycross, Richard Hillier and I got together in Oxford, concerned about some things that were happening. In terms of our analogy, the foundation was wonderful but the walls looked weak. There seemed to be as many contracts as there were doctors in this work. There were few, if any, education and training standards and no agreed curriculum. There was no co-ordination of research, no attempt to explain to politicians and health planners what we were doing. There seemed too few opportunities for us to get together and share ideas. As pioneers we often felt lonely and needed mutual support. We wondered if others might agree with us that an association for hospice doctors might help us all. A few weeks later, 92 of us met in Birmingham and so was born the APM [*Association for Palliative Medicine*], (and in a sense out of the APM and its sister organisations grew the EAPC [*European Association for Palliative Medicine*], the IAHPC [*International Association for Hospice and Palliative Care*] and our National Council) but even then we had little idea what lay ahead. We had visions and dreams – not blueprints.

Some of you may have presumed that when, in 1986 and 1987, Gill Ford, Graeme Thorpe and I, the team from the APM, negotiated specialty status for palliative medicine we knew what the future held and where palliative medicine would be in 10 or 20 years time. Quite the contrary! I think Gill will agree with me that all we knew was that our work needed specialty status to give it authority, credibility, and standing with our colleagues in other specialties, and with the JCHMT [*Joint Committee for Higher Medical Training*], and a greater chance of getting it into general hospitals and medical school curricula. Far from being clear what our future held, we

'I never thought that our gaining specialty status would make such a dramatic change as it did in our work and how colleagues saw and used us.'

even had to negotiate our name (*Hospice Medicine* and *Terminal Care Medicine* were immediately ruled out as being 'too soft'); try to forecast how many Senior Registrars [SR] would be needed (we grossly underestimated); convince the powers-that-be that doctors would be prepared to make palliative medicine a lifetime career (nearly 30 were already doing so); and convince them that we were serious about what they agreed was a rigorous SR programme proposed by us (incidentally a programme very different from the present ones).

Call me naïve, but I never thought our gaining specialty status would make such a dramatic change as it did in our work and how colleagues saw and used us. Nor did I ever imagine it would so influence the development of palliative care in Australia, New Zealand, the Far East and North America. In the same way I never thought the founding of the National Council for Hospice and Specialist Palliative Care Services and what was then called the Scottish Partnership Agency would so influence the work and lives of colleagues, not only in Britain but around the world. How important it is that we in the UK never forget how, world-wide, colleagues watch us with interest.

What seems important to me is that we do not get upset when some ventures fail, others enjoy short term success, when some reject our teaching and others tweak it to satisfy their dreams of empire. We never had a blueprint. Heretical as it is to say so today, we never did comprehensive needs assessments in those days. We didn't have crystal balls then and we don't need them now, but what we *do* need is highly developed sensitivity to the needs of our patients (which we are now learning to assess), open-mindedness and flexibility.

In other words, to take seriously that mantra we are always chanting – *palliative care is patient-centred care*. As patients' needs change, as they

always do, so we must tailor our work accordingly. Easy to say, but is it not true that world-wide palliative care workers are struggling to re-align and re-focus what they do and how they do it for many groups of people we have overlooked (or should we say neglected) for the past 30 years?

My guide seemed to read my mind. '*The astonishing thing,*' he said '*was that they managed to develop exactly the right type of buttresses or vaulting or ornamentation of the capitals when they got to that point in the building but many of those laying the foundations or putting the first layer of stone had never heard of such things and never seen them. How could they – they had not been invented or discovered then! The miracle of a cathedral is that they adapted and changed, and sometimes had to invent, to meet new needs and problems as they went along. They were not frightened to try something new or just build on to the old when that seemed good enough.*'

I hope that applies to us. Is there a risk that palliative care providers in the developed world are becoming less creative, less imaginative, less flexible, less able to modify old ideas or ways of working, than is desirable? One of the great strengths of the early days was that care and even teaching models were tried, modified, changed again, producing a rich diversity across the country. That took considerable courage. I see a danger in conforming, ironing out differences, striving for standardisation. History has taught me that uniformity is one way to achieve an easier, more comfortable, less demanding life if that is what we seek, but not the way to develop strength. That lies in our ability to live with change and to be courageous enough to be 'different'. As I shall say, I have no doubt that palliative care is different.

'One thing that was exciting,' my guide went on, '*was the vast number of trades and crafts involved in the making of such a place. Few had ever met*

'If they couldn't build a cathedral without a multitude of interdependent craftsmen, all skilled, all dedicated, how can we do it in palliative medicine?'

before, most had no idea how others did their work and, inevitably, there were disputes and quarrels as one group said they were more important than others. Stone masons putting up giant pillars regarded themselves as more indispensable than families of wood or stone carvers or other artisans working away in a corner out of sight of the others and probably seldom spoken to. There are many records of fights and angry disagreements.'

So, multiprofessionalism is not new! What is new is the *interdisciplinarity* we keep speaking of. How do we not only learn better what colleagues can offer and how they work, but how we can support each other? If they couldn't build a cathedral without a multitude of interdependent craftsmen, all skilled, all dedicated, how can we do it in palliative medicine? Perhaps it's worth recalling that in our early days there was a handful of doctors, even fewer social workers, and most units had no physiotherapists, occupational therapists, psychologists or pharmacists, *but* countless nurses were eager to come into this work.

We have done much to highlight the benefits of genuine interdisciplinarity but – dare I say this – today I see more evidence of territorialism than genuine, mutually supportive interdisciplinarity in our world of palliative care. I wonder if we have robust evidence that interdisciplinarity is as useful, nay, as essential as we say it is? When, after all these years we are finding it so difficult, we must be careful never to give the impression to those just establishing palliative care services that interdisciplinarity is both essential and easy to achieve.

'Why did we have to have these massive Gothic cathedrals?' I asked my guide.

'Oh, that's easy. They weren't primarily places of worship for the local people but were built on the highest hill so that from miles around people could

see them and be reminded that there was more to life than money and possessions and the everyday trials of daily life. They stood for hope. Each cathedral was a reminder that there is a higher being and some things in life more important than others. The stained glass windows were story books for the illiterate. The music of the choirboys spoke of angels. The gaudily painted walls spoke of happiness and brightness in an otherwise grey and desolate world torn by war and plague. The clergy trained in this cathedral went out into the little churches and parishes scattered over the land. This cathedral was the powerhouse, the inspiration, the proclamation that there is more to life than we can see or measure.'

No – I'm not suggesting that palliative care was created to remind us of God, though for many of us it does. Nor do I believe it can reverse the secularisation of our society though I wish it could.

What I am saying is that no-one can receive palliative care – and you and I cannot practise it – without being conscious that there is vastly more to life than flesh and blood. One of the few anxieties I have about our work is that in time we will fragment our care as we each become ever more specialised even within our specialty, seeing every aspect of suffering as yet another symptom to be relieved, whether it is constipation or nausea or spiritual anguish. The more members we have in the interdisciplinary team the more tempting it will be to delegate, for example, spiritual care to some other member of the team without knowing how they manage to help. In other words, I fear lest we become no more than symptomologists and prescription writers.

I passionately believe that those who come into our work must themselves be sensitive to spiritual matters, must have had more training in the humanities than people like me ever had,

'Forget those features which make palliative care unique and we shall become... "just another specialty" and our society, our patients and our specialty will be poorer.'

and all of us must be big enough to admit that as yet there are things in this work we can scarcely describe, far less measure. Not for one minute am I suggesting that 'evidence-based medicine' is not important. I am saying there are some things we may never be able to measure. I think Ballint (1964) was right when he said: *'The doctor's best prescription is himself.'* These are profound words which I believe to be true but how many of us know ourselves as we should?

If, as my guide kept saying, the cathedrals were unique, so do I personally believe palliative care is unique (*though, let me hasten to add, we ourselves are not unique at all!*)

Palliative care is unique – not because we work as a team offering holistic care, not because we live with dying and death and despair and cannot cure anyone, not because we lay such store on honesty in all our dealings, and not because we regard communications as at the heart of all we do.

All of these could be claimed by many colleagues in other specialties, and rightly so.

We live in a world characterised (and I believe damaged by) fundamentalism in politics and religion, and by polarised views, where everything is black or white; in a world where image and reputation are all-important; in a world where judgements are often made on slender evidence; in a world which divides people into good and bad, and countries 'developed' or 'developing'; in a world which enjoys discussing rather than practising ethics.

Palliative care reminds us that there are few absolutes in this world, but a thousand shades of grey, and innate good in every single person – good worth looking for and nurturing even in the final days of life. In a world which lays such store on certainty, palliative care proclaims to the

world that Man can live with and even thrive on uncertainty, provided he is respected and – dare one use that debased word – loved, as a fellow human being on this precarious journey we call life. Palliative care proclaims to the world that men and women want to feel not only needed but valued. How we do that remains one of the greatest challenges facing our specialty.

In a world which regards all suffering and loss as disasters to be prevented, removed or hidden, palliative care proclaims that – mysteriously, inexplicably – personal human growth can and often does evolve out of tragedy, happiness out of sorrow. History is replete with examples of how loss, in its many guises, can be profoundly painful, but can be more constructive and liberating than destructive. In a world where, with good reason, we have come to question the honesty and integrity of many around us, palliative care stands out as an example of the power of honesty in all our dealings. In such a world, palliative care is unique because it proclaims that fact and its workers show how Man can live with loss, can even grow as a result. Forget those features which make palliative care unique and we shall become (to quote Michael Kearney's words) 'just another specialty' and our society, our patients and our specialty will be poorer.

I look back on our first 25 to 30 years as challenging, exhilarating and rewarding beyond words, and on my chance to contribute in some way, as more than I ever expected or deserved. In fact that is one of my strongest emotions when I think of palliative care – amazement that so many like myself were plucked from anonymity and obscurity to become contributors to one of the truly great creative movements in modern history: the movement that proclaims that every man or woman is of value, matters and is deserving not only of our skills but of our friendship and our humanity.

'If there is one area where we, in the UK, have not yet done enough, it is in bringing the principles of palliative care to the millions living and dying in Africa, India and South America.'

I have to admit, however, that I have a few anxieties, some of which I have alluded to.

I hope we continue to recognise how privileged we are to be in this work and that we never fall prey to the all-pervasive apathy and cynicism of our modern society, or the disillusionment and disappointment we so often see in our professional colleagues in hospital and primary care. Few are as privileged as us being in at the beginning of something so great, having the chance to model and make something worthwhile and, all the time, serving patients so uncomplaining and so embarrassingly generous in their expressions of gratitude.

I hope we never forget how important it is to be sensitive to need, and courageous and flexible enough to respond imaginatively. Palliative care is nothing if it is not responsive, as well as innovative, ever ready to try something new. We can only be responsive, however, if we possess sensitivity, the hallmark of our specialty. Developing sensitivity in ourselves and in our students must be one of our objectives.

I hope none of us ever loses the sense of excitement that characterised the earlier years. At the same time I hope we are never seduced by the consistently high approval ratings that characterise palliative care. If you are like me, you don't deserve such thanks for providing what should, after all, be the quality of care everyone has a right to. We are, after all, offering no more, and hopefully no less, than what every patient has a right to expect. Providing such quality palliative care will always be taxing but, forgive me saying so, it was hard in 'the old days' too!

I hope we can prevent palliative care becoming yet one more example of Western affluence, sophistication and self-indulgence, and that we find ways of enabling those in the developing

world to adopt the principles and model services that meet their needs and cultures so different from ours, without having to endure our patronising paternalism. If there is one area where we, in the UK, have not yet done enough, it is in bringing the principles of palliative care to the millions living and dying in Africa, India and South America. Europe is now increasingly well served but we dare not ignore the three quarters of the world's population which has no palliative care whilst we have so much.

Perhaps a last word from my cathedral guide. *'It's true that cathedrals have now become little more than tourist attractions, but look at the influence they have had on the world. They have inspired some, trained others, and brought meaning to countless lives. For centuries, they were beacons of hope and love in a dark world. Their importance lies as much in what they have done in the past as in what they are today.'*

Perhaps you disagree with me or are embarrassed by the ramblings of a man in his anecdote. I have to say that I believe we shall be judged in years to come as much by how we have shared our skills and insights as by the treatment we have prescribed or lectured about; by the way we have focused on the whole man when so many others are fragmenting medicine; by how effectively we have worked without looking for reward of any kind.

If we fail, old men like me will go to our graves knowing that, far from changing the world as we might have done, we have created a care philosophy and programme for the privileged, and failed millions less fortunate than even our poorest citizens.

'And now finally...' thank you again for inviting me.

**National Council
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