

PALLIATIVE MEDICINE IN THE UK c.1970–2010

The transcript of a Witness Seminar held by the History of Modern Biomedicine Research Group, Queen Mary, University of London, on 28 February 2012

Edited by C Overy and E M Tansey

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ABBREVIATIONS

AHP	Allied Health Profession
APM	Association for Palliative Medicine
CRMF	Cancer Relief Macmillan Fund
DGH	District General Hospital
DHSS	Department of Health and Social Security
DoH	Department of Health
FFA	Fellow of the Faculty of Anaesthetics
FRCS	Fellow of the Royal College of Surgeons
ICRF	Imperial Cancer Research Fund
IPE	Interprofessional Practice Education
JCHMT	Joint Committee on Higher Medical Training
LOROS	Leicestershire and Rutland Organisation for the Relief of Suffering
MRC	Medical Research Council
MRCGP	Member of the Royal College of General Practitioners
MRCP	Member of the Royal College of Physicians
NICE	National Institute for Health and Clinical Excellence
NSCR	National Society for Cancer Relief
PCT	Primary Care Trust
RCGP	Royal College of General Practitioners
RCT	Randomized Control Trial
SAC	Specialist Advisory Committee
SHO	Senior House Officer
SR	Senior Registrar
UCH	University College Hospital

WITNESS SEMINARS: MEETINGS AND PUBLICATIONS

The Witness Seminar is a particularly specialized form of oral history, where several people associated with a particular set of circumstances or events are invited to meet together to discuss, debate, and agree or disagree about their memories. This format was first used by the Wellcome Trust's History of Twentieth Century Medicine Group in 1993 to address issues associated with the discovery of monoclonal antibodies, and since then more than 50 meetings have been held on biomedical topics. This has proved an ideal way to bring together clinicians, scientists, historians and others interested in contemporary medical history and to encourage the creation and deposit of archival sources for present and future use.

The History of Twentieth Century Medicine Group became a part of the Wellcome Trust's Centre for the History of Medicine at UCL from October 2000 until September 2010. It has been part of the School of History, Queen Mary, University of London, since October 2010, as the History of Modern Biomedicine Research Group, which the Wellcome Trust continues to fund under a Strategic Award entitled 'The Makers of Modern Biomedicine'.

Once an appropriate topic has been identified, often with the help of external advisers, suitable participants are invited. This inevitably leads to further suggestions of people to invite. As the organization of the Seminar progresses, a flexible outline plan for the meeting is devised, usually with assistance from the meeting's chairman.

Each Witness Seminar is fully recorded, the discussion is transcribed and the unedited transcript immediately sent to every participant. Each is asked to check his or her own contribution and to provide brief biographical details. The editors turn the transcript into readable text, and incorporate participants' minor corrections and comments. Biographical and bibliographical details are added as footnotes, as are more substantial comments provided by participants. The final scripts are then sent to every contributor, accompanied by forms assigning copyright to the Wellcome Trust. Copies of the original, and edited, transcript and additional correspondence generated by the editorial process are deposited with the records of each meeting in Archives and Manuscripts, Wellcome Library, London.

For all our volumes, we hope that even if the precise details of the more technical sections are not clear to the non-specialist, the sense and significance of the events will be understandable to all readers. Our aim is that the volumes inform those with a general interest in the history of modern medicine and medical science; provide historians with new insights, fresh material for study, and further themes for research; and emphasize to the participants that their own working lives are of proper and necessary concern to historians.

ACKNOWLEDGEMENTS

The topic of ‘Palliative Medicine in the UK c.1970–2000’ was suggested as a Witness Seminar by Dr Bill Noble and Dr Michelle Winslow and we are grateful for their assistance over several months in planning the meeting. We are also grateful to Sir Kenneth Calman for his excellent chairing of the occasion; Dr William Notcutt for a very pertinent and personal introduction and to Dr Michelle Winslow for her comments and advice on the draft transcript. We also thank several people for providing images and documents for the Appendices: Dr Mary Baines, Sir Kenneth Calman, Dr Richard Hillier, Ms Janet Gahegan and Dr Michelle Winslow, and for permission to reproduce images we thank Dr Mary Baines, Sir Kenneth Calman, Mr Toney Feasey at St Joseph’s Hospice, Hackney, the Wellcome Library, London and Ms Sabine Tuck at the Association for Palliative Medicine. Additionally, our thanks go to Ms Denise Brady, Librarian at St Christopher’s Hospice for help with footnotes, also to several of the Seminar participants for their help with the reconstruction of a short missing section of the recording (pages 53–60).

As with all our meetings, we depend a great deal on Wellcome Trust staff to ensure their smooth running: the Audiovisual Department, Catering, Reception, Security and Wellcome Images. We are also grateful to Mr Akio Morishima for the design and production of this volume; the indexer Ms Liza Furnival; Mrs Sarah Beanland and Ms Fiona Plowman for proof reading; Mrs Deborah Gee for transcribing the seminar and Mr Adam Wilkinson and Mrs Lois Reynolds who assisted in running the meeting. Finally we thank the Wellcome Trust for supporting this programme.

Tilli Tansey

Caroline Overy

School of History, Queen Mary, University of London

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(partially published in volume 27, *Cholesterol, atherosclerosis and coronary disease in the UK, 1950–2000*)
- 2007 **DNA fingerprinting**

The transcripts and records of all Witness Seminars are held in archives and manuscripts, Wellcome Library, London, at GC/253.

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Technology transfer in Britain: The case of monoclonal antibodies

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Monoclonal antibodies: A witness seminar on contemporary medical history

Tansey E M, Catterall P P. (1994) *Medical History* **38**: 322–7.

Chronic pulmonary disease in South Wales coalmines: An eye-witness account of the MRC surveys (1937–42)

P D’Arcy Hart, edited and annotated by E M Tansey. (1998)
Social History of Medicine **11**: 459–68.

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Lock S P, Reynolds L A, Tansey E M. (eds) (1998) Amsterdam: Rodopi BV, 228pp. ISBN 90420 0396 0 (Hfl 125) (hardback). Reprinted 2003.

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Today’s medicine, tomorrow’s medical history

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INTRODUCTION

I am very privileged to have been asked to write an introduction to this monograph, as I have never considered myself to be a specialist in Palliative Care. Throughout my career I have been an anaesthetist with an interest in Pain Medicine,¹ but during that time I set up the Palliative Care Team in the Great Yarmouth and Waveney locality. However, in reading this volume I have realised how much I owe to these pioneers of Palliative Care who themselves came from a variety of backgrounds and developed their interests and involvement as a result of a burning passion to improve the care of the dying.

The more I read, the more I realised that my career had been built on the foundations of knowledge and wisdom from most of the participants of this colloquium, a third of whom I have met at some time over the last 30 years. It has been a fascinating journey of re-discovery to me to read through and re-live this experience.

I was appointed a consultant at a new District General Hospital (DGH) in Great Yarmouth, Norfolk, in 1982. I had had some formal training in Pain Management in Nottingham which did involve seeing patients at a local Hospice Unit and seeing quite a number of patients with cancer pain problems in our various clinics.

One of my reasons for coming to Great Yarmouth was that this was a newly established DGH, with the opportunity to write my own job description. Within a couple of years, I was the 'young Turk' who approached the District Health Authority and the GPs about starting and developing a Palliative Care Service. Eventually, I was given the go ahead to produce a reasonable plan that, importantly, was not going to cost them any money! I spent the next 18 months talking to as many people as possible, both in the locality and afar, trying to find a way forward and to find the fundamental underlying principles that would guide us.

Back at home in Great Yarmouth, our ideas were beginning to come together. Among others, I met with John Talbot In Norwich and Henry Garnett of National Society for Cancer Relief / Macmillan.² Having been told at the outset

¹ Dr William Notcutt participated in the Witness Seminar on 'The Medicalization of Cannabis'; see Crowther *et al.* (2010).

² See pages 12, 17 and 18.

that there was virtually no money, I realised that we needed to invest in people rather than bricks and mortar. The standard model of Palliative Care at that time seemed to revolve around the hospice, but a visit to Thelma Bates and St Thomas's Hospital in London³ made me realise that there were other ways one could go. Visiting patients on the main wards and advising on their care introduced me to the concept of bringing the 'Hospice to the Patient' rather than taking the 'Patient to the Hospice'. I also soon learnt that Palliative Care should be for all patients and not just those with cancer.

Therefore, we decided to base our local service on a specialist team of Macmillan nurses. The team would be embedded within the Pain Service, providing a 'secure' home. This had an unexpected consequence. We were located centrally within the hospital and I later realised that this meant that Palliative Care was on 'Prime Real Estate' and thus making the statement that this was an important service and not relegated to a distant portacabin.

We supplemented the principles above with a further concept, that there were to be no 'No Go' areas. Palliative Care would need to be delivered within the community, in general practice, in outpatient departments, on wards, in the intensive care unit, in nursing and residential homes and within psychiatric services. Naturally, it was going to be impossible to deliver all this agenda at the outset, particularly as we initially only had one nurse. However it set the goals for the future.

We realised though that it was not deliverable unless we had a foundation of developing a strong education programme. Interestingly, the community nurses were the early enthusiasts for this. It was they who were having to deal with the problems of pain and other symptoms in peoples' homes without any significant training in how to deal with these issues. The doctors were much less interested and this needed a different strategy. Their education was undertaken covertly by the Macmillan and Community Nurses, gently giving advice, making suggestions etc.⁴ It is a testimony to our early Palliative Care team that they were able to get hospital doctors, GPs and nurses on their side and mostly supporting the treatment concepts that they were trying to introduce. A growing amount of educational material became available and we even developed our own *Care of the Dying* booklet, customised to our own locality and circumstances and

³ See page 7.

⁴ See Appendix 4.

widely distributed. By the early 1990s this would be well superseded by books by Claud Regnard, Robert Twycross and others who provided a growing volume of literature to support the delivery of basic and specialist palliative care.⁵

In the early 1980s, in North Yorkshire, a group of anaesthetists interested in Cancer and Pain Management had set up an annual three-day conference at Scargill House, near Kettlewell. This attracted 40 to 50 attendees mainly to talk about issues around pain and palliative care. This forum, led by Keith Budd⁶ and colleagues, made it possible to learn and share ideas, particularly as speakers such as Eric Wilkes⁷ came in and inspired and enlivened the sessions. These meetings went on for several years in Yorkshire and elsewhere and provided a source of valuable education at a time when there was little else available.

After a lapse of about 10 years, a group of us restarted the meetings in 1998 under the banner of the Philosophy and Ethics Special Interest Group of the British Pain Society. These stretch across the subjects of pain and palliative care, philosophy, religion and ethics, still with the same interactive and multidisciplinary format.⁸

Within our rural community we already had six ‘cottage’ hospitals functioning as GP units, alongside the main acute DGH. These were all targets for improving Palliative Care, for they were all caring for the dying. For a few patients undoubtedly a traditional Hospice would have been an optimal location for their last days, but I had major reservations because most patients wanted to die at home.

From the late 1980s, various groups within our community would agitate to start fundraising for a Hospice and I became unpopular for my resistance. None of these enthusiasts would undertake a detailed needs assessment of the community along with a properly worked out business case to demonstrate that we should heavily invest all our resources in such a project. Firstly, the cost of building and running such a separate unit would require a large investment which to this day, would have to come entirely from charitable funds. We are

⁵ For example, Regnard and Davies (1992); Twycross (1986; 1994).

⁶ Dr Keith Budd is Emeritus Consultant in Pain Management, Ilkley. In 1988-89, under the presidency of Keith Budd, the Intractable Pain Society and the British Chapter of the International Association for the Study of Pain (IASP) merged into a single, interdisciplinary pain organization which later became known as The British Pain Society. He authored and edited several books including one on Cancer Pain.

⁷ See page 6.

⁸ For the British Pain Society, see page 17.

not a rich community. Secondly, such a unit would take a significant number of experienced nurses out of the surrounding healthcare system, to provide high quality care to a small number of patients. I was very concerned that this would leave a large rump of patients within the hospitals and community with a depleted access to quality care delivered by experienced staff. Therefore, we retained the approach of providing a ‘Ford Escort’ service for the many rather than a ‘Rolls Royce’ service for the few.⁹ A broadly based District ‘Terminal Care’ committee supported this approach.

By the early 1990s we still only had three Palliative Care nurses. They were not only delivering the care across a district with a population of 220 000 but also struggling to lead education locally. However, in the 1990s we were achieving nearly 50 per cent of deaths occurring at home. We struggled to get Palliative Care on the health agenda but saw hospices elsewhere in the wider region receiving the lion’s share of what limited funding there was. We had to continue to go to Macmillan, cap-in-hand, to fund further members of staff. The team expanded slowly and grew to include support staff and therapists whilst also becoming involved in home care and bereavement support. The charity sector has been an essential contributor.

In 2002, I stepped back from leading Palliative Care to focus on research. However, in the last 18 months I have returned to support my colleagues and to help in the development of a new Palliative Care Support Unit at our local Hospital. We still agonise over the care delivered locally and recently our current Consultant Lead asked the challenging question in public as to whether our Hospital was ‘Hospice Friendly’. We still do not have Palliative Care beds, but we have now decided that this is the next logical step, seeing it as a needed service within the acute hospital environment to improve the management of complex problems. Overall our progression has been the reverse way round to most other places.

Palliative Care is still growing, but there are still great gaps in its delivery. Sadly there is still much to be taught and much to learn. The continuing and harrowing examples of those who have missed out on the ‘One chance to get it right’ are still too frequent.¹⁰ Embedding Palliative Care in every area of both undergraduate and postgraduate education is therefore essential but a continuing difficulty.

⁹ See note 171.

¹⁰ Notcutt and Gibbs (2010).

I salute and thank the pioneers of Palliative Care who have struggled through the decades with limited resources and support but with a sustaining passion to improve the care of those with life-limiting diseases. Their work over the last 40 years has brought Palliative Care to the heart of the NHS making the UK a leader in this field. The principles of Palliative Care are as true today as when I first learned them 30 years ago. I commend this Witness Seminar on Palliative Medicine to all.

Acknowledgement

Finally I acknowledge that the real pioneers in our locality over the last 25 years have been Kathy Nobes, Andrea Baxter-Pownall and Gerda Gibbs and their colleagues.

William Notcutt

James Paget University Hospital, Great Yarmouth, Norfolk

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The transcript of a Witness Seminar held by the History of Modern Biomedicine Research Group, Queen Mary, University of London, on 28 February 2012

Edited by C Overy and E M Tansey

PALLIATIVE MEDICINE IN THE UK c.1970–2010

Participants*

Professor Sam Ahmedzai	Dr Richard Hillier
Dr Mary Baines	Dr Andrew Hoy
Sir Kenneth Calman (Chair)	Professor Jane Maher
Professor David Clark	Dame Barbara Monroe
Ms Marjory Cockburn	Dr Bill Noble
Dr Christina Faull	Dr Colin Murray Parkes
Baroness Ilora Finlay	Dr Julia Riley
Dr Gillian Ford	Professor Clive Seale
Mrs Jean Gaffin	Professor Jane Seymour
Dr Paresh Gajjar	Professor Tilli Tansey
Professor Rob George	Dr Robert Twycross
Professor Geoffrey Hanks	Dr Bee Wee

Among those attending the meeting: Ms Janet Gahegan, Mrs Sheila Richards, Ms Sabine Tuck, Dr Michelle Winslow

Apologies include: Dr Sara Booth, Dr Derek Doyle, Ms Heather Enticott, Professor Irene Higginson, Professor Nigel Mathers, Dr David Oliviere, Mrs Marina Phillips, Mrs Jess Wilkes

* Biographical notes on the participants are located at the end of the volume

Professor Tilli Tansey: Since the mid-1990s we've held Witness Seminars as a way of recording the history of contemporary medicine. The theme of palliative medicine was suggested by Michelle Winslow and Bill Noble from the University of Sheffield, and we are very pleased to have had their input in the organization of the meeting. The purpose is to record your comments, your history, your experiences, so please feel free to add a comment. We intend to transcribe, edit and publish this volume and therefore nothing you say will be published without your written permission. Our meetings are all published and are freely available on the web. Two that you might be particularly interested in are 'Innovation in Pain Management',¹ and I know several people at this meeting came to that earlier one, and one held more recently was on the 'Impact of Platinum Salts in Chemotherapy Agents'.² That meeting was chaired by our present chairman, Sir Kenneth Calman, and we're delighted that we've been able to persuade him to come back and chair this meeting today. Sir Kenneth, of course, as you all know, has been Chief Medical Officer of both England and Scotland. He's now Chancellor of the University of Glasgow, where he started his career as a lecturer in oncology. And he's now doing an MLitt there as well. We're delighted that he's taken the time to come and talk to us today and to chair this meeting and to keep you all in order. You might also be interested to know, if you look at the platinum compounds meeting, that he is also a published poet.³ So without further ado, may I hand over the meeting to Kenneth Calman?

Sir Kenneth Calman: Thanks very much Tilli, and welcome to everybody. It's wonderful to see so many old friends in the room here. I've been at a couple of these meetings before and their success depends entirely on the audience. We need to record your thoughts, what happened and when it happened. One of the things I think about palliative care, of course, is that the UK really led the way. Therefore from the 1970s onwards, you can tell me if I'm right about the timing later, the UK really had a major international role in developing palliative care. I began my interest in this as a lecturer in surgery and I came down to the Chester Beatty in 1972 at the Royal Marsden to do an MRC clinical fellowship.⁴ It was great fun: I learnt a lot of immunology, but at the

¹ Reynolds and Tansey (eds) (2004).

² Christie and Tansey (eds) (2007).

³ See Christie and Tansey (eds) (2007): Appendix 1, pages 78–81.

⁴ The Chester Beatty Research Institute in Chelsea (now the Institute of Cancer Research).



Figure 1: Meeting at St Christopher's Hospice c.1976. Clockwise from top: Dr Cicely Saunders, Dr Robert Twycross, Professor Kenneth Calman, Dr Michael Williams (a surgeon from Canterbury), Dr Thelma Bates, Dr Mary Baines, unidentified, possibly Dr Therese Vanier, Dr Tom West.

same time, I went out to St Christopher's Hospice⁵ and met the team there, many of whom are here today. I happened to find a photograph that might interest you (Figure 1). I've identified nearly everybody in the photograph.

After I went to St Christopher's, I was the secretary to a little research group that used to meet about every three or four months in the 1970s, to begin to talk about what kind of research was required and how it could be developed. Which is why I came across this photograph in my bunch of slides and it's remarkable to see it. It was a wonderful experience and I still clutch Colin Murray Parkes' book,⁶ which is on my shelf along with one or two others of other people around this table. I also met another chap in London at the time,

⁵ St Christopher's Hospice, Sydenham, was founded in 1967 by Dame Cicely Saunders and is widely recognized as the first modern hospice; see Baines (2011).

⁶ Parkes (1972).

called Ronald Raven.⁷ Ronald was interesting because he had the concept of rehabilitation of the cancer patient, and that was a novel concept at the time. I thought it was quite an exciting one, so I visited his place, at the same time I went back up to Glasgow, and for some strange reason, at the age of 32, and a registrar in surgery, they made me a Professor of Oncology. I've never quite understood why. It was great fun because there young Sam Ahmedzai came along, and Ilora Finlay was there for a little while too. I think that's where I began to develop further my interest in palliative care. At that time, we set up a thing called Tak Tent, which is an old Scots phrase for 'take care', which was about supportive care for families, and indeed it began in our house in the late 1970s, early 1980s.⁸ I think that's all I want to say by way of introduction for myself except I still continue to have a little interest in this. The National Cancer Research Institute has got two interesting working groups right now: one on survivorship, which I chair at the moment; and the other on end of life care.⁹ And it's important in that the broader community in health across the UK, because it is across the UK, is bringing together the health departments, the research councils, etc. in these two major areas. So let me repeat: this is entirely up to you. Should you wish to talk, please put your hand up, and I hope that we'll get a lot of contributions; we have a flexible outline programme (Table 1). What we have decided to do is to get one or two people to begin the discussion and it's up to you to fill in. Mary Baines is going to open the discussion on doctors and hospices.

Dr Mary Baines: I'm enormously grateful to Professor Tansey and others for putting on this Witness Seminar and for asking me to lead off on the first topic of doctors in hospices. The main part of what I'm going to say is a summary of the replies that I had from 33 doctors who worked at St Christopher's before formalized training was started, and to whom I asked the questions in front of

⁷ Mr Ronald Raven (1904–1991) was Consulting Surgeon at Westminster Hospital (1947–1969) and Senior Surgeon at the Royal Marsden Hospital and Institute of Cancer Research, (1962–1969); see Staunton (1992). His publications on rehabilitation of cancer patients include: Raven (ed.) (1972); Raven (1975, 1986).

⁸ Tak Tent, Cancer Support Scotland, was formed by Sir Kenneth Calman in 1980; see www.cancersupportscotland.org/about-us/history.html (visited 22 May 2012).

⁹ The UK Steering Group for research in survivorship after cancer and end of life care and the UK end of life care Research Interest Group.

<p>Doctors in hospices Who were the doctors? Why practise in a hospice? Where and when did doctors join hospices? What was the role of religious orders, the voluntary sectors, the NHS and the Royal Colleges?</p>
<p>The medical specialty Why was the Association for Palliative Medicine (APM) formed? What was the view of other disciplines and medical specialties? How did academic work begin? How did professional training begin?</p>
<p>Relationships with other professional groups How did multi-disciplinary teams form? How did relationships with General Practice and other specialties develop?</p>
<p>Growing the specialty What was the impact of growth? What was the specialty's contribution to research, education, politics, ethics and public health?</p>

Table 1: Outline programme for ‘Palliative Medicine in the UK, c.1970–2010’ Witness Seminar

us (see Table 1), especially ‘Why practice in a hospice?’¹⁰ However, there were three other important groups of doctors, as well as those from St Christopher’s, that need mentioning. In the early days a number of senior doctors, either consultants or GPs, chose to move to hospices and become medical directors. Their number, of course, includes Professor Eric Wilkes¹¹ and Richard Hillier, who is here. They brought both maturity and their own particular skills. It might be that they lacked training and knowledge, but don’t forget that this was at a time when the knowledge base in palliative care was very small. For example, when I joined St Christopher’s in 1968, Cicely Saunders (Figure 2)¹²

¹⁰ Copies of some of the replies from the doctors will be deposited with other papers from this meeting in Archives and Manuscripts, Wellcome Library, London at GC/253. See also Baines (2012).

¹¹ Professor Eric Wilkes (1920–2009) was a GP in Derbyshire 1954–73, Professor of Community Care and General Practice, Sheffield University, 1973–83 and Medical Director of St Luke’s Hospice, Sheffield, 1971–86. See Ostrovskis-Wilkes (2010). An interview was conducted by the Hospice History Programme in 1995, see www.hospice-history.org.uk/byoralsurname?id=0121&search=w&page=0 (visited 7 January 2013).

¹² Dame Cicely Saunders OM DBE FRCP FRCS (1918–2005) (hereafter Cicely) trained as a nurse, then as a social worker but later read medicine at St Thomas’, qualifying in 1957. She subsequently spent seven years at St Joseph’s Hospice Hackney. She was the founder and Medical Director of St Christopher’s Hospice, Sydenham, from 1967 to 1985 and Chairman from 1985 to 2000. See du Boulay (1984, 2007). She participated in a Witness Seminar on pain (Reynolds and Tansey (eds) (2004)).



Figure 2: Dame Cicely Saunders at the Witness Seminar
'Innovation in Pain Management', December 2002.

gave me this piece of paper entitled 'Drugs commonly used at St Christopher's Hospice.'¹³ 'Mary,' she said, 'this is symptom control. You learn that and put it into practice and you'll be alright.'

The second group of doctors was the researchers, and with Robert Twycross and Geoff Hanks here, I'm going to leave them to expand on those. The third group was very important: these were people who visited hospices and advised us because, with the new medical specialty, there was a major risk that we would be professionally isolated. We guarded against that, and right from the beginning, Colin Murray Parkes came weekly to advise; we had an anaesthetist who specialized in pain control who came every week; Thelma Bates visited regularly to advise on the use of radiotherapy and chemotherapy;¹⁴ and Richard

¹³ For the list of drugs, see Appendix 1.

¹⁴ Dr Thelma Bates (b. 1929) was a consultant radiotherapist and oncologist (later Clinical Director of the Oncology Centre) at St Thomas' Hospital, London, where in 1977 she established the Terminal Care Support Team, the first hospice team in a UK general hospital; see Bates *et al.* (1981). An interview with Dr Bates was recorded by the Hospice History Programme in 1997; see <http://www.hospice-history.org.uk/byoralsurname?id=0007&search=b&page=0> (visited 7 January 2013).



Figure 3: Tom West's leaving party, 6 February 1992, held in Mary Baines' home, at which 17 of the 33 respondents in Mary Baines' January 2012 survey on palliative medicine were present. L to R: Seated: Marie Murphy, Sue Closs, Mary Baines, Kirsty Boyd, Richard Scheffer, Valerie Rowe, Sara Booth. Standing: Louis Heyse-Moore, Tony O'Brien, David Oliver, Stephen Kirkham, Tom West, Michael Kearney, Therese Vanier, Nigel Sykes, Andrew Hoy, John Ellershaw.¹⁵

Carter did symptom-orientated autopsies at St Christopher's where a post-mortem room was built at the time the hospital was built.¹⁶

But now to the largest group; as I said, I circulated 33 doctors who had started clinical work at St Christopher's from 1968 to the early 1990s, all before formalized training was introduced (Figure 3).

Every one of them replied; 100 per cent, and I have here in this pink folder an enormously moving testimony giving the motives that they had for going into hospice medicine.¹⁷ It would take a week then to do justice to this but, with only

¹⁵ Dr Mary Baines wrote: 'The sad thing about [this photograph] is that Cicely was at the party but left earlier before the photo was taken.' E-mail to Ms Caroline Overy, 14 September 2012.

¹⁶ Professor Richard Carter (b. 1934) was a clinical and experimental histopathologist at the Royal Marsden Hospital, London, and Institute of Cancer Research between 1974 and 2001.

¹⁷ See note 10.

a few minutes, I'm going to mention three themes that kept coming up. The first thing that struck me was the number of doctors who had been influenced by the bad death of an individual or sometimes a group of patients. A few quotations: 'When I was a medical student a patient in severe pain told me he wanted to jump in the river'; 'A GP who was dying was lied to by the consultant in order to encourage him'; 'No-one on the GU Unit knew how to relieve pain or help families'; 'The surgical grand round did not acknowledge the terminally ill man but greeted all the other patients cheerfully'. I could go on. Interestingly, no fewer than five respondents had lost a parent from cancer. The second theme that recurs is that poor care is not inevitable – there is a better way. For no less than 50 per cent of this group, this awareness came through exposure to Cicely herself. Two of us were medical students with her. We had no escape. Many others heard her lecture while at medical school. One wrote to me: 'Reading Cicely's writings was like a Eureka moment for me. I thought "This is the kind of medicine I want to practice"'. Others were inspired by different pioneers who they mentioned; some of you here today.

The third thing that is frequently repeated is that hospice medicine is centred on the whole person and family, not the diseased organ. Many referred to Cicely's concept of 'total pain' which she first described back in 1964, with its emphasis on emotional, social and spiritual as well as physical care.¹⁸ A good number of respondents felt, as Cicely herself did, that God was calling them into this work. But these early doctors faced major problems. A move to hospice¹⁹ was considered professional suicide: uncharted territory; bad for your career; and

¹⁸ Saunders (1964a). For a discussion of Cicely Saunders' concept of total pain see Clark (1999).

¹⁹ Dr Mary Baines wrote: 'Cicely Saunders used the word [hospice] in the title of St Christopher's in common with the early hospices such as St Joseph's Hospice. I understand that it means "a resting place for travellers". At the beginning, there was no other word to express the type of medicine, which was practised with the exception of "terminal care". On the whole, people preferred the term "hospice medicine" or simply "hospice". So, a "move to hospice" was not just a change of place but a move to a branch of medicine with no prospects, no career path and it was often considered "professional suicide". In about 1972, Professor Balfour Mount visited St Christopher's. He was a Canadian urological surgeon and he went back to start an inpatient unit in his hospital, the Royal Victoria Hospital, Montreal. He said that he could not use the word "hospice" because, in French, it means something like a workhouse. In addition, it was muddling to think of a hospice inside a hospital. Our librarian [Denise Brady at St Christopher's] thinks that "Palliative Care", the term invented by Balfour Mount, was first used in 1975. So "a move to hospice" is an old term. People would now say that they were going into "Palliative Medicine". And the prospects are now very good!' E-mail to Ms Caroline Overy, 1 October 2012.

dangerous to move out of the NHS. We have so much to thank these doctors for, represented today by Andrew Hoy. As we know, they went on to become the leaders in the new specialty of palliative medicine.

Calman: That's a remarkable introduction: I hope you'll be able to have some way of keeping the replies you received and using them in the future, because they are so powerful.²⁰ The issue of leadership, of personal experience, all comes through very, very strongly. You mention Richard Carter, who was an old friend at the Marsden while I was there and we kept in touch for ages; that's another little link for me.²¹

Dr Colin Murray Parkes: My interest was also triggered by anger. The shock as a young doctor working in a general hospital where I was taught not to get too close to the patients or I'd begin to suffer with them. As a young psychiatrist, I did all the wrong things. I did get close to my patients. I got close to two patients who had both attempted suicide after the loss of a loved person. I got very interested in the developing field of psychology of stress and loss, and felt that this was somewhere I wanted to go. In a way I was in love with medicine. I was also wanting to be a psychiatrist, and I found a way of combining the two, in a sense, when I was invited by Cicely to come and join the staff at St Christopher's as a visitor once a week. I had the great privilege to chair an open meeting each week with all members of staff who wished to come. It was not a management group but it had a great influence on the management, I think. At that time, none of us knew quite what we were doing except Cicely. I can remember discussions about 'should nurses wear uniforms or not?' and 'what should we do when a patient arrives at the hospital? Should the senior nurse remain on the ward and wait for the patient to come up, or maybe continue her ward round with Cicely, or should she immediately break off and go down to welcome the patient in the ambulance?' We adopted the last of these alternatives. It was little things like this, which I think made a great difference to the holistic care that was growing up at that time. My own particular interest in bereavement, in family psychiatry and in the idea of therapeutic communities, all came together at St Christopher's and it was a tremendous privilege to play a part in contributing to that community and to see it develop over the years.

²⁰ See note 10.

²¹ See note 16.

Baroness Ilora Finlay: I think there was an interesting effect right across the UK that was happening at that time, because those of us that weren't in London – I was down in Cardiff at the time – were aware that we also had a sense of indignation at our own impotence in looking after patients, a sense of anger at our own inability and seeing things done around us, or not done. Mostly it was 'omission through fear' in colleagues and that something had to change. So, that was acting as a catalyst and in the very early 1980s, I think it was about 1980, there were four of us down in South Wales who had by osmosis picked up what was going on elsewhere. There was Deidre Hine, who later became Chief Medical Officer; Peter Beck, a senior physician at the time, who is now the Lord Lieutenant after his retirement; there was myself and Nigel Stott, who was later to become Professor of General Practice in the area.²² We all met in my little house. I didn't have enough chairs so we sat on the floor with a cup of coffee and decided that we had to do something about the way people in South Wales were dying. I think we were also inspired a bit by Julian Tudor Hart, his theory of the Inverse Care Law,²³ and that kind of thinking that was going on. There was a sense that actually things could perhaps be different even though we really didn't know what to do. That led to our own education at that time. So the motivation was, I think, much wider than the group that you may have been looking at. What I find interesting is now that we've been teaching doctors from around the world with distance learning, and we've had several thousand through, that motivation of 'I don't feel able to do what I want to do', 'I feel angry at what I have seen', 'I want to change things', is still a very strong motivator in people who are coming forward now to learn. So in a way we may think that we are somewhere but I think we're at the beginning of a very long journey.²⁴

²² Dame Deirdre Hine (b. 1937) was then a specialist in community medicine; she was Chief Medical Officer, Welsh Office (1990–1997); Peter Beck (b. 1941), Lord Lieutenant for South Glamorgan since 2008; Nigel Stott (b. 1939) was Professor of General Practice, University of Wales College of Medicine (1986–1999).

²³ 'The availability of good medical care tends to vary inversely with the need for it in the population served.' Hart (1971): 405. Julian Tudor Hart (b. 1927) was a GP in South Wales from 1961 to 1988; from 1968 he conducted independent epidemiological research population-oriented service innovations. He contributed to the Witness Seminars on 'Population-based Research in South Wales' (Ness *et al.* (eds) (2002)) and 'Research in general practice' (Tansey *et al.* (eds) (1998)).

²⁴ See page 77.

Dr Robert Twycross: I'm fascinated by this topic of how it all began. We know that Cicely was the key person, and possibly most of us in this room are here because of her, directly or indirectly. There are other names from the early 1970s – I don't know whether there are people here who can fill in the gaps. Thurstan Brewin, a radiotherapist in Glasgow, who was probably instrumental in getting the Marie Curie Cancer Care to transform its nursing homes into fully fledged palliative care units with specialist medical staff.²⁵ I'd love to know what people remember about Thurstan and his contribution.²⁶ And Ronnie Fisher, an anaesthetist whose vision led to the first Macmillan unit opening in Christchurch, Dorset in 1975. He approached the National Society for Cancer Relief (NSCR), now Macmillan Cancer Support, for assistance, hence the name Macmillan Unit. Because he appealed to the NSCR, Major Henry Garnett, the Chief Executive, also caught a vision.²⁷ When Major Garnett took over as Chief Executive in about 1970, the income for Macmillan was about £100 000 a year. Within a few years, that figure had increased to more than £1 million a year, a tremendous achievement. With the help of Sir Michael Sobell,²⁸ the new president of the NSCR, so-called Continuing Care Units were soon set up in Northampton, Southampton, Oxford and Northwood. It is important to emphasize the tremendous catalytic effect that NSCR/Macmillan Cancer Support has had, and is still having, in relation to the provision of palliative care in the UK. Without its input, what could I or Richard Hillier have done?

²⁵ Dr Thurstan Brewin (1921–2001) was a Consultant at the Institute of Radiotherapy and Oncology, Glasgow from 1961; he was later Deputy Director, and Director from 1985 until his retirement in 1987. He was subsequently Medical Director of the Marie Curie Foundation; see Rees (2008).

²⁶ Dr Gillian Ford wrote: 'Dr Brewin was a help but Major General Michael Carleton-Smith, the new CEO of Marie Curie was greatly influenced by Cicely and changed the role of the charity's care homes to that of hospices.' Note on draft transcript, 14 April 2012.

²⁷ Dr Robert Twycross wrote: 'This led to palliative care facilities being built in various parts of the country in the mid- to late 1970s and 1980s, and the parallel establishment of the Macmillan Nursing services, and much else besides.' Note on draft transcript, 10 April 2012.

²⁸ Sir Michael Sobell (1892–1993) was an industrialist and philanthropist who made his fortune through the manufacture of radio receivers and television sets. In 1962 he set up the Anne and Michael Sobell Trust (the Sobell Foundation since 1977) to support health, medical, housing, education and youth charities. In 1966 the Trust paid for the offices for the National Society of Cancer Relief (NSCR) in Dorset Square, London NW1, and gave £200 000 each to the Michael Sobell Cancer Hospices at the Mount Vernon Hospital, Northwood and the Churchill Hospital, Oxford. He was president of the NSCR from 1967 to 1984. See Davenport-Hines (2004).

I'm also interested to know how Eric Wilkes got his vision in Sheffield.²⁹ Were these all spontaneous events dotted around the country or were they in some way linked to Cicely?

Dr Gillian Ford: I think it's sometimes forgotten that the hospice world, and particularly St Christopher's, had a huge amount of support from the Department of Health. Sir George Godber,³⁰ the Chief Medical Officer, was certainly a fan, but perhaps more important was Dame Albertine Winner,³¹ who was able to do a little bit of pushing and shoving when needed. It didn't rest only with those two. The first Chief Scientist at the Department of Health and Social Security (DHSS) was Dr Richard Cohen³² and, in the late 1960s, early 1970s, he was keen to evaluate the work at St Christopher's Hospice, particularly the home-care side, and supported, through special funds, Colin Parkes' work on bereavement during the early 1970s in the context of an 'experimental domiciliary service for patients in the terminal stages of illness'.³³ That was indicative of the Department's support and, of course, it reached as far as Ministers and Secretaries of State, who were very proud to say that hospice work had been exported successfully throughout the world thanks to what was going on in the UK.

²⁹ See pages 14–15.

³⁰ Sir George Godber (1908–2009) was Chief Medical Officer from 1960 to 1973.

³¹ Dame Albertine Winner (1907–1988) was a physician and administrator; she worked in the Ministry of Health from 1947 to 1967, becoming Deputy Chief Medical Officer in 1962. She supported Cicely Saunders' plans for St Christopher's Hospice and after her retirement in 1967 became the first Deputy Medical Director at St Christopher's, Chairman in 1973 and President in 1985. See Saunders (2004).

³² Dr Richard Cohen (1907–1998) joined the Medical Research Council (MRC) in 1948 where he became Deputy Chief Medical Officer, MRC (1957–1962). In 1962 he moved to the Ministry of Health (Department of Health and Social Security from 1968) with a specific brief to develop Health Services Research (the work of Dr Murray Parkes on evaluating St Christopher's bereavement service was part of the Health Services programme). He then became Deputy CMO until 1972. He was the Department's Chief Scientist, DHSS, from 1972 to 1973 when he was succeeded by Sir Douglas Black.

³³ Sir Keith Joseph, the Secretary of State for Social Services, DHSS (1970–1974), stated that 'The evaluation of an experimental domiciliary service for patients in the terminal stages of illness is being undertaken by Dr Cicely Saunders as part of a programme of work associated with the out-patient clinic at St. Christopher's Hospice and is supported by my Department at a cost of about £5,500 per annum. The service covers patients normally resident in the eight boroughs surrounding St Christopher's.' Hansard, Written Answers (Commons) of 17 December 1971, Social Services, Home Terminal Care (HC Deb 17 December 1971, vol 828 c220–c222W), online at http://hansard.millbanksystems.com/written_answers/1971/dec/17/home-terminal-care (visited 24 July 2012). For Dr Colin Parkes' work see Parkes (1979a and b).

Professor Sam Ahmedzai: I must say I feel very much in awe sitting amongst everybody that we've got here today. I also want to say that, although all roads lead to London, actually there were pockets of interest elsewhere. Although a lot of my junior colleagues regard me as quite ancient, I'm actually quite pleased to say I was in the second wave. I wasn't in the very first wave, so I can't comment on the sort of questions that you've raised, because I wasn't there. But I did come along in the second wave and I put this down to my contact with Ken, when I was your Senior House Officer (SHO) in Glasgow. It was after I moved from Manchester to Glasgow when I worked with you, Ken, and you took me under your wing and brought me down to St Christopher's. I have to say, I'd never even heard of St Christopher's at that point when I was an SHO in oncology, and through that contact I went to a couple of research meetings, and I was again, in awe. I heard you, Robert [Twycross], speaking at a meeting and I thought, 'Wow, this is something that I'd like to get into.' I want to mention another name, which I hope will come up sometime, and that's Kerry Bluglass, who was the Director of Education then.³⁴ If you want to know why people join hospice, it was due to Kerry that I was put in touch with the Leicestershire Hospice; in fact, I got head-hunted for that job because I was all set to go and become a chest physician, and I was whisked off to start a new hospice at Leicester.³⁵ I put that down to Kerry and the sort of cabal of people at St Christopher's who captured my imagination back in the early 1980s.

Calman: These personal links will come up all the way through; people you've met and worked with and talked to give you the catalyst for change in one form or another.

Marjory Cockburn: I'm speaking as a nurse and from my experience at St Luke's Hospice, Sheffield. It has been mentioned that it would be interesting to know how Eric Wilkes became involved with hospice.³⁶ Eric trained at St Thomas' Hospital. He knew Cicely Saunders personally. He knew what her feelings were about care of the dying. He followed closely all that she was doing, and when

³⁴ Dr Kerry Bluglass is a Consultant Psychiatrist and Senior Clinical Lecturer at the University of Birmingham. Her interests include bereavement, child abuse and fabricated illness. She was appointed as the first Director of Studies at St Christopher's in 1981.

³⁵ Professor Sam Ahmedzai was Medical Director of the Leicestershire Hospice for nine years.

³⁶ See page 13.

she started raising money to open St Christopher's, he was working in a large Derbyshire practice, he persuaded the doctors in Sheffield to do a survey of the needs of dying patients. He also did it with the GPs, and the results were analysed and showed a desperate need for a similar facility in Sheffield.³⁷ So eventually the money was raised and St Luke's was open in 1971. St Luke's, in fact Sheffield, in those days, was very slow to take on anything new and Eric was thought to be mad, completely dotty, and didn't know what he was doing. On the day that St Luke's opened, the headline in the local press was: 'Abandon hope, all ye who enter here', which took some getting over. Education started at St Luke's almost immediately through Eric and the teaching of medical students, and also through our first matron, Eileen Mann, who was a registered tutor and realized that the only way to spread the word of hospice care was by teaching.³⁸ So, from the word go, the doors were open to students and people from all over the world. Let's remember that it was in this country that we taught the Americans about the care of the dying, so we had a continual flow of Americans, others as well. That was how St Luke's got started, and the education went on daycare, grief forum, a whole procession of different innovations that, of course, were spread around the country. Now fortunately, hospice care, palliative care, is much more accepted.

Calman: So many things that I'd like to comment on but I'm going to shut up.

Mrs Jean Gaffin: My formal association with palliative care didn't start until 1991, but because we're talking of St Christopher's and because nobody's talking about patients, it was around 1970–72; I had a neighbour who went into St Christopher's, and I visited him. I asked his wife on the way there: 'What's the difference? Why is he not in St Helier?'³⁹ Why is he in this place called St Christopher's which is so difficult to get to?' And she said: 'When he went into St Christopher's, they cut off his number tag on the wrist and said, "You're not a number; you're a person"'. And I've never forgotten that remark.

³⁷ See Wilkes (1964, 1965).

³⁸ Eileen Mann (d. 2011) was a ward sister at St Thomas' Hospital, London, when Eric Wilkes was a medical student there. She was the first Matron of the St Luke's Hospice from 1971 to 1976 and was instrumental in setting up the St Luke's Education Programme for training nurses in palliative care. See Anon (2011).

³⁹ St Helier Hospital, Carshalton, Surrey.

Professor Jane Maher: You were mentioning Henry Garnett, and I thought I would bring Jennifer Raiman⁴⁰ into the mix, who was an important person in recognizing the need for the voluntary sector to support doctors: doctors' training, consultants, senior lecturers. Probably she was one of the most influential people within Macmillan in actually focusing on the fact that we needed both doctors and nurses in terms of that process. I think at one point during Jennifer's time at Macmillan, between 25–50 per cent of trainees and doctors were being funded by the charity, and I think she's probably an unsung hero in the mix.

Professor Geoffrey Hanks: A comment about the fact that there were obviously other developments going on at the same time, apart from the founding of hospices and palliative care. One of the relevant developments was the emerging interest in the treatment of chronic pain and the setting up of pain clinics, which also happened in the 1970s. The first inpatient chronic pain unit in the UK was in Oxford and run by John Lloyd.⁴¹ I think an interesting comparison could be made of the progress of these two new specialist areas.⁴² The medical discipline of palliative medicine managed in a relatively short period of time to become recognized as a new medical specialty with a four-year higher specialist training programme.⁴³ In comparison, particularly with chronic pain, the chronic pain doctors have struggled to get this area of interest recognized, though the case was equally strong. There are likely to be many reasons for this: to start off with I think there's no doubt that having two or three Deputy Chief Medical

⁴⁰ Professor Jane Maher wrote 'Jennifer Raiman was initially trained as a psychologist and headed up Macmillan medical services from the early 1980s until the late 1990s until Macmillan's first Chief Medical Officer was appointed.' E-mail to Ms Caroline Overy, 22 October 2012.

⁴¹ The anaesthetist Dr John Lloyd opened the Oxford Regional Pain Clinic Unit in 1970. For pain clinics, see for example, Lloyd (1980, 1982). In 1979, David Bowsher, Sam Lipton and Peter Buxton established the Pain Relief Foundation (PRF) in Liverpool, a charity devoted to research into pain and its treatment, which funded the Pain Research Institute at Liverpool University from 1981; see www.liv.ac.uk/pri/html/institute (visited 14 August 2012).

⁴² Professor Geoffrey Hanks wrote: 'They overlapped to some extent because cancer pain was the most common symptom problem for patients in hospice care and initially was also the most frequent reason for referral of patients to pain clinics.' Note on draft transcript, 17 October 2012.

⁴³ Professor Geoffrey Hanks wrote: 'With the considerable help of Macmillan Cancer Relief Fund who provided pump-priming grants to set up new Senior Registrar Training Programmes the first wave of ten posts were inspected and approved by the Joint Committee on Higher Medical Training of the Royal Colleges of Physicians within four years of recognition of palliative medicine as a subspecialty of general internal medicine.' Note on draft transcript, 17 October 2012.

Officers on the weekend rota [laughter] was actually quite a useful ploy.⁴⁴ One of the things that characterized Cicely was that she had an incredible knack of surrounding herself with very effective people. The parallels with pain clinics emphasize what extraordinary progress palliative care made in those early days.⁴⁵

Twycross: A few disjointed comments: the Intractable Pain Society (now the Pain Society)⁴⁶ was founded in 1967, the same year as St Christopher's Hospice. The Intractable Pain Society was entirely anaesthetists for several years – I think I may have been the first non-anaesthetist to join it. Going back to the doctors that Mary spoke about: I do hope that all these comments could be collated and put together as a sort of insert in the report because it does seem to be so valuable.⁴⁷ But I would like to know how old they are; were they the youngsters who were coming in? What about all those oldsters? We've half touched on the oldsters but in this week's *BMJ* (*British Medical Journal*) there's an obituary to John Talbot.⁴⁸ He was born in 1923 and died last November. He was a consultant bacteriologist at Kingston General Hospital, yet he became involved at St Christopher's. What on earth would make a bacteriologist, well established in his post, start volunteering at St Christopher's, and eventually become the first medical director of Priscilla Bacon Lodge in Norwich?⁴⁹

Hospice palliative care was initially a protest movement against medical neglect in the post-war years when medicine began to evolve into the sort of specialty it is now. As doctors had more they could do to cure, then the dying presumably

⁴⁴ Dame Albertine Winner (see note 31) and Dr Gillian Ford.

⁴⁵ Professor Geoffrey Hanks wrote: 'The pain clinic experience emphasizes how difficult it is to achieve recognition and specialty status and the management of pain, both acute and chronic, is now recognized as a specialist area with its own faculty within the College of Anaesthetists which was established in 2007.' Note on draft transcript, 17 October 2012.

⁴⁶ 'The British Pain Society aims to promote education, training, research and development in all fields of pain. It endeavours to increase both professional and public awareness of the prevalence of pain and the facilities that are available for its management'; see www.britishpainsociety.org/about_what_is_bps.htm (visited 21 June 2012); see also Reynolds and Tansey (2004).

⁴⁷ See note 10.

⁴⁸ Blake (2012).

⁴⁹ Dr John Talbot became Director of Priscilla Bacon Lodge, the inpatient unit at the Priscilla Bacon Centre for Specialist Palliative Care Services, Norwich, in 1980. From the mid-1950s he had become increasingly interested in palliative medicine and as an active member of the Church of England was ordained in the late 1970s.

got more and more neglected. Maybe, if there hadn't been a Cicely, other people would have started what became palliative care in protest. Bad death, neglect, the anger would have sprung up in other places. So it could be that some of these early pioneers that I've already alluded to, could have reacted in the anger of compassion quite independently because of the general trend towards cure within the medical profession.

Calman: There are other issues to pick up on for this session: the role of religious orders, if there was any; the voluntary sector; the NHS; the Royal Colleges. Comments on that I think would be very helpful too.

Baines: Picking up from Robert, I personally don't think it was neglect. I think it was that people genuinely felt that giving, for example, injections of morphine only when the pain was unbearable was the right way to do it because they feared addiction and they feared tolerance. So I don't think it was neglect, Robert; it needed Cicely's work and your work to prove that regular giving was safe and effective.⁵⁰ John Talbot, yes, I saw his obituary. He was indeed a bacteriologist but he never worked at St Christopher's. He may have done a week or so with us on a course, but he went to be a medical director⁵¹ and brought his own expertise. I remember very well, at an early conference, asking him to speak about unpleasant smells in fungating wounds, because that was tapping into his particular expertise, and a great lecture it was.⁵² People came with their own expertise: Anthony Smith was an orthopaedic surgeon and wrote a chapter on pathological fractures.⁵³ The group which I have [of 33 respondents] are all ages,

⁵⁰ Dr Mary Baines wrote: 'Cicely's work was detailing her experience with giving regular strong opioids which she had learnt at St Luke's and applied at St Joseph's. She wrote this up in these two early publications: Saunders (1960 and 1964b). But she knew that these were her clinical impressions and needed scientific research so she appointed Robert Twycross to conduct research at St Christopher's.' See also Saunders (1976); Twycross (1974, 1975).

⁵¹ At Priscilla Bacon Lodge. See note 49.

⁵² Dr Mary Baines wrote: 'I have been in touch with the librarian at St Christopher's about this but she does not have records of the early Therapeutic conferences where John's work was presented. And we didn't write things up much then. But the point of this statement was to emphasize the different backgrounds of doctors entering hospice in the early days. This contrasts greatly with the structured training given now.' E-mail to Ms Caroline Overly, 14 September 2012.

⁵³ Dr Anthony Smith worked as a missionary doctor and later in orthopaedics. In 1984 he was appointed Medical Director of St Francis Hospice, Romford and then was Director of Studies at St Christopher's from 1989 to 1996.

but they are people who worked at St Christopher's, as distinct from people who came on a course. The oldest person, Therese Vanier,⁵⁴ is in a nursing home now. She's one of my 33.

Dr Bill Noble: I was talking to Eric Wilkes, shortly before he died, about his motivations for founding St Luke's in Sheffield, and I think his answer gives some insight as to the nature of neglect, not so much personal or on the physician's part, but sort of institutional. Once he'd understood what could be done for the dying, he put it into practice in the local community hospital in Bakewell where he had patients as a GP. His main question at that point was, 'Well, how can my colleagues in the city do the same?' Really the answer was that they couldn't because they weren't able to look after inpatients. And so his surveys of dying in cities showed some difference between his experience in rural practice and urban practice.⁵⁵

Dr Andrew Hoy: I wanted to mention one or two people particularly who I think should be mentioned and haven't yet been. To reiterate what Mary Baines was saying: I think many of us in the late 1960s and early 1970s were dissatisfied with what we saw, and that was when I was a medical student. We were indeed influenced by charismatic people, particularly Cicely. I must have heard her speaking in about 1968 or 1969, at a lecture organized by the London Medical Group.⁵⁶ There were then 12 medical schools in London, and the London Medical Group was an inter-collegiate organization that had been put together by a clergyman, the Reverend Ted Shotter, who later retired as Dean of Rochester.⁵⁷ He was remarkable because he managed to attract really very senior charismatic speakers and would put on seminars, lectures, grand rounds, all sorts of things, over the academic term to which anybody could come; 'anybody' generally meant

⁵⁴ Dr Therese Vanier was a Consultant Haematologist and trained with Dame Cicely Saunders at St Thomas' Hospital in the 1950s; she worked at St Christopher's from 1972 to 1988.

⁵⁵ For Eric Wilkes' surveys, see for example, Wilkes (1964, 1965, 1984).

⁵⁶ The London Medical Group was set up in 1963 as 'an independent, non-partisan student group for the study of issues raised by the practice of medicine which concern other disciplines'; it ran until 1989. See Reynolds and Tansey (eds) (2007) especially, Appendices 1, 2 and 3.

⁵⁷ The Very Rev. Edward Shotter (b. 1933) was the Director of Studies of the London Medical Group (1963–1989), Director of the Institute of Medical Ethics (1974–1989), and was Dean of Rochester (1989–2003). He participated in the Witness Seminar on 'Medical Ethics' (Reynolds and Tansey (2007)); see pages 7–8 for his setting up of the London Medical Group.

medical students, nursing students, allied health profession (AHP) students, but there were other people that came from outside the caring professions as well. I certainly think Ted Shotter was knowingly responsible for all sorts of interesting, innovative ideas. That was the first time I came across Robert Twycross and he, and particularly Lord Amulree, were very interested in what was later known as the Society for the Study of Medical Ethics.⁵⁸ So there was an ethical imperative that used this dissatisfaction to interest people at an impressionable age, namely medical students like myself. The other interesting thing was that, in retrospect, St Christopher's really had only been born, but it had such a long gestation that the ideas had been really very well developed. Although Colin Parkes was talking about the ways the discussions went at St Christopher's in the early days, about 'what should we do to this, that and the other', particularly the way of carrying on, it seemed, to an outside young medical student, that actually there was a very clear vision, a very well-developed vision, about what had to be done at St Christopher's. One of the things that had to be done was that it had to be outside of the NHS. It couldn't be associated with the dissatisfaction within the NHS. The other point I wanted to make was that fairly soon after St Christopher's started, there was a move towards integration with other mainstream specialties in medicine, such as oncology, and indeed clinical pharmacology: Robert Dickson, at Mount Vernon Hospital, was an oncologist.⁵⁹ Thurstan Brewin⁶⁰ has been mentioned and so has Thelma Bates.⁶¹ They were all mainstream clinical oncologists who were dissatisfied with the end of life care that they saw in their own beds with their own patients, and became interested in seeing what this new way of caring for patients was about. They were very important, in the mid-1970s, in integrating the philosophies and ideas back into the NHS, which I'm sure we'll come onto in a second. The other linkage, which I think was so very important for me, was the linkage with clinical pharmacology. There were characters such as Duncan Vere, Robert Twycross and

⁵⁸ Basil William Sholto Mackenzie, Baron Amulree (1900–1983) was Chairman of the governing body of the London Medical Group 1968–1981. The Society for the Study of Medical Ethics (The Institute of Medical Ethics since 1984) was founded in 1972, deriving from the London Medical Group and similar groups in British centres of medical education.

⁵⁹ Dr Robert Dickson, a former consultant radiotherapist at Mount Vernon Hospital, Northwood, was Medical Director of the Michael Sobell Hospice at Mount Vernon Hospital.

⁶⁰ See note 25.

⁶¹ See note 14.

later Andrew Herxheimer,⁶² who were mainstream clinical pharmacologists, and quite often academics, who wanted to put academic justification to what was going on, or certainly to investigate what was going on. That was very important for junior doctors and medical students.

Calman: Two quick comments on that. First of all, quite often through the ethics part of the curriculum, it was possible to raise issues that were difficult in other places. One of the things we did in Glasgow was to ensure that the ethics part of the programme continued issues around end of life care. In addition to that, the introduction of the Medical Humanities, which some will know about, the introduction of literature, in particular in poetry, again allowed issues like that to be raised in a context that was sometimes much easier to talk about than at the bedside, when it was quite difficult in front of the patient.

Parkes: I'd like to say a word about the volunteers because they actually became a very important part of the early hospice. Sheila Hanna was our first volunteer organizer; again this was part of Cicely's vision too, and she needed somehow to connect with the local community.⁶³ And I remember on one occasion, someone reporting that somebody had been passing the hospice in a bus and the bus conductor had turned and said: 'You don't want to go in there. You'll never get out of there alive.' This was in the first year or so, and all sorts of myths were being developed about this strange place where people went to die. I remember I was discussing this and we felt that the volunteers were not only a very important resource and point of contact with the community but that they could become an important part of the hospice, not arranging the flowers in the wards as they did in most hospitals, but be actively involved in supporting patients and families, working closely with the staff on a wide range of things: ferrying patients to and from the hospice; looking after the garden; and also some very challenging things. I was aware that we desperately needed

⁶² Professor Duncan Vere (b. 1929) is Emeritus Professor of Therapeutics in the University of London and was Head of the Department of Pharmacology and Therapeutics at the London Hospital Medical School. Dr Andrew Herxheimer (b. 1925) worked in preclinical and clinical pharmacology at St Thomas' Hospital Medical School, the London Hospital Medical College and at Charing Cross and Westminster Medical School until 1991 and is an Emeritus Fellow at the Cochrane Centre in Oxford; he was founding Editor of the *Drug and Therapeutics Bulletin* (1962–1992). Both Duncan Vere and Andrew Herxheimer participated in the Witness Seminar on 'Clinical Pharmacology'; see Reynolds and Tansey (eds) (2008).

⁶³ Mrs Sheila Hanna was the Volunteer Co-ordinator at St Christopher's involved with the recruitment, interviewing, support and education of volunteer hospice workers; an interview with her has been carried out by the oral history Hospice History Programme initiated by Professor David Clark; for details see www.hospice-history.org.uk/byoralsurname?id=0048&search=h&page=0 (visited 26 June 2012).

a bereavement service but there was no way we could afford to pay a team of psychologists to work in the hospice, but I'd already worked with volunteers in other settings and I had the feeling that, if we could pick and choose our volunteers, we might get some very good bereavement counselling out of them. In 1970 we started the first hospice-based bereavement service and Sheila played a very important part in picking out the *crème de la crème* of the volunteers.

Calman: Can I remind you that we also want some comments about the NHS itself and the Colleges and other sectors coming part of it.

Dr Richard Hillier: I'm NHS through and through until I retired. My unit in Southampton, Countess Mountbatten House, and my own entry to palliative care was, unlike anybody else here, through making my own mistakes and only to some extent through the mistakes of others. My own was because I'd made a few grand cock-ups, which was what really got me interested.⁶⁴ Interestingly

⁶⁴ Dr Richard Hillier wrote: 'Incident a): It occurred during the consultant ward round in the large and open Nightingale ward on the first day of my first house job. A young woman who was dying of breast cancer was moaning and shouting from her bed behind one of the ward screens we used to have in those days. She was clearly in considerable distress – in fact it was distressing for all the other patients, as well as disturbing for the surgical team. The consultant asked my junior colleague to give her "a grain of Diamorphine intramuscularly" (the equivalent of 190 mgs of morphine orally – a huge dose for a weak patient who had not had morphine previously). By the end of the round, she was dead. I must have looked very uneasy, for the consultant put his arm across my shoulders and said "It's alright Hillier. Sometimes you have to do this. It's OK". That was my first lesson in pain control. Ouch! In fact the consultant was an excellent doctor and a good, kind man whom I grew to admire enormously. It was just that there was virtually no knowledge and certainly no teaching about care of the dying in the late 1950s and early 60s, so caring doctors were very pragmatic. Incident b) While still a house officer, I was told to tell a lady that her husband, in his 50s was dying. I had never done it before, never thought about how to do it and had never seen it done. I recall mulling over whether to break the news gently or, on the assumption that being asked to see the doctor heralded something fairly nasty anyway, to get it out quickly. I chose the latter, suspecting that they would have guessed anyway and that any procrastination on my part would appear inept and misplaced. My first surprise was that in the tiny 6ft square sisters' office, the lady, her sister, a daughter and two sons accompanied her. The ward sister came in so there was no room for any of us to sit down. I blurted out: "Mrs Smith, I'm sorry to have to tell you, but your husband is dying and won't leave hospital." The room exploded, with howls, tears, and uncontrollable distress – as well as understandable anger towards me. Apparently she had no idea – nor did any of the family. Thankfully the ward sister kicked me out and took over. Goodness knows what it did to the family, especially as he did go home and apparently lived for some time. For myself I still feel hot just to think of it. Hardly a master class in breaking bad news! Incident c) Six years after the above incidents and when I was working for the MRC, I came across, purely by chance, Cicely Saunders' papers on pain control and talking to patients. They were a revelation; convincing and, to my surprise, an enormous relief that both could be done superbly well in the right hands and with the right help. Five years later, I went on an attachment to St Christopher's. Three years after that I was appointed Consultant in Continuing Care (an odd euphemism for hospice care if ever there was one!) in an NHS hospice in Southampton.' E-mail to Ms Caroline Overly, 11 September 2012.

enough, the Southampton Unit was born from a radiotherapist called Dr Peter Bodkin, who many years later told me that when he was a junior doctor he'd told a girl at the Marsden that she was going to die, and within 48 hours she'd killed herself. Many years later he told me: 'I swore then that I would never, ever tell anyone that again', which to my knowledge he never did. When he heard about the Christchurch Unit, pioneered by Dr Ronnie Fisher, which has been mentioned,⁶⁵ he also approached Macmillan. In 1975, Peter got together a group to try to open a unit within the NHS in Southampton, which they did successfully. One of the key things about a group of this sort is to commandeer really good people. One of these was an exceptionally good administrator of the Wessex Cancer Service, who had great vision. His name was Andrew Hayes.⁶⁶ He nurtured the planning for that unit which opened in 1977, which I led. It had 25 beds, and had a duty to work in the community with four community nurses, and a duty to cover the acute hospitals as well – all of which was pretty hard going with one consultant and a handful of staff. When I learnt that Robert Twycross had been offered two weeks to train medical students in Oxford, I approached the Medical School in Southampton, and was told, and I won't tell you who it was, that it would be very unwise if medical students were exposed to the hospice, because if they saw that people were dying in those kinds of quantities, it might put them off medicine. We had to wait another five years before this resolved when the then dean was Professor Charles George.⁶⁷

Professor David Clark: It's important to get across this bubbling up as strongly as we can. I wasn't active in it at the time, I was far too young, but the sense one gets is of a wildfire movement across the whole country. Lots of key people have been mentioned, but I think we should also recognize the important role that ordinary people in local communities played in seeking to promote and develop hospice ideas. If you take the decade of the 1980s, there was one new hospice opening every month in Britain at that time. There was a terrific period of expansion and development that was about people seizing an opportunity,

⁶⁵ See page 12.

⁶⁶ Mr Andrew Hayes was the founder and first Chief Executive of the Wessex Cancer Trust, 1981–1990.

⁶⁷ Professor Sir Charles George (b. 1941) became Professor of Clinical Pharmacology at the University of Southampton in 1975 and served as Dean of Medicine (1986–1990) and Dean of the Faculty of Medicine, Health and Biological Sciences (1993–1998). He participated in the Witness Seminar on clinical pharmacology; see Reynolds and Tansey (eds) (2008).

seeing what other communities were doing and responding in kind. One of the slightly controversial features that this then led to, was that some of the major architects of the initial development started to put the brake on hospice development itself. Eric Wilkes was in the pole position on this in the Wilkes Report, in which he actively discouraged the continued growth of independent hospices and argued very strongly for the integration of hospice principles into the mainstream of the NHS.⁶⁸ So there was a kind of two edged feature to the development, particularly in the 1980s when the expansion of hospices was absolutely at its peak.

Professor Rob George: It's quite interesting coming to that point, David, because I'm in a sense, like Sam [Ahmedzai], kind of 1B; that is, the transition between first and second generation. It was interesting that when I was a senior registrar in respiratory medicine at the London Chest Hospital, and down the road from St Joseph's (Figure 4)⁶⁹ when patients with cancer, and only cancer, were dying, it was suggested that they went to see 'Terminal Pugsley', as Dr Pugsley, who was the Medical Director of St Joseph's, was called at the time.⁷⁰

So, from the outside in general medicine, on the one hand there was a particular view about hospice, but on the other what was more significant for me, as a respiratory physiologist looking at the effects of all sorts of interventions on breathlessness, was that I was discovering that all the people who were breathless, albeit with interesting physiological problems, were also people who were struggling with the fact that they were dying. At the time we were also working with people with cystic fibrosis, well before the days of lung transplant, and, of course, these were young men and women who were dying in their teens and early twenties, and who seemed also to have indistinguishable problems from those who had cancer. However, when I rotated to University College

⁶⁸ A working group chaired by Professor Eric Wilkes was set up in 1979 on behalf of the Standing Medical Advisory Committee of the DHSS 'to consider the organization of primary, continuing and terminal care services for cancer.' Working Group on Terminal Care (1980a). This recommended: that greater attention be paid to the needs of dying patients and their relatives; that the principles of terminal care be extended throughout the health service, with integration and coordination between the primary care sector, hospices and hospitals; and that training in terminal care be given to nurses and medical students. For a summary of the recommendations see Working Group on Terminal Care (1980b): Appendix.

⁶⁹ St Joseph's Hospice for the dying in Hackney, London, was founded in 1905 under the care of the Religious Sisters of Charity. See Winslow and Clark (2005); Clark and Winslow (2006).

⁷⁰ Dr Robin Pugsley was Director of the Macmillan Home Care Team at St Joseph's Hospice from 1982 to 1986, taking over from Dr Richard Lamerton; see page 61, note 181.



Figure 4: Our Lady's Wing, St Joseph's Hospice, Hackney (1957), where Dr Cicely Saunders worked and which survived until its demolition in 2004/5.

Hospital (UCH) there was a support team there. This was my first discovery that within the health service there was something called the support team; it wasn't called palliative care there, working into the community from the hospital expressly looking after the dying. At that point I think it dawned on me that perhaps there was a different way of doing things. At that stage, of course, the HIV infections were starting up; this would be the early to mid-1980s. Interestingly, Andrew, you mentioned the London Medical Group – that was a really interesting bunch of people.⁷¹ We used to have meetings of general ne'er do goods and people who stirred up and asked questions that shouldn't be asked of doctors and their responsibilities. It was really interesting and encouraging that, as a senior registrar at that time at UCH, when I started lunchtime meetings with students saying, 'Do you want to come and talk about some of the patients you're looking after on the wards and the effect their illness is having on their lives?', within about two months I had meetings of something upwards of 30 medical students sitting, wanting to talk about the broader questions of people's suffering and illness. So in the bubbling up, I think there was something happening at a fundamental level for all sorts of people at that

⁷¹ See pages 19–20.

time. Subsequently, I got involved in NHS practice and have been in the NHS pretty well exclusively since, with one or two periods of exception. I think that's enough to say at the moment; I'll come back on HIV and things later on.

Calman: We should talk about two other things: the non-cancer palliative care, which is important; and, secondly, models of care other than the hospice. When I stepped down as Professor of Oncology and became a Postgraduate Dean, I continued a clinical load. I did that at a general hospital without any beds, but it was essentially palliative care at the hospital. Because I wasn't there all the time, the responsibility was a local clinician's and they had to get involved. And that was quite an interesting way of spreading broader messages.

Professor Clive Seale: I'm interested in the role of religious faith and I've got a question for people who were involved at the beginning that they might like to comment on. I'm aware that religious faith, and particularly the Christian faith, was a very important component of people's motivation to set up and participate in early hospices.⁷² My guess is that part of the success of the hospice movement was perhaps that, although faith drove some of the motivations of some of the people who participated in hospice care, it was suppressed to some extent in its public relations element; that it did not present itself as a Christian movement and that actually enhanced the capacity for it to be broadly accepted by, for example, the British general public. I'm also aware that in some of Colin Murray Parkes' early work and other researchers, there was quite a lot of concern about the impact of prayers being said on the ward, and there was some debate at that early time about that issue,⁷³ which I imagine is not such an issue now. So I'm wondering what the thinking was, in those early days, about the role of Christian faith and Christian observance, and how that related to public image of the hospice movement insofar as you were concerned about that kind of thing?

Calman: It's a good question for us.

Hanks: The development of hospice, although generally thought to be a 'good thing', did not meet with universal acclaim. There were lots of people who didn't think that hospice was necessarily a good idea, particularly in the early

⁷² See comments by Professor Duncan Vere in Reynolds and Tansey (eds) (2004): 15.

⁷³ For a discussion of the religious aspects of St Christopher's see, Parkes (1979a): 519–20, 521; Parkes and Parkes (1984): 122. Of this latter publication, Professor Clive Seale wrote: 'There is a short paragraph ... which shows that Parkes was still checking up on this aspect, and reporting news designed to reassure people that religion was not a problem for the patients.' E-mail to Ms Caroline Overy, 3 October 2012.

days when it soon became apparent that in spite of all these developments, the number of patients being seen by hospice staff and by specialist palliative care staff, was actually very small.⁷⁴ Colin Douglas, a physician in Edinburgh whose first claim to fame was that he was the author of a lurid (but very successful novel) about the experiences of a junior hospital doctor,⁷⁵ also wrote a personal view in the *BMJ* in which he wrote that ‘the hospice movement is too good to be true and too small to be useful.’⁷⁶ The latter point was highlighted in Eric Wilkes’ report⁷⁷ (not quite in the same terms) because Eric was concerned that palliative care wasn’t achieving coverage; it wasn’t getting to anything like the numbers of patients who needed it. That was the key for the change in emphasis in the development of new services, and if you look at the figures there was a move to stop developing new community services, and to develop hospital-based palliative care services. That continued for a substantial period of time.

Hoy: I wonder if I could pick up the theme of hospital specialist palliative care. I was head-hunted by Thelma Bates when I was working at St Christopher’s in 1976 to go and help her start the first hospital palliative care team in the UK, which was at St Thomas’.⁷⁸ We only made it by about a couple of weeks; it was on 5 December 1977, because they’d also had the same idea in Rochester. But anyway, it was the first, and it was for exactly the reasons that Geoff and various other people have mentioned: that there were a very large number of people who were dying, often of cancer, but often of non-cancers, really very badly in hospital. I have to say, there are still an awful lot of people dying really very badly in hospital in spite of sterling efforts, not least I think in the Calman–Hine report⁷⁹ and subsequent reports, to have palliative specialism as a part of hospital practice, not as a uni-disciplinary hospital team. Certainly Thelma Bates was the person who had the vision and the drive to start that. Ilora Finlay, I know, was very keen to make certain that palliative medicine was recognized as

⁷⁴ Professor Geoffrey Hanks wrote: ‘One major problem was that there were too many hospices being built often by small independent local charities without any central or coordinated planning.’ Note on draft transcript, 17 October 2012.

⁷⁵ Douglas (1975). This was the first in a series of novels following the career of a young Edinburgh medical graduate. *The Houseman’s Tale* was made into a TV mini-series in 1987.

⁷⁶ Douglas (1992).

⁷⁷ See note 68.

⁷⁸ See Bates *et al.* (1981).

⁷⁹ Department of Health and the Welsh Office (1995).

suitable for hospital practice. On a personal level, I spent about 12 years banging on the door of my various local hospitals when I was a Medical Director of the Princess Alice Hospice in Surrey, and suddenly when the Calman–Hine report came out in 1995, I was flavour of the month and everybody wanted to employ me. For 12 years before that: ‘Go away, Dr Death.’ So that was the attitude.

Dr Paresh Gajjar: I come from West Yorkshire and my perspective really is from the general practice point of view. I was a GP in the 1970s, and failure at looking after sick patients at home made me look things up. It was fascinating to hear of the developments that were going on in London, and it was Cicely Saunders who I spoke to for advice, who invited me down to St Christopher’s. The only way I could do it was to attend at weekend courses, like the ones put on by Mary Baines, and I learnt an awful lot from all these great people, ending up eventually at Robert Twycross’ courses in Oxford. So, very much self-taught, we were fairly isolated and the only local contact for me was Eric Wilkes in Sheffield. He encouraged me to establish a unit in the hospital where I worked in Wakefield. We ended up forming a palliative care team there, after I had visited the team at St Thomas’ where Andrew was in 1978, I think. We formed the team in 1979 and started improving care generally, both in the community and in the hospital, which was really an uphill struggle, with comments about ‘Dr Death’, and so on, which a lot of us are familiar with. Gradually we began to wear the resistance down, and eventually became established. Subsequently, there was a demand for a hospice.⁸⁰ It went on from there. I think somebody has said it takes about 25 years for any new idea to establish itself, and that’s probably what has happened when you look across the board in palliative care.

George: I was going to say the ambivalence, certainly, that I experienced was enormous in the mid-1980s, and it was quite interesting that because I was, as it were, hospital-grown, I was kind of okay as far as hospital colleagues were concerned insofar as I was the right shape sausage. On the other hand, there was an ambivalence about what I might be doing and talking to patients about. I was actually known – it was a derisive term at the time – as ‘The Psychiatrist’, because I used to talk to people about their illness rather than about their diagnosis. Second, and it took colleagues a very long time to accept, it was actually stopping treatments and patients getting better as a result that was one

⁸⁰ An inaugural meeting to set up the Wakefield Hospice was held in 1982. It opened in 1990; Dr Paresh Gajjar was the first Medical Director. For the development of the Wakefield Hospice see the Twentieth Anniversary Newsletter (Spring 2010) at <http://wakefieldhospice.org/Resources/Wakefield%20Hospice/Documents/Spring%20Newsletter%202010.pdf> (visited 29 August 2012).

of the strongest messages that got me acceptance in the HIV community; that drugs were poisoning patients, especially with advanced disease. Everyone then began to see that the holistic, palliative approach translated into this group as well and really did have benefits beyond simply managing symptoms.⁸¹

Baines: We haven't yet talked about home care, care at home, which, after all, is the largest part of where hospice is now. I was involved in starting the first home care team in 1969, two years after St Christopher's started, and now there are 800+ people at home, and 48 inpatient beds. So that is by far the biggest way in which hospice now works: working with general practitioners rather than taking over their care. Then the other thing is to answer Clive. In Cicely's writings she says, very firmly, that St Christopher's has a Christian foundation. This permeates through her writings. I was there pretty well at the beginning. Living in the community, as I do, it's still often thought of as a Christian foundation, and I've not met anybody who has been put off by that; a lot of people coming in feel it will respect their faith even if they have a different faith or if they have no faith. It was an inspiration for those who worked in hospices at the beginning.

Calman: I'm going to move onto the next section about the medical specialty and what it means, and Richard is going to take us through this.

Hillier: I've been told that I'll be starting the ball rolling but the ball is rolling pretty well already. I'm going to say a few words about the beginning of the Association for Palliative Medicine. There are issues about the developing medical specialty, which I may actually leave to others. I want to take you back to the 1980s, when the National Society for Cancer Relief⁸² used to run conferences in Abingdon. It was one of the big chances we all had to get together, all disciplines. At one of these, in 1984, an informal group of about eight to ten of us, which included two doctors, two nurses, a physiotherapist, a couple of social workers, a medical manager and one or two others, felt that we actually needed something a little more formal. They were looking at something that would be multi-professional and multi-disciplinary, that would be across both the independent hospices and the NHS, bringing them together; and it would be about services in hospices, hospitals and the community. Now you can imagine everybody in the group felt pretty nervous that others were going

⁸¹ See for example, George (1991); Anderson *et al.* (1991); Butters *et al.* (1992; 1993).

⁸² Macmillan Cancer Relief since 1997 and Macmillan Cancer Support since 2006.

to take over, which seems to be a feature of hospice care, as some of you will be aware. Then, at the same meeting, word got out that there had already been an approach to the Duchess of Norfolk by Eric Wilkes and Professor Peter Quilliam, a pharmacologist at St Bartholomew's Hospital.⁸³ They intended to form much the same organization but they had two very powerful people on board: Eric Wilkes and Dame Cicely, as well as the Duchess of Norfolk, who brought with her the Sultan of Brunei.⁸⁴ So, what I will call the Abingdon group obviously realized that this was unstoppable and so they backed off and that was the end of it. Very shortly after this, special interest groups began to appear. I think it was the nurses who started it off, then the hospital administrators, as they were called in those days, did the same; followed shortly after that by the social workers. So questions then began to be asked: did doctors need the same kind of thing? In 1984/5 there were two very good reasons why they did. One was political and one was professional. On the political side, a number of hospices had been visited by important people: the Queen, other members of the Royal Family, the Secretary of State, the Prime Minister and the Chief Medical Officer, Donald Acheson. Second, the Secretary of State, in July 1985, stated that, and I quote: 'Health Authorities need to look more closely at the needs of the dying and the development of specialist services.'⁸⁵ He hinted in that speech that central financial support may be made available, and I know that some of you are still waiting for that. [Laughter] Lastly the National Association of Health Authorities took the lead from this and arranged for a conference in London in December 1985, which Prince Charles attended, so did the Minister and Chief Medical Officer.⁸⁶ This had a considerable impact on thinking about where palliative care/hospices/terminal care was going. On the professional side, there were a number of doctors, some in this room, who were expressing

⁸³ Professor Peter Quilliam (1915–2003) was appointed to the new Chair of Pharmacology in St Bartholomew's Hospital in 1962.

⁸⁴ Anne Fitzalan-Howard, Duchess of Norfolk (b. 1927) founded Help the Hospices in 1984 and is the charity's President; she was appointed a CBE for her work in 1992. Hassanal Bolkiah (b. 1946) has been Sultan of Brunei (a British protectorate from 1888 to 1984) since 1967.

⁸⁵ Norman Fowler (Baron Fowler since 2001) was Secretary of State for Health and Social Security 1981–1987. We have not been able to identify the source of the quote.

⁸⁶ Prince Charles gave the opening address of the conference in which he supported the growing hospice movement. For a summary of the conference, see Smith (1985); for the proceedings, see Department of Health and Social Security, National Association of Health Authorities (1986).

a strong interest that there should be some organized structure and focal point for future developments in palliative medicine. So, to cut a long story short, in October 1985, we arranged a meeting in Birmingham and everyone was encouraged to talk to their friends, to the various hospices, and anyone who might be interested to attend this inaugural meeting. To our amazement 92 people turned up.⁸⁷ There were also 40 apologies. Among those who attended were GPs, physicians, an oncologist, surgeons, an orthopaedic surgeon, public health doctors, a medical administrator, as well as a bacteriologist and a haematologist who could not attend.⁸⁸ Several things happened. First there was a unanimous vote that we should form an association. There then followed a long discussion about what to call it. Should the word ‘Hospice’ or ‘Palliative Care’ be used in the title? It was finally agreed to call ourselves ‘The Association of Palliative Care and Hospice Doctors’. That took at least three-quarters of an hour. They also agreed to have a committee of six people, and Derek Doyle was elected Chair.⁸⁹ He, as you know, was a missionary, then a GP, then became Medical Director of St Columba’s Hospice in Edinburgh. There was Robert Twycross, who was elected Treasurer, and myself as Secretary. Three others were voted onto the committee: one was Gill Ford, sitting here in the front row, who I’m sure you all know; the second was a physician from a general hospital, a gastroenterologist called Richard Waldram, who was very wise, sensible, sane and had a very broad political vision that encompassed the big picture, not local care. There was also a vibrant young trainee from radiotherapy who wanted to go into hospice medicine. He was called Simon Dover and may have been elected because he happened to be medical adviser to *The Archers*.⁹⁰ [Laughter] When Robert resigned from being Treasurer, we also learned that Simon Dover’s mother was an international poker player and therefore he was the obvious person to have as the next Treasurer. [Laughter] So that was that. The meeting itself went well. I’m fascinated to look at the minutes of that first

⁸⁷ See Appendix 2 for a list of attendees.

⁸⁸ The bacteriologist was Dr John Talbot, who later became the Medical Director of Priscilla Bacon Lodge in Norwich. See page 17.

⁸⁹ Dr Derek Doyle was Medical Director of St Columba’s Hospice from its opening in 1977 until his retirement in 1995. An interview with Dr Doyle was recorded by the Hospice History Programme in 1996; see www.hospice-history.org.uk/byoralsurname?id=0031&search=d&page=0 (visited 27 June 2012).

⁹⁰ *The Archers* is a long-running radio soap opera broadcast on BBC Radio 4; see Dover (1989).

meeting and find that everything we talk about today was all in that meeting.⁹¹ It was extraordinary, in retrospect. There was considerable vision shown by people in the room, seven of whom are here today and who can comment if I've got it wrong. The next thing we had to consider was whether or not we should aim to become a medical specialty. There was a developing body of knowledge, there was no accreditation, we needed to develop education and training, and we needed a career pathway to attract good doctors with wide-angle vision to come and work with us. In the very early days, as I understand it, Gill and Graham Thorpe,⁹² who was also an active member of the College of Physicians, and Derek Doyle had outline discussions with several Colleges – maybe you weren't part of that, Gill? – to explore whether or not they would take us on. The College of GPs wasn't interested; they said they were doing it anyway. Derek Doyle didn't get anywhere with Edinburgh. Two big figures stepped into the ring: Gill Ford, already mentioned because she was on the committee, and Ken Calman here, who then spoke to senior members of the Royal College of Physicians.⁹³ I think the rest of the story, Gill, is yours.

Calman: It's going to be very interesting reading the transcription of what you said. You may wish to delete the occasional word.

Tansey: Please don't! [Laughter]

⁹¹ For the minutes of the first meeting, see Appendix 3.

⁹² Dr Graham Thorpe (b. 1932) was a hospital consultant on the Isle of Wight before transferring to Countess Mountbatten Hospice, Southampton, in 1980, where he worked until his retirement in 1994. An interview with Dr Thorpe was recorded by the Hospice History Programme in 1996; see www.hospice-history.org.uk/byoralsurname?id=0109&search=t&page=0 (visited 27 June 2012).

⁹³ Dr Richard Hillier wrote: 'It was the Association that triggered off the acceptance of the medical specialty by the Royal College of Physicians (RCP). Derek Doyle and Graham Thorpe did the ground work with the college – dealing with the many challenging requirements which the RCP demanded. Gill Ford's valuable experience as an ex-Deputy Chief Medical Officer, made her the ideal person to contribute some of the data requested by the College (known as the Korner statistics) and then she and Ken Calman secured the final rubber stamp with the College – friends at court so to speak! So it was a bit more of a joint effort than appeared at the meeting. Geoff Hanks rightly gave Derek Doyle considerable credit for what has been achieved, and there is no doubt that if it were not for him and Graham Thorpe, acceptance as a specialty would have been delayed for years. In the event, as you can see, the specialty was agreed only two years after the Association was formed and the first Registrar in training took up post in Southampton in 1989 followed rapidly by a whole tranche of them. This was an impressive achievement in which Ken Calman played an unsung, but important role.' E-mail to Mr Adam Wilkinson, 12 March 2012.

Ford: All sorts of things were going on in the mid- to late-1980s, which put fire and enthusiasm into getting the hospice world and the NHS closer together, and not least, of course, was the development of this particular branch of medicine as a specialty. The Department of Health was strongly behind more togetherness between the NHS and the hospice world and also had been convinced that this work would be far more influential if it was a recognized medical specialty with a training programme and so on. Others were not so convinced and hospices, in some people's eyes, were distinctly quaint backwaters where people vanished and were not heard of again – doctors, I hasten to add, not the patients. Anyway, in 1985, I was seconded to St Christopher's on a Leverhulme Fellowship, as the Director of Studies, with a remit to promote medical education and career development in care of the dying. I wrote to all the hospices and NHS units and asked what medical staff they had, what training and experience they had, what the expectations of future staffing were, how the work was expanding, and what their plans were for the future? I wouldn't say anything like 100 per cent came back, but it was still a respectable response. On that basis it looked perfectly plain that there was scope for this specialty, not just in hospices but in the NHS. Ken, you and I bearded the Conference of Royal Colleges and Faculties⁹⁴ and, to our astonishment, the door was actually open, wasn't it? We thought we were besieging a stronghold prejudiced against us, but not so. We were welcomed, we were asked for our facts, we were told that this specialty had to have a name. That was tricky; it had to have a career structure and a career training plan. So we went away and, as you say, Richard, with Derek Doyle, Graham Thorpe, Mike Kearney and others, devised a training programme. We had facts and figures to support all sorts of things that they had asked for. We had to decide on the name then and there, and opted, I think, for Palliative Medicine as the least likely to cause troubles in the future. [Laughter] Anyway, the Conference of Royal Colleges and Faculties formally advised the Department of Health that Palliative Medicine should be recognized as a specialty.⁹⁵ That did open the door for consultant appointments and training posts in the NHS and elsewhere and I think helped a great deal towards bringing units practising

⁹⁴ The Conference of Royal Colleges and Faculties of the United Kingdom became the Academy of Medical Royal Colleges in 1996.

⁹⁵ The Royal College of Physicians recognised Palliative Medicine as a specialty in 1987; see Hillier (1988).

outside the NHS together with the NHS. At the same time, the National Council was coming along,⁹⁶ or at least the idea that there should be such a thing. Of course, we've got Jean Gaffin here, who was its first Chief Executive, and that again helped to bring the NHS and the voluntary establishments together as well as all the professions involved. Do you want me to say any more about training?

Calman: I think it would be quite helpful. This is a tremendous opportunity to get a flavour of what people thought was happening. We're now up to about the late 1980s, I think. Say a little bit about training.

Ford: Consultant posts are distinctly competitive and, of course, this being a new specialty with a lot of potential growth, it did attract, I may say, some lovely, lovely people, and I think many of them are here today. Training posts were established under the aegis of the Joint Committee on Higher Medical Training (JCHMT) and we had to get hospices approved for training. I can see a photograph behind Ken of someone who was very, very dubious about the place because he felt he knew Cicely and she was out for death-bed converts.⁹⁷ [Laughter] My reaction on hearing this was that he himself had to come and look and eat his words, which he did on a visit to inspect St Christopher's for training purposes. The whole process of establishing approved training posts began, thanks to the impetus from the Royal College of Physicians, who took this specialty under its wing, set up a Joint Training Committee, did all its College things, with its inspection of posts and providing College representatives on the appointment committees for consultants.

Calman: What was happening there, how did it all begin, and how did it grow beyond that?

⁹⁶ The National Council for Hospice and Specialist Palliative Care Services (National Council for Palliative Care (NCPC) since 2004) was established as the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. Dame Cicely Saunders was the Honorary President until her death in 2005.

⁹⁷ Dr Gillian Ford wrote: 'The photo behind Ken Calman featured the late Sir Christopher Booth and it was he who made the comment about Cicely and death bed converts. I mentioned it because that attitude was shared by some folk at one time. Later he came down with Richard Lister and inspected SCH (St Christopher's Hospice) with a view to it becoming a training place for SRs (as they were then) entering the specialty of Palliative Medicine. I am glad to say that he and Dr Lister both agreed that SCH met the appropriate standards.' E-mail to Ms Caroline Overy, 29 October 2012.

Hoy: Thank you Gill and Richard. I wanted to mention the part of the College of Physicians. Who was the person who helped us on the Specialist Advisory Committee (SAC) at the College?⁹⁸ The fact was he was very supportive and nannied us for a couple of years while we were getting the training programmes together. We started very small; I think we started with no more than 11 trainees nationally. I think that included Scotland at that time, so it really was very small. Fairly soon afterwards we were allowed to go it alone. I think you must have been part of that, Gill, weren't you?

Ford: Douglas Black⁹⁹ and other Presidents of the RCP were all supportive of the specialty and its aspirations.

Hoy: Douglas Black was one of the Presidents of the RCP at the time. In any case I'd like to reiterate that we got funding for new training posts. I think at that stage they were called Senior Registrar posts from Macmillan Cancer Relief, and that was really very helpful. The posts went up exponentially. No medical specialty had grown quite as rapidly as this, from a standing start to, I can't remember the exact numbers now, but I could probably get them from the RCP.¹⁰⁰ It meant that an awful lot of inspections had to be done for new posts that were being created in a very short space of time, by a very small number of people. There were several of us who did that, including Anne Naysmith, who was crucial as the Chair of the RCP Specialist Advisory Committee in palliative medicine at that time. I know Ilora and I did various inspections and so on. So that was very important, and at one stage the people coming forwards, the females outnumbered the males nine to one. I'm not quite certain to this day why that was the case. I don't think it was anything to do with the people who were doing the inspecting, but anyway, there it is.

It wasn't the President who was so very supportive to us; it was a chair of the SAC, and palliative medicine was given a sort of subgroup status of the SAC in General Medicine. And that was the case for a couple of years until it was felt

⁹⁸ The identity of this person has not been established; further correspondence on this matter is archived with the records of this meeting.

⁹⁹ Sir Douglas Black (1913–2002) was President of the College of Physicians (1977–1982) and Chief Scientist at the DHSS between 1973 and 1977. He was succeeded by Sir Raymond Hoffenberg (1923–2007), who was President of the College of Physicians from 1983 to 1989.

¹⁰⁰ For the development and growth of palliative medicine as a subspecialty of general medicine, see Doyle (2005). For the current statistics see comments by Dr Bee Wee on pages 40–1.

by the Joint Committee for Higher Medical Training (JCHMT) that we were, if not grown up, certainly compliant adolescents in the whole process of getting the specialty off the ground.

Finlay: I'll add a bit of context to that, because at that time the College of GPs had said: 'No, we're doing it all already anyway'. That had in effect potentially closed the door to those people who came from a general practice background. There were a lot of people then who had been working very much in isolation, and the names that come to mind are people like Peter Griffiths, who had trained and had set up a unit, and were working in really very lonely conditions, treading a very lonely path. I myself came from the general practice stable and had Membership of the Royal College of General Practitioners (MRCGP), as did Richard. Now the College of Physicians was incredibly broad-minded because in setting this up, after a bit of negotiation and it did take a fair bit of a push, they agreed that an entry qualification to the specialty could either be Membership of the Royal College of Physicians (MRCP), Membership of the Royal College of General Practitioners (MRCGP), Fellowship of the Faculty of Anaesthetics (FFA), as it was then, or Fellowship of the Royal College of Surgeons (FRCS) (which covered our orthopaedic surgeon friends). There was a fierce debate, for those who came from a general practice background. So, for example, when I was appointed I was asked to accept the job without honorary consultant status, because I was employed by a charity. Even though I desperately wanted the job, knowing I had to have a seat at that table with others, I said 'No'. I got honorary consultant status and the job. There were quite a few, such as Nigel Sykes,¹⁰¹ who were then able to negotiate consultant status on the back of the precedent I had set. That entry criterion remained almost up until today. I know it is now gone for MRCGP, because the training curricula have diversified so much, but it was an entry qualification for a long time. We must give credit to whoever it was in the College of Physicians who supported us, and it's rather sad that none of us can remember his name.¹⁰²

Gaffin: If I could move away from doctors for a minute, if that's allowed, and say the National Hospice Council was formed in 1991, because you had the Association for Palliative Medicine of Great Britain and Ireland (APM), you had the hospice administrators, you had numerous hospice groups lobbying

¹⁰¹ Dr Nigel Sykes has been Medical Director at St Christopher's Hospice since 2000.

¹⁰² See note 98.

the Department. Mrs Virginia Bottomley, who was then Minister of Health,¹⁰³ said she was fed up of talking to so many groups, she wanted one. Help the Hospices,¹⁰⁴ thanks to the Duchess of Norfolk and Paul Rossi,¹⁰⁵ who was then its Chief Executive, said that they would give up their political lobbying role and give it to this new body, the National Council of Hospice and Specialist Palliative Care Services, as we were then.¹⁰⁶ We were going to be the one voice for hospices. We had representation for every group you could think of, except the caretakers. We had the Department of Health observers, we had Marie Curie Cancer Care, we had Macmillan on it. One of the tensions that I thought was very to the fore when we started was the tension between the NHS and the voluntary sector, with the voluntary sector very resentful that the NHS sector was fully funded by the NHS, and the NHS very jealous really of the potential of the voluntary sector to raise huge sums. And one of the things that stuck in my mind was the fact that, for example, the NHS hospice associated with Mount Vernon Hospital, Michael Sobell House, raised as much money from the voluntary sector to run its day centre as the best voluntary sector got from the Department. It was averaging about 30 per cent across the voluntary hospices in the UK. And I'll finish with the National Council by saying we had a policy then, as the Minister changed from Mrs Bottomley to Baroness Cumberlege, of lobbying the Government for 50 per cent funding.¹⁰⁷ We were arguing for 50 per cent funding; the voluntary sector didn't want more than 50 per cent because they thought it would give the Department of Health too much influence, and so we were lobbying for that. There were, at that time something called Circulars.¹⁰⁸ Do you remember, Gill?

¹⁰³ Mrs Virginia Bottomley (Baroness Bottomley of Nettlestone from 2005) was Minister for Health from 1989 to 1992.

¹⁰⁴ Help the Hospices, founded in 1984, is the UK's leading charity for hospice care.

¹⁰⁵ Paul Rossi was Chief Executive of Help the Hospices, Deputy Chief Executive of Macmillan Cancer Support and has been Chief Executive of the National Benevolent Charity since 2007. He has written a history of Macmillan Cancer Support; Rossi (2009).

¹⁰⁶ See note 96.

¹⁰⁷ Mrs Bottomley was Secretary of State for Health from 1992 to 1995; Baroness Cumberlege was Joint Parliamentary Under-Secretary of State, Department of Health from 1992 to 1997; see notes 103 and 200.

¹⁰⁸ For information on Circulars, see the Department of Health website at www.dh.gov.uk/health/category/publications/letters-circulars/ (visited 24 September 2012). An example of a Health Service Circular on Palliative Care from 1998 can be found at www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4011834.pdf (visited 19 September 2012).

The Department actually managed the NHS then and sent Circulars out very often, telling the NHS what to do. There were Circulars about what the NHS should do about hospice palliative care, whatever they called it. Now, during my first year, I was literally alone in secret in a cupboard for half-an-hour reading a draft of the Circular and I think the civil servants were a bit worried about me doing this, and I was able to comment and so on. It moved over the few years that I was involved, to actually a much more open consultation about the Circular. I think that says something very interesting about the civil servants in the Department of Health. We nearly got 50 per cent proposed in a Circular, and I think it was Baroness Cumberlege herself who crossed it out. So the National Hospice Council grew up to bring everyone together and speak with one voice at the Department. I don't know if David Clark, who is a better historian than me, would agree that over the years there's been a bit of a role reversal with perhaps the National Council playing a slightly narrowing role and Help the Hospices¹⁰⁹ now playing a bigger role, giving advice on commissioning and being much more political than it was in my day.

Calman: Wonderful memories being evoked of Circulars going out.

Clark: Again, I wanted to make a wider point about the specialty. It was 1987 that recognition was achieved and I think it's important to note that the next country to achieve it was Ireland, and that wasn't until 1995. I think I'm correct in saying that Britain and Ireland are the only two countries in the world that have recognized palliative medicine as a full specialty with a four-year training programme. It was as recently as 2006 that the US recognized 'hospice palliative medicine' as a subspecialty, and indeed a subspecialty of more than a dozen other specialist areas of medicine.¹¹⁰ So I think there's a piece to be explored about why, in Britain, the route was created to take this full specialty with a four-year training programme while everywhere else it has been characterized as a subspecialty or a super-specialty of something else. What were the consequences of that? I think another important question is simply how it was achieved, given the very limited edifice upon which it was built. We've heard a great deal about the amount of activity that was going on, but in terms of modern criteria of evidence-based medicine this was a very fragile edifice indeed. In fact, the year that the specialty was created was the same year that the first journal in the field

¹⁰⁹ See note 104.

¹¹⁰ For the international development of palliative medicine, see Clark *et al.* (2000); Clark (2009, 2012); Ryndes and von Gunten (2009).

was created,¹¹¹ so it wasn't as if there was a long track record of publication, at least in a specialist journal, to build on. The last question I would put is: how does a specialty emerge at this time that has no particular stage of life associated with it; has no organ of the body; and has no disease? What kind of specialty is it?

Hanks: Perhaps I could make a correction to one thing that you said, Richard? At the meeting of potential people who wanted to join an association, I was also at the meeting and I voted against the motion to create a specialist association. In fact I didn't join the APM for two or three years after that so I was the only person who got paid travel expenses to go to that meeting.¹¹² [Laughter] I was against setting up a specialist society because I thought that it would further push palliative care people away from the mainstream of medicine, and that it would act as a barrier to getting good palliative care developed on a wider scale. I certainly felt very strongly at that time that it was the wrong moment to set up a specialty, partly because there was so little basis for it, as David was saying. You know, what was palliative medicine? What did it mean? I had been appointed as a consultant in continuing care at the Royal Marsden Hospital and the choice of the term 'continuing care' was very significant because it was widely used to describe palliative care, and it was chosen because it's meaningless. It doesn't actually say anything about what it was all about. But, of course, very soon at the Royal Marsden Hospital, Horder Ward, which was the Palliative Care Unit, became known by the cleaning staff and other support staff in the hospital as the 'Departure Lounge' [laughter], because it was on the fifth floor (the top floor) of the hospital. Now I mention that, because all these issues are actually very important to what life was like being a palliative care consultant at that time, when no one actually knew exactly what it was all about. The problem of staffing: I initially had 13 beds at Horder Ward, and then we opened another unit

¹¹¹ The journal *Palliative Medicine*, edited by Derek Doyle, was first published in 1987.

¹¹² Professor Geoffrey Hanks wrote: 'My mistake! I did not go to that first meeting in Birmingham because I had no intention of joining the new Society. However I was invited to go to the second meeting in Leeds to give a lecture to the assembled audience – the first clinical update lecture to the new society. I was pleased to be invited to do this but made the point to Richard Hillier (who had invited me) that as I was not a member of the new Society and had no intention of joining, I would expect at least reimbursement of my travel expenses though I would forgo a lecture fee. Thus the comment on travel expenses. And as I had not attended the first meeting in Birmingham I had mistakenly 'remembered' this meeting in Leeds as being the first since it was the first 'proper' meeting with clinical or scientific lectures.' Letter to Ms Caroline Overy, 7 November 2012.

at Sutton, so 26 palliative care beds. I was appointed without any junior staff. The way decisions were made in those days, I went to see Professor MacElwain, the Professor of Medical Oncology, and said: 'I start tomorrow but I've got no junior staff.' He said: 'Okay, share mine.' The next day I had an SHO and a registrar. Those were some of the realities of starting out as a consultant in the NHS in palliative care.¹¹³ I was wrong in opposing the development of a specialist society. I think it made a huge difference to the development of palliative care. I reiterate that Macmillan were particularly important in making the specialty work, because at one stage there were 13 inspected jobs and Macmillan were funding 11 of them.

Calman: I've got great sympathy for what you've said. I was appointed Professor of Oncology in 1974¹¹⁴ with no beds and no staff, and it took a little while to sort things out, but it was good fun at the time.

Twycross: Can I ask the Chairman of the APM to correct the minutes of the first meeting? There was one objection. [Laughter]

Dr Bee Wee: I was not a witness to that period of time so my input is to pick up on a couple of comments from earlier on. I am currently the President for the Association for Palliative Medicine. Andrew was wondering about how many full-time equivalent consultants we have now: we have 322 across the UK, hoping to increase to 421. At the moment, our training numbers mean that if we keep going we will shoot past that target, so we are probably going to have to cut back on our training numbers in three years' time. I'm afraid

¹¹³ Professor Geoffrey Hanks wrote: 'I had one of the first fully NHS funded palliative care services in the country at the Royal Marsden Hospitals in London and Sutton and it was also the only unit in the country with attached higher specialist trainees (albeit trainees in medical and clinical oncology). The Marsden was part of the NHS but it was a Special Health Authority funded directly by the Government and thus not subject to the standard district/area and regional structure. This gave it an enviable degree of flexibility in the way it set its priorities and used its funds ... In my first five years at the Marsden I had four Senior Registrars (SRs) working part of their time with me for six months or a year. Mac [Professor Tim MacElwain] had made it clear that we needed the same medical structure as the other firms so I also had a Senior House Officer in Fulham Road and Sutton to do the clerking and day to day work on each unit. I was very fortunate indeed to have good SRs working with me and these particular individuals were pretty good! All four SRs have become world leading professors of oncology ... For me this was a rather extraordinary experience and I learnt a lot.' Extracted from a letter to Ms Caroline Overy, 7 November 2012, which is included in the records of this meeting.

¹¹⁴ See page 5.

the female:male ratio has not changed much: currently the female:male ratio is 73 per cent to 27 per cent, but the trainees' female:male ratio is 81 per cent to 19 per cent.¹¹⁵ So I think the women might stay in the majority. The other point I'd like to pick up is what David Clark said earlier on about the specialty being recognized as a medical specialty in the UK and in Ireland. I've spoken to the Irish Association of Palliative Physicians and the difficulty for them is that because there are only two countries in Europe that have recognized palliative medicine as a full medical specialty, recognition of specialty training that has taken place in the UK isn't straightforward in Ireland.¹¹⁶ For them, certainly, the establishment of palliative medicine as a specialty has enormously helped their development of palliative care services as a whole.

Ahmedzai: I'd like to carry on the theme that's been started by David and Geoff, regarding how the specialty first of all saw itself and got seen by outsiders, and it's very interesting to hear from you, Geoff, that you actually were standing away from it at the very beginning. It's because I've spent so many years working with David as a sociologist that I'm influenced – I was going to say contaminated – by seeing things from a sociological point of view. Standing back from being a doctor, it's quite clear that this was a very interesting time, there was not a homogeneous view that we were all moving forward as one joint specialty. It was clearly in some ways a fracturing of the whole movement. In 1990, along with Ian Johnson who was a consultant with me at Leicester, I published a paper in the *BMJ*, which was a survey at that time, a snapshot of the sort of ethos of palliative care units around the country.¹¹⁷ One of the questions we asked was, 'How do you view yourself as, on one extreme, a specialist unit or a pain control centre; and at the other extreme as "home from home"?' What we found when we analysed the responses was that there was clearly a split between the units that had full-time medical directors and consultants, who saw themselves as a specialist unit, and units which were run very much by part-time people, often GPs, who were not consultant-based, who saw themselves as a 'home from home'. That particular fracturing has stayed with us for a long time, and

¹¹⁵ Royal College of Physicians 2010 census; Joint Royal College of Physicians Training Board, September 2011.

¹¹⁶ Dr Bee Wee wrote: 'The issue, as I understand it from my Irish colleagues, is that if somebody has done their specialty training in the UK, then move to Ireland for a consultant appointment, they seem to have to provide all kinds of evidence to prove to the Irish Board that they have been fully trained.' E-mail to Ms Caroline Overy, 12 September 2012.

¹¹⁷ Johnson *et al.* (1990).

there are still some elements of that. At that time also, where the specialty was going in one direction and the movement was still going along in its original direction, there was also the other point you raised, Ken, the rise of the academic part of the specialty. That also went in two directions: where there were full-time doctors, consultants, then there you would have a sympathy or a sort of a positive view towards research and an academic linkage say with universities. Whereas elsewhere, there was almost a feeling of ‘well actually, we’re here not to do research, we’re here to protect people from research.’ That again is a sort of separation within the movement, which has persisted with us for a long time.

Seale: On which note, may I briefly turn to research? Thinking of the early days of research: I worked with Ann Cartwright¹¹⁸ in the 1980s, who had done a survey called *Life Before Death* in 1969,¹¹⁹ and I think she had some contact with Cicely Saunders around that time. Probably the precursors of hospice-related research, or the precursors I can think of, are in the 1950s when Marie Curie carried out a survey of cancer at home.¹²⁰ That actually was a survey of need and it revealed all kinds of needs, which were a powerful impetus for providing services. But I think probably the survey work of Ann Cartwright, John Hinton and Eric Wilkes were all of that character, in the sense that they used survey methods.¹²¹ I think Ann Cartwright was the only professional survey researcher amongst them, but they used survey methods to demonstrate need. Then once the hospice movement was founded, I think Colin Murray Parkes’ work was really moved forward into proving the value of this new service.¹²² So the classic surveys were published in the *Postgraduate Medical Journal*, a pair of studies that basically compared local hospital care with St Christopher’s hospice care, and showed the differences between them. That wasn’t a randomized control trial, and I don’t know if you’d agree, Colin, but probably if that was submitted to a funding body these days it might have a little difficulty getting funded in today’s National Institute for Health Research. It was really only with Robert Kane’s

¹¹⁸ Professor Ann Cartwright (b. 1925) was Director of the Institute for Social Studies in Medical Care from 1970 until her retirement and closure of the Institute in 1993.

¹¹⁹ Cartwright *et al.* (1973).

¹²⁰ Joint National Cancer Survey Committee (1952).

¹²¹ Professor John Hinton became Professor of Psychiatry at the Middlesex Hospital in 1966; see Hinton (1967); Wilkes (1965).

¹²² Parkes (1979a and b); Parkes and Parkes (1984).

work in America that the first RCT (randomized control trial) of hospice versus hospital care was published in the *Lancet*¹²³ and that was actually on a single site in a veterans' administration hospital in America. One sees the development of methodology from descriptive surveys to statistically controlled studies through to proper randomized control trials, and there has been work since then. I'm talking about the more social research here. Obviously there was biomedical research on symptom control, which I can't comment on, but I think that that would probably characterize the development of some aspects of the early stages of the research programme that's been associated with hospice care.

Maher: I was going to make the point that, in terms of general academic infrastructure, the Macmillan strategy was to try to appoint consultants who were senior lecturers, so that there were some sessions that were part of universities. That was a success, I think, to some extent, in seeing some of the academics who developed from those original posts, but because research infrastructure wasn't provided in addition, in the majority of cases it was very difficult for those consultants to develop an academic career. However, the one thing that it did do was to have a big impact in getting medical education into the undergraduate facility and getting teaching going. When we retrospectively reviewed the impact of the senior lecturer posts in 2007, probably the biggest impact was in infiltrating the undergraduate curriculum.¹²⁴ One shouldn't forget that in thinking about developing an academic infrastructure.

Calman: If I can comment on that. The Macmillan funding that we got in Glasgow, particularly when I left the oncology post and moved into education, was absolutely central in developing the broader educational work that was done there, and indeed across the country.

Parkes: Clive kindly referred to the research that I was involved with in the early days of hospice, and John Hinton was also with us. It's interesting that a lot of the early work was done by psychiatrists who haven't perhaps remained involved so closely in hospice as we were in the early days. I don't know whether that's because of the choice of terms like palliative care, which focus on symptom control rather than family care. I have always seen the family, which includes the patient, as the unit of care in the hospice. This said, I think we've definitely got a very broad-based palliative medicine now. I'm not really

¹²³ Kane *et al.* (1984).

¹²⁴ For a review of palliative care in the undergraduate curriculum, see Gibbins *et al.* (2009; 2010).

making a claim for a great psychiatric input, because I think, from the start, our role has been a marginal one. Having said that, I certainly published five papers in the late 1970s and early 1980s evaluating aspects of inpatient, home and bereavement care at St Christopher's Hospice.¹²⁵ Among them was a small-scale study comparing evaluations by family members of the care that had been received both in St Christopher's Hospice and in other hospitals in the area. They showed very clearly that not only pain relief but emotional components were producing better results at St Christopher's than elsewhere. We repeated this study 10 years later,¹²⁶ by which time the Wates Study Centre had been opened, and we were very much involved in educating local physicians and others involved in palliative care.¹²⁷ Although St Christopher's continued to take a significant lead in relieving emotional symptoms, the pain relief had improved enormously in other hospitals in the area.

Dr Christina Faull: I wonder if I can go back to an earlier conversation and pick up some of the tensions we've been talking about as well: tensions between the NHS and the hospice services and tensions perhaps between the specialties. And maybe also a comment as to why this wasn't picked up by the College of Radiotherapists as a specialty; why it was under the physicians? We've mentioned the Royal College of General Practitioners¹²⁸ but not the other medical Colleges; and there are tensions between palliative medicine and oncology, both branches of that, that people may wish to comment on, or be able to comment on.

¹²⁵ Parkes (1977, 1978, 1979a, 1980, 1981).

¹²⁶ Parkes and Parkes (1984).

¹²⁷ Dr Colin Parkes wrote: 'By 1973, the world was beating a path to the Hospice and our limited teaching facilities were swamped. The Wates Study Centre was opened with much improved facilities and the staff to meet the need. From the outset they had a special remit to educate local physicians and others in palliative care. When, in 1977–79, we repeated my evaluation we found that, although families reported that the relief of pain and distress at St Christopher's had continued to improve, so it had at other local hospitals, both before and during the terminal period of care. We concluded that pain and distress were no longer a serious problem in either setting. Where St Christopher's still had a significant edge over other hospitals was in the proportion of family respondents who reported very great anxiety (13% and 46%). As before, the phrases which, from a check list of six, best distinguished St Christopher's from other hospitals were "Don't Worry" (65% and 46%) and "The hospice/hospital is like a family" (87% and 8%) (Parkes and Parkes (1984)).' E-mail to Ms Caroline Overy, 10 September 2012.

¹²⁸ See page 32 and also comments by Dr Bill Noble on page 48.

Twycross: A rag bag of comments. David Clark mentioned countries where palliative care or palliative medicine is a recognized specialty or subspecialty. I think in Poland it is definitely a subspecialty and has been for some years. In India it is now a full specialty, agreed at the end of 2010 (although they're still finalizing the three-year training programme). Geoff, you were talking about the difficulties of being a consultant in palliative care in the early days, and, Richard, you've referred to that. The APM was founded in October 1985 and I was the Treasurer – I resigned after two months. I was burnt out, having moved from St Christopher's to be the first Medical Director at Sir Michael Sobell House in Oxford in August 1976. Being young and enthusiastic, I'd thrown myself into it in a big way, and although I was employed as a consultant physician, I developed the academic side, teaching medical students and supervising research fellows, etc. The patient load was increasing all the time; and after nine years I ran out of steam. That's probably a danger for pioneers. I doubt if I was the only one who burnt out. Fortunately, it's not always a fatal disease and it wasn't for me, but I had to face up to the fact I'd expanded my job and turned it into two jobs. I was trying to be a medical director/consultant physician full-time and also be heavily involved in writing, teaching and research, so I had to decide which way to go. In the end I decided to opt for the academic side, and that, of course, meant that I would have to leave Oxford as there was no academic opening locally. In the event I was enabled to stay, thanks to the intervention of the National Society for Cancer Relief (NSCR).¹²⁹ At this point, I would like to emphasize my personal debt and that of the whole specialty, to NSCR. I couldn't have stayed in Oxford had it not been for Major Garnett and the NSCR. I'd like to emphasize that point.

I trained in Oxford and so, when I returned to Oxford in 1976, all the senior doctors knew me; they had taught me. That gave me an advantage, and within a year I received a letter asking: 'Will you take medical students for a fortnight at a time?' I wrote back and said: 'Not yet. We'll take them for two half-days while they're attached to radiotherapy. We need to write down more of the science first. I'll get back to you when we've done that.' So eventually we had them in batches of 20–25 for a week-long course from about 1983. From the mid-1990s you couldn't qualify in medicine in Oxford unless you had been signed up for the palliative care module. It was compulsory, there was nothing optional about it. We had medical students saying: 'When we qualify we are

¹²⁹ Dr Robert Twycross was Macmillan Clinical Reader in Palliative Medicine at Oxford University (1988–2001). The NSCR is now Macmillan Cancer Support see note 82.

going to opt for palliative medicine’, and I believe that was because of their exposure for one week. It was ‘piggy backing’ on a background of high quality communications skills training, which went right through the clinical course, and on a background of exposure to ethics and legal aspects of medicine. One week in palliative care has been decisive for many Oxford graduates who have subsequently specialized in palliative care.

What about the research? Geoff Hanks was my first full-time research fellow paid for by the Halley Stewart Trust¹³⁰ (my time at St Christopher’s had also been paid for by the Halley Stewart Trust). My second research fellow, Claud Regnard,¹³¹ was paid for by NSCR, who had already paid for him to have a one-year registrarship with Ronnie Fisher. My third research fellow, Helen Taylor,¹³² was paid for by the Imperial Cancer Research Fund. Then, in the early 1990s I was running out of steam again and had to decide whether I’d concentrate on writing and teaching or on research. I decided on the former, partly because others at Sobell House were working for doctorates at the time, including Sara Booth and Andrew Wilcock.¹³³ However, subsequently, palliative care research in Oxford dwindled during the late 1990s – at the time that it was burgeoning in other areas of the country.

Finlay: May I go back to the period between 1987 and 1995. Certainly Marie Curie were looking at changing policy and establishing posts as medical directors. My post, for example, was this, one full-timer with a 38-bedded unit with day care; the only thing they forgot is that I might need to be able to prescribe. So I arrived on day one with no provision as to how I could prescribe anything because, although I came from the general practice stable, of course,

¹³⁰ Founded by the businessman, MP and philanthropist, Sir Halley Stewart in 1924, the Trust is a grant-giving organization with a Christian focus supporting religious, social, educational and medical projects.

¹³¹ Dr Claud Regnard is a consultant in palliative medicine and was the first Medical Director of St Oswald’s Hospice, Gosforth, Newcastle upon Tyne, from 1986 until his retirement in 2011.

¹³² Dr Helen Taylor is a consultant in palliative medicine at Ty Olwen Hospice at the Morriston Hospital, Swansea.

¹³³ Dr Sara Booth is Macmillan Consultant in Palliative Medicine at Cambridge University Hospital’s NHS Foundation Trust. She held posts in St Christopher’s and Sobell House before moving to Addenbrooke’s Hospital, Cambridge, becoming the first palliative care consultant. Dr Andrew Wilcock is Macmillan Clinical Reader in Palliative Medicine and Medical Oncology at Nottingham University, and consultant physician at the Macmillan Specialist Palliative Care Unit, Nottingham University Hospital NHS Trust.

I wasn't locally registered. That was an experience that was replicated by others around the country, going into new units, particularly when they came from general practice, there was a presumption that they would use their GP pad to prescribe. All the regulations around controlled drugs¹³⁴ were completely unknown to the people who had raised the funds to build these lovely hospice units. There was an awful lot of local pioneering that had to happen.

Going back to Clive's comment about it being Christian faith-based, I have sometimes wondered whether there were two things going on. The first was that the people who survived needed to have something else to hang on to, because they were fighting battles every day, on every front, but could never be seen to be fighting a battle. It was a bit like a musician, you're only ever as good as your last performance. So you were trying to persuade colleagues that actually you were a proper doctor, not a trumped-up GP, which certainly kept on being thrown at me, and that you might know what you were doing to a certain extent. You knew that you were being judged all the time and so you had to be very careful. That was extremely good because it meant that we could never be critical of other people at all, and that may be why relationships with some areas have been so good, with people like the oncologists.

Secondly, there would be serendipity, so somebody who had really been opposed to what one was doing, or trying to do, would suddenly have a relative who was ill. Certainly I had several phone calls on a Sunday morning or Sunday afternoon, and by going out and responding fast, that block disappeared. I think that that was an experience that others have had around the country (some of you are nodding). I don't think we should underestimate the impact of your report, Ken, the Calman–Hine Report, which Andrew referred to and I had the privilege of being on your committee.¹³⁵ Putting palliative care in there with core disciplines named in that report, did a great deal for the specialty because it aligned it with, and made it part of, cancer care that was very established.¹³⁶ It helped too with oncology, opening doors to make it much easier to get time in the undergraduate curriculum and so on. A lot of the undergraduate curriculum time was initially won by people saying: 'Well, I'm ready to give a lecture whenever you have somebody drop out. I happen to have a few slides

¹³⁴ Drugs controlled by the Misuse of Drugs Act (1971), schedule 2 controlled drugs, i.e. including opiates, etc.

¹³⁵ See note 79.

¹³⁶ See the Calman–Hine Report; Department of Health and the Welsh Office (1995): 16.

always in my pocket.’ Once they did a lecture and it was appreciated, the word got back so that when somebody dropped out somewhere else, they could acquire another lecture slot, and so on. So it quite rapidly became seen that we were there to be helpful, we were there to smooth the way for the others and to make life easier for them; we’d fill slots. That may be why, generally, we have been so well accepted across areas of teaching, across areas of research and across clinical provision.

Gaffin: I want to put on the record some of the early publications of the National Hospice Council. The work on definitions, defining what is palliative care, what is specialist palliative care.¹³⁷ Also a couple of examples of soft research. We got some money from the Department of Health to do a study of why hospice care was so incredibly white, both in terms of the staff and the patients, which 20 years ago, started that debate.¹³⁸ Also, we published the first work on hospice care and non-malignant patients, when we got Julia Addington-Hall to write for us.¹³⁹

Noble: I’d like to say a word about how fast the specialty grew, and I feel that this was partly due to the Royal College of General Practitioners (RCGP). Remember, at the time, the RCGP was still feeling a bit new and uncertain of itself, and I don’t think it wanted anything ‘flaky’, at the time.¹⁴⁰ The other thing was that it had a clear philosophy that it was not possible to subspecialize in general practice – that was completely against the grain of what they’d been working towards. They didn’t really look for any subsection of RCGP that spent most of their time doing one thing. Palliative medicine was never going to work as a division of the RCGP.

It was quite obvious at the time, however, that the leaders were spending a lot of their lives doing this special thing and it needed to be seen as different. So even when the leaders were looking for research grants, again, general practice didn’t step up to the mark. I can vividly remember one remark in an RCGP grant-

¹³⁷ National Council for Hospices and Specialist Palliative Care Services (1995).

¹³⁸ Hill and Penso (1995).

¹³⁹ Addington-Hall (1998). Professor Julia Addington-Hall is Professor of End of Life Care at the University of Southampton.

¹⁴⁰ The Royal College of General Practitioners was founded in 1952 and received its Royal Charter in 1972; see www.rcgp.org.uk/about_us/history_heritage__archives/history__chronology/history_essay.aspx (visited 4 July 2012).

giving committee: ‘I’m not sure that doctors should be doing this stuff. Isn’t that what Macmillan nurses do?’¹⁴¹

Hillier: There were two things that helped me about undergraduate training. The first one’s pretty obvious and that is when you get a sympathetic Dean of the School of Medicine, in our case Professor Charles George,¹⁴² you’re laughing. The second, and I would think is even more important, was when, in the early 1990s, there was one question involving palliative care in every finals paper. This transformed interest in palliative care across the medical school and clinicians.

Calman: One final point. Currently with my National Cancer Research Institute hat on: one or two groups, mainly charities, are getting grants in the area of palliative care, and some of them don’t know how to referee them properly. We’re going to build up, with your help, a list of accredited people who could review a grant for our particular specialty subject, which will give them credibility. So that’s another way in which the credibility of the research can be built up. Send the research grant to a group who have never thought about palliative care before and it’s likely to be turned down. If they’ve got a group of people, who would say: ‘Yes, very happy to referee that for you’ then it might change the setting.

I was going to say a little about the development of a new specialty. When I became Professor of Oncology in 1974, 60 per cent of the patients referred died in a month without treatment. This was not a palliative care service. I discussed this with my orthopaedic colleague; we had a very distinguished professor of orthopaedics in the hospital, appointed 30 years before.¹⁴³ He said that in his first year he was dealing with triple fractures with pus coming out, and they looked at him and said: ‘See what you can do with that, then, professor’, because orthopaedics was not really a specialty – general surgeons did it at the time. The reflections here, in a much more general sense, are interesting about how new specialties become established, develop and the success of some and the failures of others. That’s a general point, let’s discuss now the relationships with other professional groups.

¹⁴¹ Dr Michelle Winslow wrote that Dr Bill Noble had commented that this was at a committee on psychological problems in cancer patients in around 1990. E-mail to Ms Caroline Overy, 2 October 2012.

¹⁴² See note 67.

¹⁴³ Roland Barnes (1907–1998) was the first Professor of Orthopaedic Surgery at Glasgow University, from 1959 until his retirement in 1972.

Dame Barbara Monroe: I'm a social worker by background and I started at St Christopher's in 1987. I'm currently Chief Executive, which I think probably says something about multi-professional working, although I took over as interim Chief Executive in 2000, when St Christopher's was having financial difficulties, and I always thought rather amusedly to myself: 'Goodness things must be bad if they've made a social worker Chief Executive!' I was asked to talk about relationships and I want to address a few thoughts about that. The first was, before thinking about multi-professional relationships, the absolute importance of intense personal relationships in the development of this field. Most people who have spoken this afternoon have talked about the importance of their personal relationships. Certainly, if we think about Cicely herself, the relationships she had with all the famous Poles that we're aware of in her life,¹⁴⁴ and the very close personal friendships with people like Gill Ford, Tom West¹⁴⁵ and Mary Baines. Also the nature, almost ritualized in the story subsequently, of her relationship with certain patients; Mrs G springs to mind.¹⁴⁶ So that aspect of relationships is important. Next I think it's impossible to over-emphasize the importance the professional space held for the importance of relationships and families through the structured research of Colin Murray Parkes and John Hinton. John Hinton's work, in particular, looking at what happened in people's homes, and looking at the different trajectories of understanding and acceptance of family carers and patients, really gave some sort of intellectual backbone to thinking about relationships.¹⁴⁷ Multi-

¹⁴⁴ In 1948, while working as an almoner, Cicely Saunders became very close to David Tasma, a Polish émigré who was dying in a London hospital; the relationship had a profound influence and led to her realization of the need to change attitudes towards pain control and care of the dying. Having qualified in medicine, and while working at St Joseph's Hospice in Hackney, London, in 1960 she met another Polish patient, Antoni Michniewicz, with whom she also had an intense spiritual relationship, and who inspired her to set up her own hospice, St Christopher's. In 1963, Saunders became friendly with the Polish artist Marian Bohusz-Szysko, whom she married in 1980 after the death of his estranged wife in Poland. For her biography, see du Boulay (1984, 2007).

¹⁴⁵ Dr Tom West trained with Dame Cicely Saunders at St Thomas' and was Deputy Medical Director at St Christopher's (1973–1985) and Medical Director (1985–1993). An interview with Dr West has been recorded by the Hospice History Programme in 1997; see www.hospice-history.org.uk/byoralsurname?id=0119&search=w&page=0 (visited 4 July 2012).

¹⁴⁶ Dame Cicely Saunders had a close friendship for many years with a patient, Mrs G, who died in 1961. See Saunders (1961).

¹⁴⁷ See, for example, Hinton (1994, 1996, 1998, 1999).

professional teams: Cicely, of course, famously, was a one-woman, multi-professional team – nurse, social worker, doctor. I think that did mean that from the beginning, and certainly when I joined St Christopher's, there was a respect for other disciplines and their contribution that was very apparent, and very releasing in terms of energy and enthusiasm. It was important to the development of the work that all of us, including doctors, do, that Cicely was so clear in her articulation from the very beginning that family was important, not as a subset of carers for the dying person, but as an object of care in itself. And also the articulation of family with a strengths-based approach rather than diagnosing their problems, and that we should be working with families as partners. The idea was to help patients and families delineate what was important to them for themselves, and to offer support with that and to remember the importance of their social context. We don't always live up to those ideals, but I think they have been really important in shaping the way that we practise. Nursing is incredibly important in palliative care and it has an interesting relationship with medicine and continues to do so. My own feeling at St Christopher's was that it was as the community, as the home care service developed, that nursing really found its voice and began to partner and to argue most productively with medicine. Some of those creative tensions continue today, and they're really important. As far as social work was concerned, the early work of Elisabeth Earnshaw-Smith's writing, in a way the equivalent of some of the pamphlets written by Cicely and Mary, about emotional pain in families, was very important,¹⁴⁸ as was the work of Frances Sheldon, who, of course, also established an MSc in Psychosocial Palliative Care at Southampton University.¹⁴⁹ For myself, I think we need to remember that not everything was perfect. When I joined St Christopher's in 1987, I was absolutely shocked at the lack of any detailed attention paid to children, when somebody significant in their family was dying. So, for me, that was something I could bring, and, like Elisabeth and Frances before me, I was very concerned to create a simple

¹⁴⁸ Miss Elisabeth Earnshaw-Smith was Principal Social Worker at St Christopher's Hospice from 1980. She founded and chaired the Association of Hospice Social Workers in 1987. See, for example, Earnshaw-Smith (1981, 1982).

¹⁴⁹ Mrs Frances Sheldon (1940–2004) was appointed as the first social worker at Countess Mountbatten House, Southampton in 1977. From 1986 to 1991 she was involved with the education team at the hospice, and the courses in palliative care for hospice staff, medical students and a wide range of professional medical staff; she also developed the first MSc in Psychosocial and Palliative Care in Europe. Her writings include the textbook *Psychosocial Palliative Care*, Sheldon (1997).

articulation of what would help children when somebody in the family was dying.¹⁵⁰ All of us, as social workers, at that time, were trying to give away our insights and make it possible for other professionals to use them. We also need to remember that hospices were very much slower places then, so there was more time to debate, develop and practise new patterns of care. Certainly, when I joined St Christopher's, some patients still stayed a long time on the inpatient unit; patients with motor neurone disease might stay many months. We're now operating at about 99 per cent occupancy; most people don't stay longer than 14 to 17 days; the pace is different. So we all had time to articulate our thinking and to plan, and we need to remember that. Ward rounds were a place where you could begin to work out how to work together as multi-professional teams. Family meetings were places where cohorts of young doctors and nurses learnt from social workers and others how to talk to more than one person, because medicine still tends to focus on communication skills on a one-to-one basis. I can remember people like Michael Kearney, Tony O'Brien, John Ellershaw and other young doctors coming through and saying how important those insights were.¹⁵¹ Also, to say that all of this multi-professional effort wasn't unique, it was being done all over the place at the same time, and it wasn't unique to hospices either. Before I went to St Christopher's I worked in a specialist NHS neurology/neurosurgery unit where, as a social worker, I was absolutely engaged in training all the junior doctors, rather more so than I was when I first got to St Christopher's. In the 1970s I worked as a GP-attached social worker in a hellish housing estate for an enthusiastic group of young GPs, and I was paid for by the local authority and we used to go and do joint visits. There was an entire kind of social milieu in which all of these pieces of thinking were happening. What was different about multi-professional work in hospices was the depth of coordination, both internally and externally, including making relationships with other organizations and professionals. The doctors in the field were very interested in multi-professional work, and were generous about soliciting

¹⁵⁰ See, for example, Monroe (1990, 1993); Monroe and Kraus (1996).

¹⁵¹ Dr Michael Kearney trained and worked as a registrar at St Christopher's (1980–1982) and was for many years Medical Director of Our Lady's Hospice in Dublin. He is currently a medical director of the Palliative Care Service at Santa Barbara Cottage Hospital, California. Dr Tony O'Brien worked at St Christopher's in the mid-1980s and is Consultant Physician in Palliative Medicine at Marymount Hospice and Cork University Hospital School of Medicine, University College, Cork. Professor John Ellershaw is Director of the Marie Curie Palliative Care Institute and Medical Director of the Marie Curie Hospice, Liverpool; he is Clinical Director at the Directorate of Palliative Care, Royal Liverpool University Hospitals. He worked at St Christopher's from 1989 to 1994.

articulations of multi-professional work as the textbooks and the journals began to appear. It is quite important to note that the journal *Palliative Medicine*, which I think started in 1987, had a subtitle that said something like ‘for a multi-professional group’ or ‘a multi-professional journal’ or something like that.¹⁵² The first *Oxford Textbook of Palliative Medicine* had a heavy emphasis on the nursing contribution, but also contributions about music therapy, chaplaincy and spiritual care and physiotherapy and the importance of volunteers and much more.¹⁵³ Training and education programmes developed to promote the concept and value of multi-professional work and of working with the patient and their family. At St Christopher’s, we were training GPs and district nurses, but also teachers, the police and funeral directors. More recently this work has stretched out towards care homes and to promote the absolute importance of integrating health and social care at the end of life. When I got to St Christopher’s, a week-long training in multi-professional work had already been established. Michael Kearney, Len Lunn, Sue Hawkett¹⁵⁴ (who later worked with Mike Richards on the National End of Life Strategy¹⁵⁵) and I revamped this with lots of role play and interactive techniques, and everyone – doctors, nurses, social workers, physios and others – all worked on the same content together. This course still runs two or three times a year with 20–30 members, many from overseas.¹⁵⁶ Finally, in terms of relationships, there continues to be a tension between a medicalized approach to hospice care – and perhaps getting ever more so, recognizing, of course, that good symptom control is paramount – and a more public health, community-focused approach, including a more creative and extensive use of volunteers. This community approach will become more important as we see the full impact of an ageing population with multiple chronic conditions. Doctors tend to want everyone to have a ‘patient record’ in order to really exist, and they talk about having ‘the ultimate responsibility for

¹⁵² *Palliative Medicine*. The Research Journal of the European Association for Palliative Care – A Multiprofessional Journal (1987).

¹⁵³ Doyle *et al.* (eds) (1993).

¹⁵⁴ Reverend Len Lunn was Senior Chaplain, St Christopher’s Hospice 1987–2004; Mrs Sue Hawkett worked at St Christopher’s during the 1980s and was later Head of Life Care at the Department of Health. She was awarded an OBE in 2005 for services to nursing and palliative care.

¹⁵⁵ See note 157.

¹⁵⁶ For courses at St Christopher’s Hospice see the education section of their website at www.stchristophers.org.uk/education/ (visited 9 July 2012).

the patient'. In the future we may need a looser approach to services, with people selecting their own 'menus' and dipping in and out of a variety of supports.

Dr Julia Riley: I endorse what Barbara says. The future is a patient-centric model with care being delivered along an integrated pathway. The pathways should start with the patient participating in the development of his/her own personal plan. Different professionals can enter the patient's pathway at different times along the journey. The key to a good care plan is communication and coordination. The ability to share information across the whole of health and social care is essential. If palliative care is to make the next giant leap and lead the way towards a new model for integrated care, the ability to capture and, crucially, share information across all facets of the patient pathway is a fundamental requirement. The End of Life Care Strategy has set the building blocks for Electronic Palliative Care Registers to do exactly this.¹⁵⁷

Hoy: I had wanted to emphasize the importance of non-doctors in the development of palliative care, especially the crucial role of nurses. This was at the time when hospice-style care was being re-integrated into mainstream hospital practice. I mentioned that nurses were very important in relating to not only patients and families but also colleagues when the St Thomas' palliative care team was initiated in 1977.¹⁵⁸ Another profession was that of pharmacy. The St Thomas' team was welcomed by pharmacists when we started, not least because I believe that they wanted to see more rational prescribing within the hospital. Another group were the nurse educators at the Nightingale School.¹⁵⁹ They invited the new team into the student nurses' programme and gave us great encouragement and opportunities to teach. I also mentioned the multi-professional nature of palliative care. An example of the development and teaching of multi-professional working is the Interprofessional Practice Education (IPE) project, which has been developed at St George's. Three years ago, I was approached by the organizers of the IPE from St George's, Kingston and Brunel universities about rolling out this project in a palliative care environment. There is now a successful three-week programme running, which

¹⁵⁷ Department of Health (2008). The strategy was developed by an expert advisory board chaired by Professor Mike Richards, National Cancer Director at the Department of Health since 1999.

¹⁵⁸ See page 27 and note 78.

¹⁵⁹ The Nightingale School of Nursing at St Thomas' Hospital, London.

offers senior medical, nursing, physiotherapy and occupational therapy students the opportunity to work together on the inpatient unit of the Princess Alice Hospice.¹⁶⁰ They are encouraged to run that part of the ward effectively within the constraints of their abilities and registration. Apart from learning palliative care, they crucially learn to work together and appreciate true interdisciplinary functioning.¹⁶¹

Finlay: In Cardiff in 1987 we were pump-prime funded by Macmillan to set up the Diploma in Palliative Medicine. It had a small number of doctors, mostly GPs, in the first group of graduates, which now has over 100 doctors each year and has also allowed progression to an MSc for those who are doing well. For many of the doctors who went through the course, this was the only education in palliative medicine they had. They were running local hospice services, working like consultants, without recognition. As they gained experience it became a route for many of them to be recognized as consultants as the regulations became tighter, and they were ‘grandfather cloused’¹⁶² onto the specialist register and have gone on to be leaders and trainers in the field. We made some wonderful recordings with early pioneers, such as Mary Baines and Cicely Saunders. We developed role play to teach communication skills and examined communication skills as part of the Diploma exam. We have had many graduates who are in the world and who have gone on to develop courses of their own.¹⁶³ Indeed, imitation is the most sincere form of flattery. The course has expanded to include a palliative care route for non-medics, but interestingly we repeatedly get feedback that the medics value the course learning with other medics, as they have some distinct problems and learning needs, particularly around the science and around their general medical diagnostic roles. In some ways I am disappointed we have not had more pharmacists, physiotherapists and occupational therapists on the course over the years, but the numbers are increasing.

¹⁶⁰ The Princess Alice Hospice, Esher, Surrey.

¹⁶¹ For the report on an evaluation of this programme, see Dando *et al.* (2012).

¹⁶² A legal provision to allow exemption based on pre-existing regulations.

¹⁶³ For example, Dr Liz Gwyther (2002) in South Africa; Professor Karen Forbes (1992) in Bristol; Dr Max Watson (2000) in the UK; Dr Suresh Kumar (1997) in India; Dr Srinagesh Simha (2001) in India (E-mail from Ms Sarah Evans to Ms Caroline Overy, 2 October 2012); Baroness Ilora Finlay wrote: ‘The Melbourne course also was originally modelled on our Cardiff course; I worked with David Kissane on it.’ E-mail to Ms Caroline Overy, 3 October 2012.

Calman: I certainly remember notes that would say: ‘dietician to see’, a clear example of referral within a multi-disciplinary team.

Clark: At this time, I think palliative medicine had to face two ways. On the one hand it had to gain the respect of the wider medical community and to be seen to produce robust evidence in support of its claims and this involved a narrowing of focus. On the other hand, it had to play its part in a multi-disciplinary endeavour where the goal was the total care of the patient. I suspect that many doctors were drawn into the work by the latter emphasis, but found themselves needing to focus on the former in order to advance the knowledge claims of the specialty. There were other issues too – we saw a couple of years ago that there could be, in Max Weber’s phrase, examples of the unintended consequences of action. I am thinking here of the publicity that arose about the use of the Liverpool Care Pathway,¹⁶⁴ which was portrayed in some quarters as a kind of back-door route to euthanasia, and was misrepresented as such in the press, when in fact the instigators of the pathway (themselves opposed to euthanasia) had seen it simply as a way to ‘roll out’ good hospice principles of symptom management into the wider care setting of the hospital.

Faull: I was, I think, in the second cohort of senior registrars and I want to start by giving something of my personal journey to palliative medicine. I qualified in Newcastle in 1985 and had no recollection of any contact or teaching on palliative medicine. Conrad House, a Marie Curie home, was seen as a dark place of much suffering. I was first introduced to palliative care by hospital social workers when I worked in New Zealand. They shared with me the work of Kübler-Ross.¹⁶⁵ I tried various hospital-based specialties and remember coming across an advert in the *BMJ* for a senior registrar in palliative medicine in 1991. I spent a few days at St Oswald’s Hospice¹⁶⁶ at the suggestion of some GP friends, and then had an interview at which I failed to convince Derek Doyle that I knew enough. I was more fortunate in Leicester, although Dr Ahmedzai had told me before interview that it was unlikely that I would get the post, given that I had no experience in palliative medicine.

¹⁶⁴ See note 207. For a discussion of the adverse media publicity in October 2012, see McCartney (2012).

¹⁶⁵ Dr Elizabeth Kübler-Ross (1926–2004) was a Swiss-born American psychiatrist, author of *On Death and Dying* (Kübler-Ross (1969)), in which she introduced the Kübler-Ross model ‘the five stages of grief’, originally applied to people suffering from terminal illness.

¹⁶⁶ St Oswald’s Hospice, Gosforth, Newcastle upon Tyne.

I arrived in Leicester in what seemed to be the middle of the medicalization of dying debate. The matron at Leicestershire and Rutland Organisation for the Relief of Suffering (LOROS) had written a key chapter in this debate,¹⁶⁷ and I was thought successful in negotiating a drawer for my belongings in the ‘ward office’, which was essentially the nurses’ office. These wonderful nurses taught me the foundations for palliative care.

It would be useful to look at the impact of training doctors on hospices and on nurses. This was new for them and they were, and remain, very strong patient advocates, seeking to protect patients from anything that is less than perfect. Supporting the training of doctors was quite novel and part of this medicalization of dying debate. There are now very junior doctors, even FY1 doctors,¹⁶⁸ working in hospices, which is an amazing progression, but continues to produce tensions.

For me the Doyle Club was a key factor.¹⁶⁹ Meeting with the other 20 or so senior registrars has produced an ‘alumni’ feeling and when I had the opportunity to be an editor for the *Handbook of Palliative Care*,¹⁷⁰ which went on to be awarded the BMA book of the year in 1998, it was to my alumni colleagues I turned. These enthusiasts produced fresh and exciting work. I would like others to talk about the influence of the Doyle Club and what brought it in to play.

Monroe: I think the fact that hospices had well-developed, multi-professional teams meant that they were well placed to respond to the needs of more complex patients and families with pre-existing disadvantages and vulnerabilities, being preferentially referred in increasing numbers. To me this shift partly coincided with the rise in the number of hospital support teams. I am thinking of individuals such as refugees and asylum seekers, living in appalling housing conditions, not understanding the structures of welfare support, with poor English, children not well integrated and few social supports. Also people with primary, longstanding mental health problems or drug or alcohol problems, and families where there is a history of abuse. Also to respond to that jibe about

¹⁶⁷ Mrs Bronwen Biswas was Matron of LOROS (1985–2001) and wrote on the medicalization of dying from a nurse’s perspective; Biswas (1993). Professor Sam Ahmedzai also wrote from a doctor’s perspective; Ahmedzai (1993).

¹⁶⁸ Doctors undertaking the first year (FY1) of the two-year foundation programme, a postgraduate general medical training course in the UK.

¹⁶⁹ See pages 68–9.

¹⁷⁰ Faull *et al.* (eds) (1998).

hospices being white and middle class – ‘deluxe dying for the privileged few’¹⁷¹ – at St Christopher’s 20 per cent of our patients are non-white British and more than half come from the two most deprived quintiles of the index of multiple deprivation.

Ford: When I was appointed to run the study centre at St Christopher’s in 1985, there was already a well-established education programme of courses, lectures, national and international conferences – even that list does not cover all the events – and I think it is safe to say that there was something for everybody. The extent to which the different professions would be learning together was deliberately obscured in some instances lest the doctors might be put off applying for the week-long course if they realized how much they would be joining with other disciplines. I am glad to say that subterfuge was dropped and multi-professional events became more and more the norm with, we believed, great advantage to team working whether in hospital, community or hospice.

Comments have been made on what had been termed the ‘medicalization’ of death and the focus of palliative services on cancer. When we look at the start and Cicely’s vision of a better way of looking after dying folk, I remember the influence on her of the consultant surgeon at St Thomas’ Hospital who memorably said: ‘It is the doctors who desert the dying’,¹⁷² and later added that if she was to make a difference she would have to qualify as a doctor: ‘Doctors only listen to doctors.’ Patients with a diagnosis of terminal cancer in those days were sometimes treated with what seemed like conspicuous lack of attention. The enormous support from various cancer care charities gave the movement much needed impetus in that direction. Should palliative care services have reached out much earlier and faster to patients with other diagnoses? Perhaps it has actually encouraged physicians in other specialties to adopt similar approaches, rather than to lament that their patients are excluded. It might also be argued that the body of knowledge and research might have built up more slowly if the focus had been less narrow.

George: I would like to comment on what Barbara was saying about multiculturalism and the impression that one had from the outside, in those days at least, that hospice made it clear that it wasn’t for everyone.

¹⁷¹ In 1992 Colin Douglas wrote ‘Why should only the minority who die of malignancies – and precious few even of them – be singled out for deluxe dying?’; Douglas (1992). See also note 138.

¹⁷² The thoracic surgeon Norman Barrett (1903–1979), cited in Saunders (2001): 430.

Those coming from non-cancer clearly had the same spectrum of problems as those dying with cancer, yet it was so hard – and depressingly, it still can be very hard – to get hospice engagement for patients with unfamiliar life-limiting diseases, facing complex problems and difficult social circumstances. Because I came into palliative care medicine in 1987 through starting services for people dying with HIV in central London, caring for people based on need and not diagnosis, culture, status, etc., has been a passion for me from the start. In fact, in the early 2000s, I made the moral case for non-cancer palliative care in a seminal book of that title, edited by Irene Higginson and Julia Addington-Hall,¹⁷³ sadly neither of whom can be here today, concluding that, if dying people have a common spectrum of problems and needs as those with cancer, yet hospice and specialist palliative care services seemed to exclude them, then there must be some inherent moral worth in having malignancy. Indeed, if this absurdity was the case, then it would mean we should be encouraging smoking, etc. Anyway, where this bit most, of course, was with the arrival of the HIV epidemic when I found it extremely difficult, with the notable exception of Andrew Hoy at the Princess Alice, to get anyone admitted who did not have a cancer, which ‘fortunately’, I hesitate to say, many did in the form of Kaposi’s Sarcoma¹⁷⁴ or lymphoma.

However, there were occasions when other reasons were found for not taking HIV patients. To be fair, there were other technical issues beyond the visceral fear that HIV seemed to engender in those days, and that was the therapeutic complexities of HIV medications, that it was multisystem and that the spectrum of medical problems were often extreme and very challenging to mitigate symptomatically. This was one of the reasons for the support model for other palliative care services that we ran from the Bloomsbury Community Care Team at the Middlesex Hospital, London,¹⁷⁵ to encourage them to engage with HIV patients who lived locally but had travelled into central London for the expertise, anonymity and confidentiality that the academic centres then offered. The current version of this battle for us all, of course, is now the extent to

¹⁷³ Wasson and George (2001).

¹⁷⁴ A cancer usually affecting the skin and mouth that was one of the first HIV-related illnesses to be recognized in the early 1980s.

¹⁷⁵ For further details on the Bloomsbury Community Care Team, see George and Hart (1989); Butters *et al.* (1991).

which we move into involvement in long-term conditions, with their technical complexities and often untidy patients and the models we will need to develop to support them.¹⁷⁶

Seale: In the 1980s and the 1990s a number of us were interested in the applicability (or otherwise) of the hospice approach to care of non-cancer patients. Julia Addington-Hall was one of them, and I also remember writing about this.¹⁷⁷ As Rob George has said, there was the matter of what the hospice movement was able to do for people dying with HIV/AIDS, a problem that has of course diminished with the advent of effective antiretroviral treatment. There was considerable tension about this in the 1990s, I recall, as the public view of people with HIV/AIDS was felt by many to differ from that of people with cancer, creating something of a dilemma with hospice advocates, perhaps concerned to maintain the success of their fund-raising activities. Of course, specialist hospices like London Lighthouse¹⁷⁸ and Mildmay Mission Hospital arose at that time as well, caring for people with HIV/AIDS.¹⁷⁹

Baines: Cicely had in mind a service at home staffed by nurses on the ward who knew the patient, but obviously that wasn't going to work and so she asked Barbara McNulty, who had been a district nurse, and myself, who'd been a general practitioner, to start the first hospice at home service. This was in 1969. And I'm so grateful for this; we spent quite a number of months going round local general practitioners and district nurses saying: 'Do you want a service at home? And if so, what shape do you want it to be?' The answer we got back was: 'Yes we do want a service. We want advice on symptom control and support and counselling, but as general practitioners, we want to remain in charge of patients at home, and the district nurses to do the major part of the basic nursing that was needed.' So that was how we set up the service and it opened in October 1969.¹⁸⁰ I was the doctor, Barbara McNulty was the

¹⁷⁶ Professor Rob George wrote: 'This is the new group of patients that I call the disadvantaged dying'. E-mail to Ms Caroline Overy, 2 October 2012.

¹⁷⁷ Seale (1991).

¹⁷⁸ The London Lighthouse, Ladbroke Grove, London, opened as a residential and support centre for people with HIV in 1988; the residential unit was closed in 1998 owing to reduced need. In 2000 it merged with the Terrence Higgins Trust.

¹⁷⁹ The Mildmay Mission Hospital opened in Shoreditch, London, in 1987 as the first HIV/AIDS hospice in Europe. See also pages 64–5.

¹⁸⁰ See Baines (2010).

senior nurse, and from the beginning it was a 24-hour service, 24 hours a day. Not indeed like the 9-to-5 that sadly Macmillan introduced six years later. The second at-home service was staffed by Richard Lamerton, who'd been a doctor at St Christopher's, then went to St Joseph's and started the second service there.¹⁸¹ He'd not been a GP and he believed that GPs were no good at looking after the dying and that district nurses didn't know how to nurse them either. So his service was completely different and he did all the doctoring that was needed, and the nurses, his nurses, did all the nursing. To give him credit, the patients had excellent care, but having said that, of course, it was the wrong way round; a lot of GPs didn't want to refer to him, and slowly that service changed into the sort of service that we had. That was how we began relationships with GPs and, I think, it needs putting on record for any service. In addition, the nurse always made the first visit, and that put the nurse at the key of our service, a very important service. I think that it made nurses into specialist nurses, before the term was widely invented, and, as Barbara said, gave so many competent nurses, quite rightly, a degree of responsibility and power. They were the key for the service, but there were doctors involved in it, of course, from the beginning.

Noble: I wanted to address Clive's enquiry about non-cancer work. I started in the specialty of palliative medicine in 1996 following a career in general practice and in hospice medicine as an associate specialist. I was given the bit of the hospital service in Sheffield that was not particularly cancerous. It was a general hospital with lots of geriatric care. Naturally, as my practice and the practice of my colleagues there grew, we spread into non-cancer very easily, simply because there wasn't that much cancer around. Janet Gahegan, who is here today, was the Macmillan nurse there for many years,¹⁸² and I think I'm right in saying that we received remarkably little resistance to being called in. We were warmly welcomed by the geriatricians who, from day one, seemed to have an instant idea about what we should be doing, mainly because they probably thought: 'Well, if the oncologists are getting some of this, we want some too.' It gradually built up over the years. What happened was that our cancer practice plateaued, but the non-cancer practice continues to grow. Basically, we really never turned

¹⁸¹ Dr Richard Lamerton was a medical officer at St Joseph's from 1970 to 1982. St Joseph's Macmillan home care service started in 1975; see Baines (2010) and Winslow and Clark (2005). An interview with Dr Lamerton was carried out in 1997 by the Hospice History Programme; see [/www.hospice-history.org.uk/byoralsurname?id=0065&search=l&page=0](http://www.hospice-history.org.uk/byoralsurname?id=0065&search=l&page=0) (visited 9 July 2012).

¹⁸² Ms Janet Gahegan's personal reflections on nurses' contributions to the start of multi-disciplinary teams are given in Appendix 4.

anything down. We only turned something down if we had seen the patient first. We never said: 'Oh, that can't be for us.' That enabled people to make reasonable referrals, and I think that's probably a pattern that's experienced in other places.

Hoy: I'm fascinated, Bill, by what you're saying because I've had very similar experiences, and really I wanted to address this issue that Clive mentioned about cancer, non-cancer and so on. When the HIV/AIDS epidemic broke, in the mid- to late-1980s, there were many people dying of AIDS and no antiretrovirals. I was frankly embarrassed by the hospice movement's stricture that actually they would only take AIDS patients who happened to have a cancer. We never produced that regulation. At the Princess Alice we took about 60 or 70 AIDS patients over the next three or four years, who were clearly dying and had made an informed decision that they didn't want to die in their acute HIV unit or at home; they actually wanted to die in a hospice. The really interesting thing that did for the hospice was to make us think very clearly about what we were doing in terms of aspects of confidentiality: how did it impact on the local population's ability to support us financially? Because there were lots of worries that if we stopped being a predominantly cancer hospice we wouldn't get the funding. At that time, 90 per cent of the funding had to be found from charitable sources. Well, I can tell you that the pragmatic ladies of Surrey were far more understanding than colleagues in the hospice movement, so that the message was: 'Somebody's got to look after these people; we're glad you're doing it.' There was, if anything, an increase in voluntary funding rather than a decrease. Of course, as you've said, antiretroviral drugs then came along, and the problem has not been a problem of end of life care for AIDS patients anymore. The other issue of non-cancer patients is very interesting. Certainly before I retired a couple of years ago, the hospital specialist palliative medicine practice was quite different from the hospice practice, and the reason for that is that if you make yourself useful in a hospital, all sorts of people will come to your door and say: 'I'd like to ask your ideas about this, that and the other'. As Bill said, never turn anybody down unless you've seen them. So always go along and see them. We found that well over 50 per cent of our referrals in the hospital were non-cancer referrals, all manner of things. It wasn't the care-of-the-elderly physicians, it was the renal physicians; it was the haematologists (not necessarily with haematological cancers); it was the neurologists; it was the ITU intensivists, and so on. There seemed to be a recognition, perhaps coming with maturity, or relative maturity of a specialty, that you wouldn't dump your colleagues in it, but you would try and be helpful.

I want to make a couple of other comments for the record. I have to say that this medicalization-of-death argument leaves me cold. I think it's a false antithesis to set medicalization of death up against death as a psychosocial event. It's a false antithesis and we should have grown out of that by now. We, the doctors, have got something to contribute, but our colleagues who are non-doctors have got a huge amount to contribute as well. I'm interested that Gill Ford said that hospital palliative care was relatively unopposed in the beginning. It didn't feel like that and, in my memory, it still doesn't. Clearly, having anybody coming and telling you what to do and challenging your long-held beliefs, the more senior you got, was deeply painful. There were many very eminent consultants at St Thomas' who were jolly well not going to be told what to do by some miserable registrar who'd spent a year at St Christopher's. That was not their idea of fun. The one thing where we did score, was that we found that when people did take notice of advice we gave, lo and behold, the patients wanted to go home, and were symptom-controlled enough to do so. Within a year we had a huge caseload of community patients so, of course, we had to do what Mary has suggested, and the hospital palliative care services suddenly had very quickly to build links with the community to try to keep those patients there. Perhaps we should have seen that coming, but that was certainly an evolution that was really important.

Calman: Very helpful comments. We won't take medicalization of death to the vote today, but we'll maybe think about it.

George: A couple of disjointed comments to add more detail to the HIV story in response to Clive Seale. First of all, we must remember that this was the time when the language of need, not diagnosis, was starting to come in, and I think that change of phrasing needs to be recognized – palliative care has moved on to do that, and to see people's needs as distinct from their diagnoses.¹⁸³ As I have said, and experienced with my patients, there was a time when diagnosis was what mattered and we have to be honest about that. The second thing affirms what Bill and Andrew have said. I forbid the use of the word 'inappropriate' in the service I work as a part of. A referral may be unnecessary; it's never inappropriate. To dish out pejorative terms implying that people are idiots,

¹⁸³ Professor Rob George wrote: 'This remains an important challenge, as we are by no means there in seeing our role and relevance extending into the population with multiple comorbidities, frailty and dementia, all of whom have the needs that are familiar to us in Palliative Care.' Email to Ms Caroline Overy, 21 November 2012. For the APM Strategy for 2008 to 2010, see Noble (2009).

because they've referred the wrong patients to us gives a very bad message. A lot of our specialty's services do that. I've worked in a number of settings over the years and I find it a common feature across those palliative care services. The third thing, is to go right back to this religious question that Clive raised earlier on. It found an interesting form in the early days of HIV. Oddly enough, what was really interesting when the HIV problem arose, was that there were two groups that went looking after these patients. One was the work that was started at the Mildmay Mission Hospital, led at that time by Veronica Moss,¹⁸⁴ which came out of traditional Christian evangelicism. The Mildmay, of course, was set up as a hospital for the destitute at the time of the cholera epidemics in the nineteenth century in East London, so they had a tradition of looking after marginalized people, who no one else wanted to have anything to do with. Through the vision of Veronica and Ruth Sims and supported by Ian McColl, they rediscovered that mission:¹⁸⁵ that they might want to look after the newest generation of people that they perceived to be rejected, and so they set up the work for HIV.¹⁸⁶ Then on the other side of London there was another 'religious' community and that was the gay community; I say religious because they had a particular world view in that they had certain things that they valued more than anything else. The London Lighthouse in west London was set up by the gay community for the gay community. It was really quite difficult getting my drug users, or refugees or people with haemophilia, into the Lighthouse. Equally, there were a very small number of hospices that were open to take people with HIV, of which Princess Alice was one. I often used to go trading around to see who I could match up to get in, if I simply couldn't manage them at home. Underneath all this, for the patients there was an explicitly religious dimension to HIV, and that was that people wanted to go somewhere to die where, if you like, their ontology was recognized and their cultural needs were met. That was very, very important, because the HIV community – who were rejected initially

¹⁸⁴ Dr Veronica Moss was the Medical Director at Mildmay International, Uganda (1998–2002) and was the CEO at Mildmay Mission Hospital (2002–2008). See note 179. Mildmay International is an HIV charity based in the UK, sub-Saharan Africa and Eastern Europe.

¹⁸⁵ Ms Ruth Sims was Matron of the Mildmay Hospital from 1987 and was the hospital's Chief Executive from 1991 to 2000. Professor Ian McColl, Baron McColl of Dulwich since 1989 (b. 1933), was Professor of Surgery at Guy's Hospital (1971–1998) and is Vice-President of the Mildmay Centres of Palliative Care in London and Uganda; he has been President of St Christopher's Hospice since 2010. See Sims (1996).

¹⁸⁶ Professor Rob George wrote: 'Interestingly, the first patient admitted there [the Mildmay Hospital] was a mother who had contracted the infection through a brief period of injecting drug use 10 years previously.' Note on draft transcript, 25 April 2012.

by the traditional religious community – tended to correlate the religious community with the hospice community.¹⁸⁷ That's quite an important point to put on record.

Wee: May I move onto the point around growing the specialty? First of all some issues about the specialty's contribution to education in general, and I don't mean about palliative medicine education – I'm talking about undergraduate medical education. First of all I think we need to record David Field's work that started in 1980, and he's done it every decade since. He very generously brought me in in 2000 and has now handed it to me, and we're about to send out the survey again. Over the years he actually recorded the development of palliative medicine within the undergraduate curriculum, and I think that's an invaluable piece of history.¹⁸⁸ It's very interesting to look at the trends: the initial ones were focused more on death and dying; it's now more a palliative medicine survey. Those trends have been very interesting to watch. The second thing is that the Association for Palliative Medicine (APM) developed a curriculum for medical students and for GPs – Ilora was part of that work in the early 1990s. So that's gone on and it is on that basis that in 2006, Paul Paes and I did a Delphi study, which developed a consensus syllabus for undergraduate palliative medicine that has been endorsed by the APM, so that is now the standard curriculum.¹⁸⁹ The final influence in education has been that there has been a number of us here in this room, who have become involved in medical schools and postgraduate deaneries, not with a palliative-care hat on, but in a generic way. That has given us a bit of an influence within the curriculum. Even though it's not been about beating our own drum, it is about gaining that respect. Now, I have a challenge, and it's a question that I hope the collective experience here might give some answers to: as part of the generation that's trying to steer the specialty now and into the future, we do have some dilemmas. For instance, we have always been very willing to help, to step into slots, to be willing to do anything without charge.¹⁹⁰ The environment is changing around us, and part of the difficulty that some of us face now, is how do we meet all those needs that have become

¹⁸⁷ Professor Rob George wrote: 'The Mildmay was critical and instrumental in dispelling that for the gay community. Over time as the immigrant HIV population grew in the 1990s they also developed the mothers and babies unit and a very significant work with refugees and the African community in general, that support initiatives abroad as well.' Note on draft transcript, 25 April 2012.

¹⁸⁸ Field (1984; 1995); Field and Wee (2002). For palliative care in current medical curricula, see note 124.

¹⁸⁹ See Paes and Wee (2008).

¹⁹⁰ See Baroness Ilora Finlay's comments on pages 47–8.

required of us, that we would love to give; but we're working in an environment where, unless you're in an entirely independent sector, those of us working in the NHS are completely constrained by those resources. We also work with junior colleagues coming up who have learnt to work according to the clock. They do grow out of that a little but that culture, I fear, is not going to shift back entirely. Listening to the challenges that you've all faced, I'm aware that this can't be huge compared to what you had. I suppose I'm saying there are different challenges, and if there are any pieces of advice here about how we should steer ourselves, that would be really helpful

Calman: I don't want to lose that; there's quite a lot of data you mentioned there, and it is important to record that because it's helpful to the Medical Student Service. To comment again that, when I became Postgraduate Dean,¹⁹¹ I think it did help significantly because here was somebody who knew what the area was about, and therefore you got into places you might not have got in other ways.

Finlay: A few comments. I'll try to keep each little chunk short. Going to the HIV one initially, that was the time too where there was the 'Don't die of ignorance' public campaign.¹⁹² What happened, when I was working for Marie Curie cancer charity, was that in order to be able to take HIV patients, first of all, the staff needed educating. For one nurse, that involved me seeing her husband, spending time explaining to him that she could look after a patient with HIV and he could still have sex with her and it would be fine, and it could be unprotected sex. Huge ignorance was out there. That one encounter revealed that several other staff were having similar conversations at home. It also meant that we had to get the referrer to say that the patient might have a lymphoma or a Kaposi's Sarcoma, but it would not be ethical to investigate them further, because of the state of their illness. That allowed us to say that they might have a malignancy, which allowed us to take the patient. Marie Curie subsequently saw the light and things moved on and broadened. We did have the same with end-stage respiratory failure, which might be an unproven lung cancer and so on, for a bit. But we'd move forwards, subsequently taking different disease groups

¹⁹¹ Sir Kenneth Calman was Dean of Postgraduate Medical Education at the University of Glasgow from 1984 to 1988.

¹⁹² The AIDS awareness campaign with the slogan 'AIDS. Don't Die of Ignorance', was launched by the Government in 1987. A leaflet was delivered to every household and the public information 'tombstone' advertisement was broadcast on television; this can be viewed at http://nationalarchives.gov.uk/films/1979to2006/filmpage_aids.htm (visited 10 July 2012).

on non-invasive ventilation, then going into acute care, into ITU, helping people with treatment withdrawal and so on. It's always been a major step forwards in education for all the staff in all the disciplines. In the process we've had to rapidly upskill ourselves and learn from those around us. We're going to be continually evolving because the science in all these different medical disciplines is moving forwards and we have patients from all these disciplines. Now modern cardiology is going to throw a lot of challenges to us, in looking after these patients in end-stage heart failure. Our education remit will have to go up vertically across all the disciplines and across the science as well as our research base. I notice that this is called *Wellcome Witnesses to Twentieth Century Medicine*, and I risked straying into the twenty-first century; is that allowed?

Tansey: That's fine.

Calman: Please do.

Finlay: There is this question here before us: 'Politics, ethics and public health'. When Ken became Postgraduate Dean in Glasgow, and later when I became Vice-Dean in Cardiff,¹⁹³ we had a seat at the table with all the deans, including at the Council of Heads of Medical Schools. That was helpful in driving forward the fact that palliative medicine had to be in everybody's curriculum, because they soon got fed up with being asked whether it was. In terms of politics now and where we're going and ethics, I think we contributed to the ethical debate, and the ethical debate around decision making and around conversations is very, very much wider.¹⁹⁴ I know it has had this focus around assisted suicide and euthanasia, which has been disproportionate to the other areas of ethics in which we've contributed. With politics I would certainly concur with Bee's comments on tariffs and contracts in a rapidly changing world. One of the problems perhaps, as a specialty, is that we've done so well that we have a long way to fall. We have to keep ahead; that's a real challenge, I think, to keep ahead of ourselves. I would concur with the anxiety that the training programmes, European working-time directives, etc., are forcing a rigidity of thinking. It becomes difficult to maintain the standards, such as the one we've put across the whole of Wales, that every patient must be assessed within 24 hours of referral. We can do it because we've got seven-day working across the whole of Wales, but it was very difficult to get people to move from five-day

¹⁹³ Baroness Ilora Finlay was Vice-Dean of the School of Medicine at Cardiff University from 2000 to 2005.

¹⁹⁴ For ethics in palliative care, see, for example, Randall and Downie (1999); Webb (ed.) (2000).

working to seven-day working, and to get people who hadn't been on call to participate in an on-call rota across the whole country. It will be difficult to maintain those standards over time if we end up going down the English road, and I hope we don't. Tariffs and quantifying what one does will be difficult because of the heterogeneous nature of the patient population; it is hard to see how palliative care will latch on to the end of different care pathways. The political dimension has been crucial to our development as the national strategies were written in 2007 and 2008 for England and Wales, Scotland and Northern Ireland, and subsequently implemented.¹⁹⁵ Phase two is taking the strategic planning forwards, which is a new challenge to the discipline. We have come a very long way, but the momentum has to be maintained, to maintain that profiling. In public health terms, there has been a huge amount done as we've taken referrals from children and families across all ages. We see people with learning needs and complex disability in particular, who've been excluded or been in hard-to-reach groups. There's now this whole momentum about talking to people, talking to children, supporting children as relatives, children who are being bereaved around the whole country, not just those known to our services. Barbara has been key in leading a lot of that family work and awareness of the needs. I do have a slight anxiety that it mustn't be ghettoized, such developments need to happen everywhere, not remain in a few pockets, but bringing everybody on board is quite a difficult task and requires delicate negotiation.

Hanks: A brief answer to your question about the Doyle Club and the history.¹⁹⁶ The idea for the Doyle Club was suggested by Bill O'Neill,¹⁹⁷ who was my Senior Lecturer at St Thomas' and it arose out of a conversation we'd had about a lot of these new training programmes, that there was a need for people doing these programmes, because they were all new, to be able to meet together and scheme and discuss politics and generally be organized. So that's how it came about that we [the Academic Department of Palliative Medicine at the United Medical and Dental Schools of Guys and St Thomas' Hospitals] gave some money for

¹⁹⁵ Department of Health (2008).

¹⁹⁶ See page 57.

¹⁹⁷ Dr William O'Neill was Consultant Senior Lecturer in Palliative Medicine at St Thomas' Hospital (1991–1993).

the annual dinner, and then things grew from there.¹⁹⁸ It has been an important influence in the development of the specialty. It partly reflects also on Derek Doyle, and it is a great pity that he hasn't been able to be here and join in today, because he was so involved in many of the firsts in palliative medicine: he was the first author/editor of the *Oxford Textbook of Palliative Medicine*. The Doyle Club reflected his involvement in the training; and he was the first chairman of the APM, and very closely involved in the specialty recognition. So Derek has really been at the forefront of many things.

Calman: He was a great mentor and support for me and, in Scottish terms, he really led the field in that area, and we owe him a great debt north of the border, as well as in the UK as a whole.

Gaffin: Before I say something about politics, let me talk about Derek Doyle. I've mentioned some of the early publications of the National Hospice Council¹⁹⁹ and Derek Doyle, who was our Vice Chairman from the Council's formation in 1991, was closely involved in the drafting of all of them, and was a huge influence, as was Gill Ford, in what the Council did and achieved in the early 1990s. About politics, it was so easy in those days: you wanted to go and see the Minister, Julia Cumberlege, you went to see Julia Cumberlege;²⁰⁰ there was a wonderful sympathetic group of civil servants working in the Cancer Policy Team (you'd gone by then, Gill, so it wasn't you); they were a team that you could go and talk to.²⁰¹ Sue Hawkett, a senior nurse who had worked at

¹⁹⁸ Professor Geoffrey Hanks wrote: 'Bill O'Neil organised the first meeting of the Doyle Club and engineered an invitation for himself although he was not eligible as he had just been appointed a Consultant Senior Lecturer in the Department working with me. The whole point of the Doyle Club was that it should provide a congenial forum for specialist trainees to meet without interference or influence to discuss topics of mutual interest. The new Senior Registrar Training programmes were very much a topic for discussion for us at the time because both Bill and I had been involved both directly and indirectly in various aspects.' Extracted from a letter to Ms Caroline Overy, 7 November 2012. Further details by Professor Hanks on the Senior Registrar Training Programmes are included with the records of this meeting.

¹⁹⁹ See notes 137, 138 and 139.

²⁰⁰ Julia Frances Cumberlege, Baroness Cumberlege (b. 1943), was Joint Parliamentary Under-Secretary of State, Department of Health (1992–1997) and Opposition Spokesperson for Health (1997).

²⁰¹ Mrs Jean Gaffin wrote: 'The Council was lucky to be working with a particularly committed and interested group of civil servants in the Cancer Policy Team, sympathetic to what the newly formed Council was aiming to do on behalf of NHS and voluntary hospice and palliative care services.' E-mail to Ms Caroline Overy, 29 October 2012.

St Christopher's who I'm also sorry isn't here today,²⁰² also played a huge role. If I put on my current palliative care hat, which is as trustee of a local hospice,²⁰³ it's so difficult to talk to anybody locally about commissioning palliative care. People change every five minutes in the Primary Care Trusts (PCTs), because they're being sacked. It's terrifying to think what any qualified provider will mean, what kind of competition there's going to be, so that I'd like to turn the clock back and have you [Kenneth Calman], and Gill back in the Department, and be able to feel that there was someone to talk to. I know you've got the 'End of Life Strategy', but whether or not people are really going to take notice of that, or even going to take notice of the NICE Quality Standards on End of Life Care, which Bee chaired so successfully,²⁰⁴ or whether anybody's going to be asked to take any notice of them in this bright new world, I have got terrible, terrible doubts.

Maher: In the interest of thinking about things that have spread ideas, I wanted to mention the importance of describing ideas and counting processes related to palliative care, as part of routine data collection. The work of Julia Verne and the End of Life Care Intelligence Network,²⁰⁵ the Gold Standards Framework spread programme in palliative care,²⁰⁶ and the Liverpool Care Pathway spread programme,²⁰⁷ particularly in the acute care sector. There were several large programmes where generalists and specialists joined up with improvement

²⁰² For Mrs Sue Hawkett, see note 154.

²⁰³ Mrs Jean Gaffin is a trustee at St Luke's Hospice, Harrow and Brent, London.

²⁰⁴ National Institute for Health and Clinical Excellence (NICE) (2011). For the NICE project team and expert group, see www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp (visited 10 July 2012).

²⁰⁵ Dr Julia Verne is the Clinical Lead of the National End of Life Care Intelligence Network which 'aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector, to adults approaching the end of life.' See www.endoflifecare-intelligence.org.uk/home.aspx (visited 22 October 2012).

²⁰⁶ The Gold Standards Framework 'is a systematic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting.' See www.goldstandardsframework.org.uk/ (visited 16 October 2012).

²⁰⁷ The Liverpool Care Pathway for the Dying Patient was developed between the Royal Liverpool Hospital and the Marie Curie Hospice to provide the best quality end of life care regardless of the healthcare setting; see Ellershaw and Murphy (2011); see also note 164.

bodies, for example the Modernisation Agency,²⁰⁸ and later NHS Improvement.²⁰⁹ This introduced the importance of palliative care to groups who would not have otherwise thought of it, and, while there's a lot wrong with simply counting activities and processes (which are not always the most important things to count), we shouldn't underestimate the impact this can have. These sorts of programmes are important in embedding palliative ideas into routine practice through electronic databases. The Macmillan GP facilitators introduced in 1992 also made important links between generalism and specialism.²¹⁰

Professor Jane Seymour: I want to offer a reflection on the relationship between palliative medicine and nursing that's based partly on my own role as a nurse, and partly as a commentator studying palliative care over many years. What the work that Saunders and many of you here in the room did was to open up a space for nursing. I don't know whether my colleagues might agree, but the spectacular success of, for example, Macmillan nursing was largely because of the partnerships, the strong partnerships that were forged between medicine and nursing, enabling nursing leadership to take root, particularly in hospitals, where there was a vacuum. I'm responding to Bee's points and it's something that I've been thinking a lot about recently. Nursing is really under threat at the moment, and if we're able to upskill generalists, which is the buzzword that's going around now, and also actually make a difference to end of life care for the vast majority, then it's nursing that we have to turn to. What's needed is an interprofessional examination of end of life care, and that palliative medicine, because it is a powerful specialty, perhaps now needs to think about working more closely in partnership with nursing leaders to see how the great need that is out there, can be addressed in a new and different way, while drawing on the inspiration of the past.

²⁰⁸ The NHS Modernisation Agency was defined in 2004 as 'part of the Department of Health. Established in April 2001 as a result of the NHS Plan, it helps to ensure that investment throughout the NHS is matched by the necessary reforms to provide the highest quality of service and satisfaction for its users.' Department of Health (2004): 5.380. The agency was abolished in 2006.

²⁰⁹ 'NHS Improvement was formed in April 2008, bringing together two existing national improvement programmes – the Cancer Services Collaborative (including Diagnostics) and the Heart Improvement Programme. It also extended its work to create a three-year Stroke programme within existing resources. Its current work programme is defined through the Department of Health on behalf of the NHS in the key policy areas of Cancer, Heart, Stroke, COPD and Diagnostics and forms part of the NHS Medical Directorate led by Sir Bruce Keogh.' NHS Improvement (2011): 5.

²¹⁰ For evaluations of the GP facilitators project, see Royal College of General Practitioners, Cancer Relief, Macmillan Fund (1995); Ingleton *et al.* (2003).

Cockburn: I would like to add a little to what you've been saying about nursing. I've felt very conscious while I've been sitting here that there hasn't been very much input from the nurses. I would like to say that the interdisciplinary relationship that started has been essential throughout at Sheffield. I know London isn't Sheffield, but Sheffield is very much a community city, and the people are very villagey, and I'm sure you all know what that means. It was essential that nurses were part of the growth of the hospice right from the word 'go', and when we opened our day centre it was nurses who went round and spoke to the GPs to invite them to send their patients for day care so that when they needed full-time care, they already knew the place and were known to the staff. This was tremendously helpful. The doctors were invited to visit their patients in the bed unit. I think there were two who did; most of them didn't. Well, I know doctors are very busy, and, we have to remember I'm talking about the 1970s onwards, which was a very different world from that of today. In the day unit, GPs were told that the day-unit doctor was not taking over the care of their patient, so no patient had their medication altered without one of our doctors discussing with the GP what should be done, and what they felt might be suitable. So there was teamwork going on all the time, and it was out of the relationship gradually being built up with GPs that we were able to start a home care programme, which developed quite quickly because we weren't quite so much held in suspicion by our local GPs as we had been to begin with. At that point we set up teams in our general hospitals to be there to visit patients for whom they wanted advice, and not necessarily patients with cancer. The nurses became known to their colleagues and were often involved in discussions about conditions, not necessarily related to cancer. You can see how the whole care blossomed with nurses very much involved in the spread of hospice, or what is called now, the end of life pathway. I'd like to finish by quoting an example of where we are today in our hospitals: last week a very dear friend of mine died of her cancer. It was not possible for her to be transferred to the hospice. She was looked after superbly well in the general hospital where she was a patient. Not only was she looked after superbly well, but so was her family. I think that speaks well of where end of life pathway work can go on today.

Calman: You've reminded me of a little paper I wrote in about 1969, working in a world famous surgical unit. I looked at 100 letters sent out about cancer patients to ask what the GP had been told. They'd all been told how many

stitches had been put in, and all the things that had gone on in the operation, but for the majority, the GP was not told what the patient had been told about his illness.²¹¹ Quite interesting.

Riley: I think today, our history would be incomplete without the mention of the Cicely Saunders Institute, because it has established research and I think our history and future depend on research. It is a hub for all of us, for qualitative and quantitative research, and unless we have the evidence now, we can't move this specialty forwards. So it's important that we include it, even though Irene [Higginson] is not here.²¹²

Clark: One personal observation I would like to make is related to the way in which palliative care, and palliative medicine within it, has been, I can only speak now personally, very receptive to the engagement of social scientists. I suspect that in some respects this is rather different to other specialties in medicine. I was jotting down a list as Clive talked about Ann Cartwright: Clive Seale, David Field, Nicky James, myself, Jane Seymour, Julia Addington-Hall, Sheila Payne, Allan Kellehear, Richard Harding, and new people coming along now like Steve Conway at Teesside, are all making a contribution from a social science perspective, to a better understanding of the work of palliative care.²¹³ This is really very unusual and I think you would struggle to find a list like that in many other areas. I've been very struck over the years at how poorly engaged social scientists, particularly sociologists, have been with the field of oncology.

²¹¹ Calman and Murdoch (1974).

²¹² The Cicely Saunders Institute, developed by King's College London and the charity Cicely Saunders International, opened in May 2010 as the first purpose-built institute for research into palliative care. Professor Irene Higginson is Director and Head of Department.

²¹³ David Field is a medical sociologist and was Deputy Director at the Centre for Cancer and Palliative Care Studies, Institute of Cancer Research, Royal Marsden Hospital; Professor Veronica (Nicky) James is the Executive Dean of the School of Health and Life Sciences, Glasgow Caledonian University; Professor Sheila Payne holds the Help-the-Hospices Chair in Hospice Studies and is the Director of the International Observatory on End of Life Care at Lancaster University; Dr Allan Kellehear was Professor of Sociology at the University of Bath (2006–2011); he is currently Adjunct Professor, Department of Community Health and Epidemiology at Dalhousie University, Halifax, Nova Scotia, Canada; Dr Richard Harding is Reader in Palliative Care at the Cicely Saunders Institute, King's College London; Dr Steve Conway is Senior Lecturer in Research Methods in the School of Health and Social Care, Teesside University. For Professor Julia Addington-Hall see note 139 and for Professor Jane Seymour, Professor Clive Seale and Professor David Clark see biographical notes.

So, I do think it has been a welcoming discipline from that point of view. Sometimes you've welcomed us in as people who have then caused trouble. [Laughter]

Calman: Rubbish, rubbish. [Laughter]

Clark: Barbara was using that phrase 'the critical friend', which I think the social scientist has tried to be to palliative care; the notion has been very important, and numbers of us have made careers out of this and have gone on to get chairs in the field. I don't think you can find another medical specialty that so quickly has embraced the perspectives of the social sciences, and particularly sociology, in the way that palliative care has.

Ford: Early in the 1990s, the Department of Health funded an Open University course on 'Death, Dying and Bereavement', which was enormously popular for both professionals and the public too, and which, I think, was a good response by the Department of Health to the fact that the hospice and palliative care movement had mobilized so many volunteers in their field of activity. I do wonder now, whether the elderly, whose needs are going to dominate us for at least the foreseeable future, need to have some similar support, from informed and confident volunteers and carers in the community, which is going to shoulder the major part of the burden. Or so the politicians expect.

Ahmedzai: This meeting's been wonderful for all of us, because it helps us to reflect, and also to share in some of the really good things that have happened in palliative medicine in the last 30 or 40 years, though we need to be realistic sometimes about some of the weaknesses and the failures as well. Although we talked earlier on about the change in direction with non-cancer with lots of people talking about the opening of doors to non-cancer, I think there may actually be some selection bias going on here: if you look at the national statistics from the Hospice Information Service, the proportion of non-cancer patients across the country is still 10, 12, c.15 per cent maximum; so, 1 in 6, whereas it's actually only 1 in 4 people who die with cancer. So, it sounds like we've still got a long way to go yet. We shouldn't be congratulating ourselves too early across the whole country. Maybe some of the people here are pioneers in non-cancer palliative medicine, palliative care, but that message clearly hasn't got complete widening.

Hoy: That's hospice, that's not palliative medicine, of course.

Ahmedzai: I'm quoting figures from the National Hospice Information Service.

Hoy: That's hospice inpatients beds.

Ahmedzai: I believe that quotes figures from all palliative care services. Well, that's something to be looked into.²¹⁴ Can I mention another area where I think that, again, it's a bit of an elephant in the room? We have done a fantastic amount of work in the care of the dying, but one of the things that is in the definition of palliative care, at least in the latter definition of palliative care, is that little statement, 'many areas of palliative care also apply early in the course of disease.'²¹⁵ One of the things I'd like us to think about and reflect on, is how have we actually made that happen? To what extent does that happen? Have we addressed the issues of suffering; I don't mean physical suffering, but psychosocial, spiritual suffering, at other stages of disease, whether it's cancer or non-cancer? We're very good at congratulating ourselves about palliative care in the UK, but when you go outside of the UK, you come across countries, like Scandinavia, where going into diseases at the beginning is part of the way that they do it. They think it's strange that we're necessarily focusing on the end of life. Although the end of life strategy and the end of life movement and pathway has been very good about formulating the end of life, it has rather focused the fact that we are concentrating on end of life. So, a challenge or a question I'm putting out is: is that all we're going to be? Or, is there any intention ever to respond to that little statement about many parts of palliative care also being concerned with the earlier stages of disease? It's a philosophical question: who is going to take care of the suffering at earlier stages of disease?

²¹⁴ Mr Adrian Jones, Information Analyst at the National Council for Palliative Care, supplied the following statistics for palliative care services as a whole: 77.4 per cent are cancer patients, 16 per cent have conditions other than cancer and 6.5 per cent not recorded. He wrote: 'Or taking just those recorded, 82.9% with cancer and 17.1% with a condition other than cancer. Because this is over all settings, there are the usual caveats on double counting, where someone might have used a service in more than one setting.' E-mail from Mr Andy Pring to Ms Caroline Overy, 29 October 2012. Dr Andrew Hoy wrote: 'the point that I was making was that other specialist palliative care facilities, for example, the hospital teams, now have input to a much higher percentage of non-cancer patients. In other words, it is important to define the locus of care when discussing whether we have succeeded in extending care to this large group.' E-mail to Ms Caroline Overy, 3 November 2012. Further correspondence with Dr Hoy and Professor Ahmedzai is included in the records of this meeting.

²¹⁵ See the Calman–Hine report, Department of Health and the Welsh Office (1995), 'Palliative care should not be associated exclusively with terminal care. Many patients need it early in the course of their disease, sometimes from the time of diagnosis', page 16. See also the WHO definition of palliative care which states: '[Palliative care] is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications' (Sepúlveda *et al.* (2002): 95).

Calman: One of the things that's been interesting is to see the rise of interest in survivorship. That would be one of the ways in which you could pick up something early, having got a disease or whatever it is, the issue is how you're going to survive. Macmillan have been very positive and helpful with that, but that could be the route into the problem.

Parkes: Barbara Monroe mentioned her shock at the failure of St Christopher's to approach the area of childcare, particularly the care of bereaved children.²¹⁶ This went right home to me because, as a psychiatrist, I know very well there's a huge literature demonstrating the potential psychological damage that children can suffer when their parents die, or when they suffer the loss of a sibling, and issues of this kind.²¹⁷ This has always been something in my mind. Indeed, I can remember many discussions at St Christopher's in the early days about whether we should be admitting children, whether we should be supporting bereaved children, and there was a general feeling, and I've heard this again and again, that first of all, if you care for the parents, the children will be looked after. That applied whether it was the patient who was dying, or the child who was bereaved. In more recent years, an entire range of hospices for dying children have been developed, which I think is a great step forward.²¹⁸ There has also been a development in bereavement care; there are a number of bereavement services for children across the country.²¹⁹ I suspect that they're only scratching the surface. I believe that there's still a large number of children who desperately need support. I don't know whether there's been a change in climate, where now parents are more willing to ask for help for their children, and that may be one of the reasons that the service is beginning to come into being, but this is one area where I feel we still have a long way to go.

²¹⁶ See page 51.

²¹⁷ Dr Colin Parkes wrote: 'Although children often show remarkable resilience, there are many studies that reveal an increased risk of lasting mental health problems depending largely on the quality of care that the bereaved parent is able to give. The right support given to both the parent and child at this time can be expected to bring lifelong benefits. See, for example, Balk and Corr (2001); Luecken (2008).' E-mail to Ms Caroline Overy, 10 September 2012.

²¹⁸ Dr Colin Murray Parkes wrote: 'We should note that the first children's hospice was Helen House, near Oxford. This opened in 1982 under the leadership of Sister Frances Domenica.' Note on draft transcript, c.11 April 2012.

²¹⁹ For example, the Childhood Bereavement Network, the Child Bereavement Charity, Winston's Wish, the charity for bereaved children; see Rolls and Payne (2003).

Baines: At a conference, a few years before she died, Cicely was asked by somebody: ‘Dame Cicely, if you were training in medicine now, what field would you go into?’ Like a shot, because she’d obviously thought about it, she said: ‘Dementia.’ That is what has made me so delighted that St Christopher’s is now going into a large number of care homes, and improving care there, and indeed into dementia care. There’s the new Oxford book by Victor Pace and others: *Dementia: From advanced disease to bereavement*.²²⁰ So Cicely would be pleased, not only with what we’ve done, but with what we’re now going on to do.

Twycross: May I come back on non-cancer, being involved earlier in the disease? Any individual can only do a certain amount. So, unless there is adequate staff, people will, possibly literally, kill themselves if they’re expected to take on *all* dying patients, *all* cancer patients at the time of first referral, etc. You’ve got to have adequate staff. People like Richard and me, and like Geoff and others in this room, really took a packet when we started off. We really were down on our knees within a few years. I would say to the upcoming generation: ‘I don’t want you to work to contract, I want you to have a calling, a commitment, but do look after yourselves.’ We’ve got to be realistic. Ilora said earlier on: ‘We’re only beginning’, and I think that was in relation to infiltrating the medical fraternity as a whole. Do you remember saying, “We’re only beginning?”²²¹

Finlay: Yes I do, and what I meant was that our services need to in-reach into these subgroups such as dementia, such as recognizing the needs of children.

Twycross: Okay; but I think things may well be cyclical. I was co-author of a paper that came out in the late 1970s. It was a survey at a London teaching hospital, and one of the case histories in it was about a 90-year-old man who was admitted in pain, remained an inpatient for three months, and eventually died still in pain.²²² Everything that should have been done was done, but one to three weeks too late. A classic case of the ‘one step behind syndrome.’ What I emphasize in the limited teaching I still do, is to stress that palliative medicine is a form of emergency medicine, because terminally ill patients typically haven’t got a lot of time left; we’ve got to get in there and get on with it. Tomorrow is second rate, and may be too late. This same ‘one step behind syndrome’ played itself out in the life and death of a friend of mine who died a month ago. I find

²²⁰ Pace *et al.* (eds) (2011).

²²¹ See page 11.

²²² Hunt *et al.* (1977).

it incredible. He had myeloma: he got bone pain. They said: ‘Oh, well, yes, we’ll organize an MRI’ and the MRI is delayed two weeks. ‘Oh, we’ve got the MRI result, we’ll refer you to the radiotherapist.’ In the late 1970s, for example, if I thought clinically someone had early cord compression, or something like that, I would get 12mg of dexamethasone, ask them to swallow it with some water, ring up the radiotherapist and say, ‘I’ll have this guy’s back X-rayed and could you see him at the end of clinic this afternoon?’ Before that guy went home he’d have had his first course of radiotherapy. But it doesn’t happen now, as far as I can see.

Finlay: Yes it does.

Twycross: Yes it does? Good! Wonderful! But it doesn’t happen in Oxford. Well done, congratulations; I’m delighted. I know where to die now. On a hillside in Wales. [Laughter]

We haven’t really looked at the early research into physical aspects of care. We heard a lot about the bereavement and certain psychosocial areas. I think we should record somewhere that Cicely always rejected the description of hospice care as ‘tender loving care’. I forget the expression she used; it could have been ‘efficient, loving care’ or ‘efficient medical care’.²²³ If we put that into twenty-first century parlance, she would have said that hospice care is evidence-based. She collected data right from the word ‘go’, and then she appointed Ron Welldon,²²⁴ followed by me, to assist as she concentrated on other matters. Okay, we didn’t have hundreds of randomized controlled trials (RCTs) up our sleeve, but we worked from basic knowledge of anatomy, physiology, pharmacology, psychology and we tried to piece things together, and, rightly or wrongly, we took the results from other specialties. I would claim that we were evidence-based right from early days even though we might not have had our own portfolio of RCTs.

We’ve already spoken about Macmillan and the great part they played in the 1980s in setting up senior lectureships in particular. What I would like, Ken and Tilli, is a box perhaps where we list the professorships and when they were

²²³ Dame Cecily Saunders advocated ‘efficient loving care’; see Saunders (1978b): 198.

²²⁴ Ms Denise Brady, Librarian at St Christopher’s Hospice, wrote: ‘Dr Ron Welldon was the first Director of Clinical Research at St Christopher’s Hospice and was appointed in 1969. He died in 1970. During this time, he analysed the notes of the first 500 patients. He began work on the first drug trial at St Christopher’s. He laid the foundations for research at the hospice which was later continued by Dr Robert Twycross.’ E-mail to Ms Caroline Overy, 3 October 2012.

introduced and who funded them.²²⁵ It would be very interesting and it's part of the story. We need to expand on the details of the academic departments in the UK. Interestingly, and this is going back to bad practice in Oxford, but let's see if this happens in Wales [laughter]. When I was doing consults, I would look at the drug chart and I would find in England's premier teaching hospital people prescribed, for example, phenytoin thrice daily, or digoxin twice daily, and I would advise the junior doctors that generally it was necessary to take these drugs only once a day. I may be wrong, but I suspect that many hospital consultants do not rigorously monitor what their patients are being prescribed, do not rigorously monitor the inevitable polypharmacy. This could be a national scandal.

There's another name we haven't mentioned: Sue Ryder. Surely we should put in a box to say what it has done?²²⁶ We've mentioned paediatrics; what about Richard Hain.²²⁷ Religious motivation: yes, Cicely was motivated by her Christian faith and sustained by it, as Mary has been, and I have been, and many others in this room. I recognize that others don't have this particular motivating force, but they all had the motivating force called compassion, and compassion is perhaps the basis of Christianity, so it's a bit cyclical.

In 1982, when I went to Japan for the first time, and I said 'There aren't many Christians in Japan, so what's the essential characteristic for someone working in palliative care?' I concluded that the basic essential is a belief in life. There's compassion, but you had to have the belief in life, meaning that life has meaning and purpose, and therefore there is, even if you don't understand it, meaning in suffering, and there is meaning in the weeks and days before your death.

²²⁵ It has not been possible for the editors to compile a list of this nature.

²²⁶ The Sue Ryder Foundation (Sue Ryder Care from 2000, and Sue Ryder since 2011) was established in 1953 by (Margaret) Susan [Sue] Ryder (Baroness Ryder of Warsaw from 1979) (1924–2000), who, after working in a relief unit in Europe after the Second World War, set up the 'Sue Ryder Foundation for the sick and disabled of all age groups' and opened a care home in Cavendish, Suffolk. The charity currently has currently 14 care centres across the UK, and provides home care and community-based services for the end of life and long-term needs. See Ryder (1975, 1998).

²²⁷ Dr Richard Hain is Senior Lecturer in Paediatric Palliative Medicine at the University of Cardiff School of Medicine. His research interests include patient and families' experiences of palliative care and evidence-based symptom control in children and he has developed a paediatric option for the Diploma/MSc in palliative medicine. See, for example, Hain *et al.* (2012); Mellor and Hain (2010).

Noble: Two very brief points: one about children and families. There was a brief flurry of activity to bring family therapy into palliative medicine in the late 1980s at the Tavistock Clinic,²²⁸ and really it didn't take root, which was a shame, and it was one of the things that Eric Wilkes regretted. I think that's also reflected in general medical training, that we're not trained to look after families as much as the individual. That's one thing.

The other thing is that I find it remarkable, given the fact that we've had so much difficulty getting resources for research, in particular resources for pharmacological research, and for development, that we seem to be in a better place now to control pain and symptoms than we were many years ago. I don't know if I'm alone in this, but it seems to me that more of my patients are less affected by drug side effects now and more comfortable and wider awake than they ever were back in the early days. I don't quite understand the process by which we got here, given the paucity of the evidence that's produced it. So it might be what Robert was saying, about applying first principles, attention to detail, imagination, I don't know, but I think it is something that the specialty has done.

Wee: I think a quick point of information about our developments and research. David Clark talked about how we work with social scientists and I think the involvement with social scientists has done an awful lot for palliative medicine researchers. However, the fact remains that out of almost 400 consultants in the country, I run an annual Senior Lecturers Group and there are 30 people on that list, for more than half of whom senior lectureship is for teaching, not for research. Those who are researchers, are juggling research, teaching and clinical. I think we've got a long way to go yet. A lot of that is London-centric, and centered around very few places. It is almost impossible to get it started anywhere else, and most of those senior lecturers are working solo, and that's the reason for having the annual meeting.

Gaffin: This is a meeting of stars. The only reference to smaller hospices has been slightly derogatory, although David Clark might not have meant it, about them all growing up in the 1980s. I'd hate this seminar to finish without paying tribute to the people who do keep going the small hospices all up and down the country. They might not produce good research, and they might not be the

²²⁸ The Tavistock Clinic, London, was established in 1920 as the Tavistock Square Clinic for Functional Nervous Disorders. It joined the Portman Clinic in 1994 to become the Tavistock and Portman NHS Trust and became a foundation trust in 2006. For a detailed history see www.tavistockandportman.nhs.uk/sites/default/files/Our%20history_0.pdf (visited 11 July 2012).

most wonderful in terms of going to meetings and all the rest of it, but hospice at home, going into nursing homes and, above all, helping a hell of a lot of people to die better, is something that I think we shouldn't lose in the discussion about the stars. I love the stars dearly, but I think we also ought to remember the foot soldiers as well.

Calman: Yes. Can I concur with that, that the number of hospices around who have huge community support and do an enormous amount; it's really very important that we recognize that too. Indeed, perhaps we might have something about how they have developed too? Can I bring things together then briefly, partly because I've got a wee dog at home who's not well, and I'd like to get home tonight. My own sort of reflections: first of all, your comments, it's been tremendous.

I found this inspirational; it's quite remarkable, actually. The names and places that have been mentioned. I had forgotten about Mildmay, for example. I was a little bit interested in that in the mid-1990s as things were developing, and these memories are really quite important. My first memory, to bring us back, was not long after I met Cicely, I realized that her husband painted, and he painted a beautiful picture of a dove. For those of you who don't know Gaelic very well, Calman in Gaelic means dove, so it sits now in the pride of place in my home. Second thing, I wrote a little paper once called 'Memories'.²²⁹ It was in the *Lancet*, and the purpose of this was to pick up the little things that happened, that you don't talk about very often, and which actually mean so much to individuals as they live. One of the striking ones was a young lady with ovarian cancer; I remember her very well. Quite an attractive young lady and she was unwell. I sat down beside her and did my good doctor bit, hand on her shoulder and asked: 'Everything all right?' As soon as I left her mother said: 'That was a disaster. She knew when you did that that her time had come.' You do everything that you think that's right, and it turns out not to be. The last point, the word that hasn't been raised today and I thought it might have been, is the word 'healing' because a lot of what we do is about healing. And that's making wholeness, it's not necessarily curing. It's a phrase which I, because I'm getting older now, and I've read quite a lot about medical history and education, healing has been a central concept in medicine and that's what it's about. That means that you do something that makes people feel better. So thank you very much for coming. I've thoroughly enjoyed this and I've got to go home and see my wee beagle now, thanks.

²²⁹ Calman (1988).

Tansey: May I add the thanks of my group to all of you for coming and for speaking so frankly. It's been a fascinating afternoon. I'd like to thank Lois, Caroline and Adam who've been walking around with the microphones. If you haven't already seen any of our volumes which are at the back, do please have a look at them. You might be particularly interested, for example, in the one that we had on Medical Ethics for which Ken wrote the introduction,²³⁰ or the one on Innovation in Pain Management, which David chaired, and Dame Cicely attended.²³¹ Please do think about your history, depositing your own archives, or come to talk to us or to the archivists here. This contribution is only that: it's a contribution towards a history of palliative medicine; it's not the history of palliative medicine. Do think about your own archives, your own place in history. Now we invite you to enjoy a glass of wine, but before that, please join me in thanking Ken for his excellent chairmanship.

²³⁰ Reynolds and Tansey (eds) (2007).

²³¹ Reynolds and Tansey (eds) (2004).

Appendix 1

Drugs commonly used at St Christopher's Hospice¹⁶¹DRUGS MOST COMMONLY USED AT ST. CHRISTOPHER'S HOSPICEANALGESICSFor mild to moderate pain

Paracetamol (Panadol)
Soluble aspirin
Dextropropoxyphene Co. (Distalgesic)

For moderate to severe pain

Diamorphine by mouth in small doses in mixture given below:

Standard Mixture by mouth (a variant of the Brompton Mixture)

Diamorphine Hcl	2.5 - 30 mg. (usually 5-10 mgs.)
Cocaine	10 mgs.
Rectified Spirit	2.5 mls.
Syrup	5 mls.
Aqua Chlor. ad	20 mls.

Syrup prochlorperazine (Stemetil) 5 - 10 mgs. is added separately as the dose is given routinely unless disliked by patient.

Syrup chlorpromazine (Largactil) 25-50 mgs. for nausea when sedation also is needed.

Methadone (Physeptone)	5 - 10 mgs. up to 4 hourly	} All by mouth if possible
Phenazocine (Narphen)	5 - 10 mgs. up to 4 hourly	
Dipipanone Co. (Diconal)	1 - 2 up to 4 hourly	

For severe pain (injections usually essential)

Diamorphine (Heroin) 5 - 40 mgs. (usual dose 10-30 mgs.) in standard mixture as above.

Injections 2.5 mgs. as starting dose for frail patients.

Otherwise begin at 5 mgs. Occasionally we need to be bold and use 60 or even 90 mgs. After 60 mgs. it is often more helpful to increase the phenothiazine being given than to increase the analgesic further.

Diamorphine is rarely given alone and usually with a comparatively small dose of one of the drugs mentioned from the phenothiazine group. This potentiates its action by relieving anxiety and enables a smaller dose to be effective.

Of the first 500 patients here, 60% never needed more than 10 mgs. 11% needed 20 mgs., and 10% 30 mgs. or over. 19% needed no diamorphine

For vomiting and anxiety - promazine (Sparine) 25 - 50 mg., or if heavier sedation is needed as well, chlorpromazine (Largactil) 25-50 mgs. or injection methotrimeprazine (Veractil) 12.5 - 25 mgs. This drug has an analgesic effect of its own and may be a very valuable adjuvant for severe pain.

¹⁶¹ A copy of the list of drugs that Dr Cicely Saunders gave to Dr Mary Baines when she arrived at St Christopher's Hospice in 1968 (see page 7). Supplied and reproduced by permission of Dr Mary Baines.

If the patient shows signs of tolerance or psychological dependence, or is sleepy on the dose needed to control pain, amiphenazole (Daptazole) may be added with the morning doses either by mouth (100 mgs) or by injection (30 mgs), dissolved in the diamorphine. (This is rarely needed). If the patient is nauseated by diamorphine we use phenazocine (Narphen) 2-4 mgs. by injection or 5-15 mgs. orally. It is not so powerful an analgesic and higher dosage is bulky if only standard ampoules are used.

We use diamorphine in preference to the other opiates, but alternatives are Morphine by mouth in the same mixture as above, 5-30 mgs.

Morphine by injection, 5-60 mgs.

Omnopon by injection 10-40 mgs. Beyond this dose it is better to change to morphine, and morphine 30 mgs. is rather more powerful than Omnopon 45 mgs. (Patients vary in the equivalents they need among the higher doses).

Nepenthe 15-30 mgs. in aqua chloroform. Usually given with tabs. soluble aspirin dissolved in the mixture.

COMMON SYMPTOMS AND USUAL TREATMENT

ANOREXIA

Prednisolone 5 mg. b.d., or t.d.s. Occasionally larger doses.

This often concerns patients as much as any other symptom. The great benefit of enjoying food once more and the sense of well-being given may bring a remarkable improvement to their general condition. We believe that here the side effects of steroids are acceptable.

Cyclizine 50 mg. b.d. when there is any degree of real distaste for food.

NAUSEA

Cyclizine as above

Syrup prochlorperazine (Stemetil) 5-10 mgs.

Change other drugs if any are likely to be causing nausea as side effect.

VOMITING

As above

Iced drinks, iced lollies, etc. Stout sometimes the most welcome drink.

Meat and sweet things are usually nauseating, but patients have many idiosyncrasies.

Injections:

Cyclizine (Valoid) 50 mgs. up to 4 hourly. Usually once or twice daily.

Prochlorperazine (Stemetil) b.d., 12.5 mgs., dimenhydrinate (Dramamine 50 mg)

Chlorpromazine (Largactil) 25-30 mgs. or

Methotrimeprazine (Veractil) 12.5 - 25 mgs. } when sedation is also required.

DYSPHAGIA

3

Iced drinks, etc.

To clear Mousseau-Barbin or other tubes, ginger beer or other fizzy drink
Xylocaine, Mucaine emulsionsIf the patient has excessive salivation, Largactil (which causes dryness
of the mouth fairly frequently) may help, or small doses of atropine

Use diamorphine for such discomfort as well as for pain.

SORE or DIRTY TONGUE

Frequent drinks and mouth washes.

Acid or chewing sweets may be tolerated.

Chlorhexidine (Hibitane) and dequalinium (Dequadin) lozenges and paint
lipsalve for dry, cracked lips, neomycin and hydrocortisone cream for
peeling and sepsis.

Nystatin oral suspension for monilia.

Vitamins

CONSTIPATION

"What Sister and the patient like works best."

Milpar, Dioctyl, Dorbanex, Senokot.

Regular glycerine or dulcolax suppositories for severe constipation to
avoid grinding pain and diarrhoea from large doses of aperients, and tabs.
Dioctyl Forte t.d.s. until a result is obtained, then regularly as required.SORE and STICKY EYES

Neomycin or similar eyedrops

TYSPNOEA and or COUGHFramol, ephedrine, choline theophyllinate (Choledyl). Preferred
by patients in that order. Watch for retention.Sedation for the accompanying anxiety, diazepam (Valium), phenothiazines
Steroids

Aminophylline suppositories p.r.n.

Expectorant Mixture - "Benylin Expect." Mist. Ammon. Chlor.

Methadone or diamorphine as linctus, mixture or injection. Always used
for distressed patients even where bronchospasm is present. Add Veractil
for distress or where continual sedation is necessary. Antibiotics when-
ever purulent sputum is causing distressing cough. Add hyoscine when
patient is dying with excessive secretions and "bubbly" respirations -
distressing to relatives if not to the patient. Always given with an
opiate.ANXIETY, MENTAL DISTRESS, CONFUSIONOccasionally small regular doses of chlordiazepoxide (Librium) 5-10 mgs.
Much more commonly small doses of the drugs in the phenothiazine group.
Promazine (Sparine), chlorpromazine (Largactil). Syrup Veractil
when available.

Frank confusion - syrup or injection chlorpromazine (Largactil). Dose as needed. If injections are needed either methotrimeprazine (Veractil) or chlorpromazine (Largactil). If this is not effective, or if an urgent crisis such as a severe haemorrhage occurs - Inj. Hyoscine, always with an opiate. With frail patients begin at 0.2 mg. May need to increase to 0.8 mg. (rarely). 4

DEPRESSION

Mist diamorphine and attention to mental and physical distress. Amitriptyline (Tryptizol), imipramine (Tofranil) plus tranquillizer or sedative as needed.

INSOMNIA

We do not use opiate drugs merely as sedatives, although for the first few nights they may act as such, both because of their sedative effect and because of the relief of the patient's pain. The sedative effect tends to wear off before the analgesic. After that, if need arises, patients either have an hypnotic by mouth or a drug of the phenothiazine group added to their injection. We do not usually give barbiturates to our patients, especially those over the age of 70, because of the danger of accumulation, but on occasion they are the best sedative and do not cause confusion. We use butobarbitone and occasionally Tuinal.

Chloral is probably the best of all, but patients may not tolerate its taste, however disguised, and the various tablet or capsule forms do not, so far, seem to be effective. Used most often as chloral glycerolate (Syrup Somnos).

Diphenhydramine (Mandrax), nitrazepam (Mogadon)

When heavier sedation is needed we add Largactil 25-75 mgs. tabs or syrup. It is helpful sometimes to give a long-acting sedative or a tranquillizer earlier in the evening. Alcohol with the evening drink is probably the best sedative of all, particularly for men and for the elderly.

FUNGATING GROWTHS

Cleaned with eusol and liquid paraffin 1:4 if offensive.

Dressed with Melonin, N.A. or Paracet dressings or liquid paraffin on old linen if available.

Antibiotics locally or systemically p.r.n.

Polymixin Spray

FREQUENCY and NOCTURNAL URINARY INCONTINENCE

Any infection is treated, and sedatives are reduced if possible.

Emeprium Bromide (Cetiprin) or

Propantheline (Pro-Banthine) may control incipient incontinence.

Appendix 2

Participants at the inaugural meeting that approved the formation of the Association of Palliative Care and Hospice Doctors in October 1985¹⁶¹*Dr Hillier*

MEETING IN BIRMINGHAM
- FRIDAY, 25TH OCTOBER 1985 -

<u>GROUP NO:</u>	<u>PARTICIPANT:</u>
4	✓ AHMEDZAI, DR. S.
4	✓ ARTHURTON, DR. M.W.
4	✓ BAINES, DR. M.
4	✓ BARLOW, DR. AM.
8	✓ BARRINGTON-WARD, DR. E.J.
1	✓ BATES, DR. T.
2	BERKELEY, DR. J.S.
5	✓ BIRCHALL, DR. I.A.
10	✓ BROCK, DR. J.E.S.
5	BULMAN, DR. J.N.
4	✓ BURNE, DR. R.
4	✓ CAMPION SMITH, DR. C.
1	CARR, DR. A.
3	✓ CASSIDY, DR. S.
7	✓ CLEARY, DR. M.T.
8	✓ COLLIER, DR. S.
3	✓ CONSIGLIO, DR. R.V.A.
4	✓ COOPER, DR. D.
2	✓ CORCORAN, DR. R.
8	✓ CROUDACE, DR. J.
10	CURLE, DR. J.M.
10	DEAS, DR. K.S.
9	✓ DENT, DR. R.G.
6	✓ DORWARD, DR. W.F.M.
6	✓ DOUGLAS, DR. S.
8	✓ DOVER, DR. S.
3	✓ DOYLE, DR. D.
3	✓ DUFF, DR. Y.
7	✓ DYMCK, DR. B.
3	✓ EDDISON, DR. P.
9	✓ EVANS, DR. N.M.H.
10	✓ FERGUSSON, DR. M.L.
10	✓ FORD, DR. G.R.
6	✓ FREEMAN, DR. R.H.

¹⁶¹ Supplied by Dr Richard Hillier and reproduced by permission of the Association for Palliative Medicine.

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<u>GROUP NO:</u>	<u>PARTICIPANT:</u>
2	✓ GAJJAR, DR. P.D.
7	✓ GREAVES, DR. C.W.K.H.
4	✓ GRIFFITHS, DR. P.
2	HALLIDAY, DR. G.M.
7	✓ HANRATTY, DR. J.F.
6	✓ HAYES, MR. A.
1	✓ HEYSE-MOORE, DR. L.
5	✓ HILL, DR. D.O.
2	✓ HILLIER, DR. R.
3	✓ HOGAN, DR. A.E.H.
5	✓ HOLLIDAY, DR. C.M.
9	✓ HOY, DR. A.M.
8	✓ HUGHES, DR. T.J.
9	✓ HUNT, DR. T.
8	✓ JEPSON, DR. B.A.
2	✓ KAY, DR. J.M.
9	✓ KAYE, DR. P.
1	✓ KEARNEY, DR. M.K.
1	✓ KERIN, DR. P.
5	KINGSBURY, DR. A.
7	✓ KIRKHAM, DR. S.R.
1	LAMERTON, DR. R.
4	✓ LANGLEY, DR. D.R.
7	✓ LEVEAUX, DR. V.M.
7	✓ McCARTHY, DR. J.B.
1	✓ McCARTIE, DR. K.M.
7	✓ McILLMURRAY, DR. M.
3	✓ McKENNA, DR. M.A.
8	✓ McKERROW, DR. M.M.
6	✓ MARTIN, DR. L.C.
6	✓ MILLARD, DR. P.M.R.
5	✓ MONYPENNY, MR. E.

.../

- 3 -

<u>GROUP NO:</u>	<u>PARTICIPANT:</u>
9	✓ NAYSMITH, DR. A.
5	✓ OLIVER, DR. D.
3	✓ PIM, DR. A.J.
2	✗ PUGSLEY, DR. R.
7	✓ QUINN, DR. J.
6	✓ REES, DR. D.
9	✗ REGNARD, DR. C.
2	✓ REVILL, DR. H.
9	RICKARDS, DR. F.S.
6	✓ RILEY, DR. A.P.
10	RUSSELL, DR. P.
5	✓ SCURR, DR. M.
9	✓ SEIGLEMAN, DR. M.
1	✓ SILVER, DR. P.S.
9	✓ SMITH, DR. A.M.
10	✓ STUART, DR. M.
8	✓ TAYLOR, MR. J.
2	✓ THOMPSON, PROFESSOR J.W.
8	✓ THORPE, DR. G.
1	✓ TWYGCROSS, DR. R.
6	✓ WALDRAM, DR. R.
6	✓ WALKER, DR. D.J.
10	✓ WEDLEY, DR. J.R.
5	✓ WILES, DR. E.J.
7	✓ WILLIAMS, DR. J.H.B.
3	✓ WILSON, DR. F.O.
10	✓ WOOD, DR. C.

Appendix 3

Minutes of the inaugural meeting that approved the formation of the Association of Palliative Care and Hospice Doctors in October 1985¹⁶¹

ASSOCIATION OF PALLIATIVE CARE AND HOSPICE DOCTORS

Minutes of the Meeting Held at the Roman Catholic Chaplaincy, Newnam House 29, Harrison Road, Edgbaston, Birmingham, on Friday 25th October, 1985 to inaugurate a Professional Association for Doctors having a special interest in the care of the dying.

Minute 1/85 Welcome and introduction

Dr. Derek Doyle welcomed an audience of some 90 doctors (attendance list attached), saying that he had received apologies from 40 people who were unable to be present but who expressed enthusiastic support for the establishment of an association. He valued, in particular, the encouragement of Dame Cicely Saunders; and was glad to convey her commitment and best wishes to all those present.

2/85 The Need for an Association

Dr. Richard Hillier gave a brief historical synopsis of developments in terminal care since the early 1970's; and described, in particular, the way in which the interest of independent charities and the NHS had come to overlap leading to a range of meetings for both teaching and liaison purposes which had taken place within professional groupings or on a multidisciplinary basis, and at national or local venues. Both the nurses and administrators committed to hospice care had now set up their own "special interest" groups; and it seemed to be the doctors alone who had not yet made any formal arrangements to meet as a group and to work together for the medical advancement of hospice type care.

Dr. Hillier considered that there were two particular sets of reasons justifying the establishment of an association at this stage:-

(a) Political

Various developments had occurred during the previous twelve months which served to heighten

¹⁶¹ Supplied by Dr Richard Hillier and reproduced by permission of the Association for Palliative Medicine. The attachment referred to in point 7/85 is not available.

the political profile of the Continuing Care Movement. These include visits by members of the Royal Family, the Prime Minister, the Minister of Health and the Chief Medical Officer to various hospices, and the initiative of the National Association of Health Authorities in calling a Study Day for early December. This proposal linked with a statement by the Minister of Health made during July, to the effect that Health Authorities should look more closely at the needs of the dying and the development of specialist services - with a hint that central financial support might be made available for innovative proposals.

(b) Professional

Over the past three years the Royal Colleges had expressed particular interest in the development of radiotherapy and oncology training requirements and had recently agreed to accept the additional commitment to consider and recommend appropriate facilities for doctors wishing to specialise in terminal care. There was an urgent need for a professional association to which this Inter-Collegiate committee could turn for advice.

Dr. Hillier concluded that a certain momentum had now developed - exemplified by the number of people present at the meeting - which indicated a strong interest amongst doctors for some organised structure which would offer a forum and focal point for future developments in terminal care. He said that the programme for the day was based on the sequence of:-

- reaching an agreement to set up an association
- discussing the sort of rules/constitution that might be considered appropriate
- agreeing the precise objectives for the association, and their order of priority.

Two brief papers on / continued

rules and objectives have therefore been prepared as the basis for discussion. He hoped that they would encourage healthy debate, but that it might be possible to reach outline agreement on both areas of interest before the end of the day.

3/85 The Establishment of an Association

Following a brief discussion during which all speakers from the floor expressed strong support for those who had taken the initiative in calling the meeting, Dr. Doyle proposed that a vote be taken on the principle of forming an association. There was a unanimous vote in favour from all those present, with the rider that the new association should be open to membership throughout the British Isles.

4/85 Draft Rules of Association

Dr. Robert Twycross said that the draft rules submitted for discussion had been based on the published rules of other learned and professional societies. It seem necessary to propose some formal structure for the guidance of the inaugural committee during its first year in office; and whatever was agreed that day could well be revised and amended at the first Annual General Meeting of the Association in the autumn of 1986.

Participants then broke up for group discussion sessions, and subsequently reported their recommendations to a reconvened meeting of all those present. A series of votes followed as a consequence of which the following draft rules were adopted for the Association's inaugural year:-

- (i) NAME
"Association of Palliative Care and Hospice doctors of Great Britain and Ireland"
- (ii) MEMBERSHIP
 - (a) "FULL: Open to all doctors actively involved in the clinical practice of Hospice Type Medicine"

(b) "ASSOCIATE open to all other interested doctors (no voting rights)

(iii) OVERALL OBJECTIVE

The association is instituted for the advancement of palliative care and hospice medicine.

(iv) FEES

Deferred subject to further consideration and recommendations from the inaugural committee in the light of likely budgetary requirements for the coming year. In the meantime an initial contribution of £20 per person for full membership rights was agreed.

(v) ORGANISATION

An inaugural committee of just three officers, (Chairman, Secretary and Treasurer) and three committee members should be elected to hold office for one year only. Of these six members, at least two should be NHS and two non NHS staff. The committee should have power to co-opt in order to secure an even balance of specialist or geographic representation.

(vi) SECRETARIAT

To be provided by the Wessex Regional Cancer Organisation for the inaugural year up to and including the first Annual General Meeting.

(vii) FINANCIAL MANAGEMENT

A bank account should be opened in the name of the Association, with any two of the three office holders empowered to sign cheques.

It was agreed that the inaugural committee should work on the basis of these rules which should be amended and/or "tidied up" in the light of practical experience

gained during the first year of office; and should then be presented for formal adoption at the first A.G.M.

5/85 Cost of Inaugural Meeting

It was agreed that the committee should be empowered to re-imburse the various costs involved in calling and holding the present meeting.

6/85 Election of Committee

Dr. Hillier called for nominations for the election of officers and committee members, names to be submitted during the lunch break.

At the closing time for nominations, the following people had been proposed for the appointment of officers:-

Chairman:	Dr. Derek Doyle
Treasurer:	Dr. Robert Twycross
Secretary:	Dr. Richard Hillier

There being no further nominations, it was agreed that all three should be elected "en bloc".

The following nominations were agreed for the election of three committee members:-

Dr. Thelma Bates
Dr. Simon Dover
Dr. Gillian Ford
Dr. Richard Waldram
Dr. Christine Wood

On the first ballot Dr. Gillian Ford and Dr. Richard Waldram were declared elected. Dr. Thelma Bates and Dr. Simon Dover shared an equal number of votes in third place. A second ballot was therefore held between these two candidates, Dr. Christine Wood having been eliminated; and Dr. Simon Dover was subsequently elected.

It was agreed that a brief initial committee meeting

should be held later that day; with the first formal meeting of the committee scheduled for Tuesday, 3rd December, following the NAHA meeting in London.

7/85 Objectives of the Association

Dr. Derek Doyle introduced a list of draft objectives, tabled for consideration in discussion groups. During the subsequent "report back" session, it was agreed that the priority of the various objectives should be re-arranged to more closely reflect the opinions expressed at the meeting; and that the wording of some of the objectives should similarly be amended or amplified. It was agreed that the secretary should prepare a paper on this basis in time for the Executive Committee Meeting to be held on the 3rd December.

A synopsis of the draft objectives, re-arranged in their new priority order reached as a consensus following the comments of the discussion groups, is attached.

8/85 Arrangements for future Meetings

It was agreed that the Association should aim to arrange a general members meeting at least once every six months. These should preferably be in the form of whole day meetings, allowing some time for the consideration of business matters, but programmed mainly as a seminar on a subject of clinical or educational interest.

It was agreed that the next meeting should be held on Friday, 7th February 1986 at Boddington Hall, Leeds; and that Professor Scott, Chairman of the Standing Inter-Collegiate Committee on Oncology, be invited to speak on the topic of "professional recognition of training in terminal care".

Signed
(Chairman)

Date

Appendix 4

Some thoughts and personal reflections on nurses' contributions to the start of multi-disciplinary teams in some hospitals¹⁶¹

Ms Janet Gahegan

In the late 1970s in Sheffield, Professor Eric Wilkes appointed two ex-district nurses to work from St Luke's in the community and spread the gospel of palliative care to the GPs and their district nursing colleagues. This was slow to take off but after a time, with funding from the Cancer Relief Macmillan Fund (CRMF), more of these nurses were appointed both in Sheffield and throughout the country. Following the success of this, in 1981 he persuaded CRMF to fund a post for three years in the Royal Hallamshire Hospital in Sheffield. An ex-district nurse was appointed to teach palliative care to nursing staff in the hospital. She was also to facilitate discharge of these patients into the community and refer them onto her district nursing colleagues. If, after three years, this was a success, then the hospital would take over the funding.

CRMF were reluctant to fund any more posts at first but when it was seen to be successful in about 1984 they then began to fund more posts for Macmillan nurses in other hospitals.

Nurses were put in positions usually with support from the local hospice and maybe an interested physician or anaesthetist. However, they were essentially working alone.

Initially progress was slow. The nurse was usually referred patients who had been given 'bad news' and she would be asked to go and talk to them. This afforded her an opportunity to discuss pain relief and symptom control. These nurses, however, did not have the 'power of the pen', and consultants, registrars, and house officers would need to be persuaded to prescribe medication that they may have been unfamiliar with and which often seemed excessive and inappropriate.

However, once a successful outcome was achieved, then more referrals would follow and this would swiftly snowball, particularly in the larger hospitals. These nurses soon became inundated with requests to educate fellow nurses, who were very keen to learn about palliative care as this was at the very heart

¹⁶¹ Letter sent by Ms Janet Gahegan to Professor Tilli Tansey, 2 March 2012.

of what nursing was all about and a great source of job satisfaction. There were also requests to talk to physiotherapists, occupational therapists, chaplains, pharmacists, dieticians, etc. However, the main part of the role was supporting the patients.

Many of the original nurses became quickly burnt out and CRMF began to appoint second nurses to work alongside them. However, before this could be done, the hospital had to agree to pick up the funding after the original three years.

Specialist Macmillan nurses were appointed to work in the hospitals but still the need grew. It was often at this point that physicians were appointed to take the work forward and form a team. In the hospital, the nurses played an important part in paving the way to getting these teams accepted.

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Biographical notes*

Professor Sam H Ahmedzai
 FRCPS(Glasgow) FRCP(London)
 FRCP(Edinburgh) (b. 1950) is
 Chair and Head of the Academic
 Unit of Supportive Care in the
 University of Sheffield, and is
 Honorary Consultant Physician
 in Palliative Medicine. He served
 as Lead Clinician for Supportive
 and Palliative Care in the North
 Trent Cancer Network and
 for the Sheffield Adult Cancer
 Survivorship project and has been
 Editor-in-Chief of the Oxford
 University Press book series
 on supportive care since 2004,
 and also Editor of the journal
*Current Opinion in Supportive and
 Palliative Care*, and the section
 on supportive and palliative care
 for *BMJ Clinical Evidence*. He is
 clinical expert adviser for NICE
 NHS Evidence and has been Harry
 H Horvitz Visiting Professor at
 the Cleveland Clinic and Spinoza
 Visiting Professor at the University
 of Amsterdam, Netherlands, and
 a council member of the British
 Pain Society, a member of the
 Commission on Assisted Dying,
 and a member of the Scientific
 Advisory Board for Target Ovarian
 Cancer.

Dr Mary Baines
 OBE FRCP HonDUniv (b. 1932)
 trained at Cambridge and then
 at St Thomas' Hospital where she
 was a contemporary and friend of
 Cicely Saunders. She worked in
 general practice for ten years then,
 in 1967, when St Christopher's
 Hospice was opened, Cicely asked
 her to join her on the small medical
 team. In 1969, she was involved
 with the setting up of the first
 hospice home care service. As the
 senior physician to St Christopher's,
 she helped to train a large number
 of doctors wishing to make a
 career in palliative medicine. Her
 publications have been mainly
 concerned with the management
 of pain and other symptoms in
 patients with advanced cancer
 and she has written extensively,
 including chapters in four Oxford
 textbooks. Her research has been
 into the pharmacological treatment
 of patients with inoperable
 intestinal obstruction. She retired
 from clinical work in 2002 and was
 appointed Emeritus Consultant at
 St Christopher's Hospice. In 2011
 she received the Floriani Award
 at the European Association for
 Palliative Medicine Congress.

* Contributors are asked to supply details.

Sir Kenneth Calman

KCB FRCS FRSE (b. 1941) graduated in medicine in 1967 at the University of Glasgow and proceeded to MD and PhD, being initially involved in medicine as a lecturer in surgery. An MRC Clinical Fellowship took him to the Chester Beatty Research Institute in London in 1973 and he returned to Glasgow to be Professor of Oncology from 1974 to 1984. He became Postgraduate Dean in Glasgow, then Chief Medical Officer for Scotland, Chief Medical Officer for England and subsequently Vice-Chancellor at the University of Durham. He has been Chancellor at the University of Glasgow since 2006.

Professor David Clark

PhD (b. 1953) was educated at the Universities of Newcastle-upon-Tyne and Aberdeen. He was appointed Professor of Sociology at Sheffield Hallam University in 1993 and in 1995 became Professor of Medical Sociology at the University of Sheffield. He was Professor of Medical Sociology and Director of the International Observatory on End of Life Care at Lancaster University from 2003 to 2009, when he was appointed Director of the School of Interdisciplinary Studies at the University of Glasgow.

Ms Marjory Cockburn

MBE SRN ONC SCM HV (b. 1927) trained as a nurse at King's College Hospital, London. She worked in the Nuffield Orthopaedic Centre in Oxford (1953–1956) and the Nuffield Maternity Unit and Churchill Hospital, Oxford (1956–1957) after which she gained her Health Visitor's Certificate. She then attended the Church Mission Society training college (1959–1961), and worked in Nigeria (1961–1973). In 1974 she joined St Luke's Hospice in Sheffield where she remained until her retirement in 1990. She was very involved with nurse education at St Luke's and spoke at many seminars and conferences on the care of the dying, patients and family. Since retirement, she has acted as a consultant in the setting up of a hospice in Guernsey and is involved with various bereavement groups in Sheffield and in London. She was awarded an MBE in 1991 for her hospice work.

Dr Christina Faull

FRCP MD DipClinHyp PGCertMedEd (b. 1961) qualified from the University of Newcastle-upon-Tyne Medical School in 1985. She undertook general professional training in medicine in New Zealand and Tyne and Wear followed by a

three-year period in research in psycho-neuro-endocrinology with training in psychiatry. She was awarded her MD in July 1993 for ‘Anatomical and physiological relationships between central serotonin and osmoregulated vasopressin secretion’. She worked as a consultant in Birmingham at the University Hospital and at St Mary’s Hospice and has been a consultant in Palliative Medicine at LOROS, the Leicestershire and Rutland Hospice and the University Hospitals of Leicester, since 2003. In 1999, *Handbook of Palliative Care*, edited by Dr Faull, Professor Yvonne Carter and Dr Richard Woof, was awarded Medical Book of the Year by the BMA; in 2003 *Palliative Care: An Oxford core text* (with Dr Woof) also received this award.

Baroness Ilora Finlay

FRCP FRCGP (b. 1949) qualified from St Mary’s Hospital Medical School in 1972. She was the first Medical Director of Holme Tower Marie Curie Centre, Cardiff (1987–2000) and has been Consultant in Palliative Medicine, Velindre NHS Trust, Cardiff, since 1994. She has been the course director of the Diploma and MSc in Palliative Medicine, Cardiff University (formerly University of Wales College of Medicine) since 1989. She was Vice-Dean, School

of Medicine, Cardiff University (2000–2005) and since 1996 has been Honorary Professor in Palliative Medicine. She was made a Life Peer (Baroness Finlay of Llandaff) in 2001.

Dr Gillian Ford

CB FRCP DUniv (b. 1934) qualified in medicine (Oxford and St Thomas) in 1959. After junior hospital posts, she joined the Department of Health and Social Security, becoming deputy Chief Medical Officer in 1977. She was seconded to St Christopher’s Hospice in 1985–1999 as Director of Studies to develop palliative/hospice medicine as a medical specialty and promote training and education in the subject on a multi-professional basis. She was Chief Executive at SCOPME (1989–1990) then Medical Director of Marie Curie Cancer Care from 1990 to 1997. Post-retirement she worked for Ministry of Justice as member of Appeals Tribunals for Incapacity and other benefits. She is a long-term volunteer and trustee of St Christopher’s Hospice and is now a Vice President. She was Chair of the Advisory Committee of the Open University course on ‘Death and Dying’, and a Privy Council nominee on the GMC.

Mrs Jean Gaffin

OBE JP HonFRCPCH (b. 1936) was a mature student at the London School of Economics following several years as secretary after which she taught social policy and administration, including eight years in the Nursing Department of the Polytechnic of the South Bank. She then moved into the voluntary sector where the last of four Chief Executive Posts was with the National Council for Hospice and Palliative Care Services. After retirement she chaired an NHS Community Trust and then Brent PCT. She was the first Chairman of the Patient Liaison Committee of the British Pain Society, and helped set up and became Vice Chair of the Chronic Pain Policy Coalition. She is currently a Trustee of St Luke's Hospice (Harrow and Brent).

Ms Janet Gahegan

SRN SCM NDN(Cert) (b. 1939) trained as a nurse at the Royal Hospital, Sheffield in 1961 and worked on the wards and intensive care unit there. After leaving to have a family she returned in 1970 to qualify and take up a post as district nurse in Sheffield where she worked for 11 years. Following this, she trained and practised as a midwife for a short time. In 1984 she was appointed as a Macmillan nurse to set up the service in the

Northern General Hospital in Sheffield where she worked for 15 years. During this time she was involved in teaching and supporting new services that were set up in other hospitals. She retired in 1999 but continues to give input to the bereavement service in the Sheffield Macmillan Unit for Palliative care at the Northern General Hospital.

Dr Paresh D Gajjar

DObstRCOG FRCGP (b. 1945) trained at Leeds hospitals, entering general practice in 1972. He was a GP trainer, Yorkshire Faculty Tutor and CME tutor (1977–1988) and was Hospital Practitioner in Palliative Medicine (1975–1990). He established the Wakefield Palliative Care Team in 1979 and Wakefield Hospice in 1990, and was Medical Director and Consultant Palliative Care Physician at the Wakefield Hospitals and the Hospice (1990–2000). From 2000 to 2005, he was Consultant Physician, Senior Clinical Lecturer in Palliative Medicine and a member of the team commissioning the Macmillan Palliative Care Unit at the Northern General Hospital, Sheffield. He retired from clinical practice in 2005.

Professor Rob George

MA MD FRCP (b. 1953) is a Professor of Palliative Care in the Cicely Saunders Institute, KCL and Consultant Physician, Palliative Care, Guy's and St Thomas' Hospitals NHS Foundation Trust. He trained in chest and general medicine, but developed a passion for the young dying during his doctorate research in chronic respiratory failure and adult cystic fibrosis. Triggered by the HIV epidemic in the 1980s, he established and led the Palliative Care Centre at UCL Hospitals and its community from 1987 to 2003, which pioneered needs-based palliative care. He is an adviser to the Department of Justice, sits on various ethics committees and working parties. Academically, before joining the Cicely Saunders Institute, he was Senior Lecturer in Ethics at UCL. His overarching interest is to understand the nature of suffering in postmodern culture, its response and the complexities that this introduces to care modelling and service delivery.

Professor Geoffrey Hanks

DSc(Med) FRCP FRCPE FFPM (b. 1946) is Professor Emeritus of Palliative Medicine in the University of Bristol, having retired in 2006 (appointed 1993). He continues as a Professor in the Department of Molecular

Medicine and Cancer Research in the University of Science and Technology in Trondheim, Norway, and was previously Sainsbury Professor of Palliative Medicine in the United Medical and Dental Schools of Guys and St Thomas' Hospitals (1991–1993), the first Chair in Palliative Medicine in Europe. He was Consultant Physician in Charge of the Palliative Care Units at the Royal Marsden Hospitals London and Surrey and Honorary Senior Lecturer in Medicine at the Institute of Cancer Research (1983–1991) and a Senior Lecturer and Honorary Consultant in the Department of Clinical Pharmacology at St Bartholomew's Hospital Medical College (1986–1991). He has held many other positions and has been a member or chairman of various expert advisory boards, both in the UK and overseas. He is currently Honorary President of the European Association for Palliative Care and a Vice-President of Macmillan Cancer Support. He is an expert on opioid analgesics and cancer pain, and is senior editor of the *Oxford Textbook of Palliative Medicine*, the globally acknowledged comprehensive textbook in this area (now in its 4th edition). He was Founding Editor of the *European Journal of Palliative Care*, published in English and

French, and was Editor-in-Chief of *Palliative Medicine*, the leading peer-reviewed journal, from 2002 to 2012.

Dr Richard Hillier

MD FRCP MRCGP DObstRCOG (b. 1940) trained at Bart's Hospital (1958–1964) and, after house jobs, obtained a junior fellowship at the National Institute for Medical Research, (1966–1970). During this period, he spent 18 months with the British Antarctic Survey at Signy Island (1967–1968). He then moved into general practice in Exeter and latterly Portsmouth (1970–1976). Wishing to learn more about palliative care, he worked at St Christopher's under Cicely Saunders and Dr Mary Baines, and moved into palliative medicine. He became Consultant and Senior Lecturer in Palliative Medicine at Countess Mountbatten House (NHS), Southampton (1976–2003). During this period, he served as Chairman of the Association for Palliative Medicine for Great Britain and Ireland, Consultant Adviser to two Chief Medical Officers and, latterly, specialist adviser to the House of Lords Select Committee on the Joffe Bill on assisted dying. He was a pioneer in palliative medicine by default and 'stood on the shoulders of giants'. After retirement, he had the privilege of working at

St Joseph's Hospice, Hackney, where Dame Cicely worked for seven years developing her ideas, which led to the founding of St Christopher's Hospice in 1967.

Dr Andrew Hoy

MBBS FRCP FRCR MRCGP DMRT LRAM (b. 1949) trained at University College London and Westminster Medical School (1967–1973). After junior medical posts in London and Leicester, he worked at St Christopher's Hospice for a year under Dame Cicely Saunders, Drs Tom West and Mary Baines (1976–1977). He helped initiate the St Thomas' Terminal Care Support Team with Dr Thelma Bates in 1977, while becoming accredited in Clinical Oncology. In 1985, he was appointed Founding Medical Director of the Princess Alice Hospice in Surrey. He was also subsequently Consultant in Palliative Medicine at Epsom and St Helier University Hospitals NHS Trust until his retirement from clinical practice in 2010. He was a founder member of the Association for Palliative Medicine, serving in various capacities, including Chair of the Association and Chair of the Specialist Advisory Committee at the Royal College of Physicians. He was a Trustee of Help the Hospices, Editor of the *European Journal of Palliative Care* and external teacher

and examiner for the University of Cardiff Diploma in Palliative Medicine. He is a facilitator in advanced communication skills for the National Cancer Action Team, and was a member of the team that developed the current format for the NCAT workshops.

Professor Jane Maher

FRCP FRCR FRCPE (b. 1953) trained at King's College London, Westminster Medical school, Harvard University/Massachusetts General Hospital and the Royal Marsden Hospital and has worked as a consultant clinical oncologist at Mount Vernon Cancer Centre since 1986. Between 1986 and 1999 she developed both general oncology services for five separate hospitals and specialist head and neck cancer services for three health regions. In 1993 she co-founded the Lynda Jackson Macmillan Centre, which won both an NHS Nye Bevan Award and a Special Commendation from the Prime Minister 'for the NHS Organisation that has demonstrated the most innovative ways of spreading best practice'. Since 1999 she has focused her clinical activity on breast and advanced prostate cancer, to enable her to work with Macmillan Cancer Support as Chief Medical Officer and with the NHS as a clinical leader, most recently with NHS Improvement

as a National Clinical Adviser for Aftercare and Survivorship. She has academic appointments at University College London and at Hertfordshire University and established a UK Primary Care Research Collaborative involving five universities. She has had a long-term interest in consequences of cancer treatments.

Professor Dame Barbara Monroe

DBE CQSW FRSA (b. 1951) has been a social worker for over 35 years working in a variety of settings. She joined St Christopher's Hospice in 1987 and became Chief Executive in 2000. She is founder and Director of the Candle Children's Bereavement Project at St Christopher's and was Chair of the national Childhood Bereavement Network for eight years. She is Module Leader on the MSc in Palliative Care and Policy run jointly by St Christopher's and King's College London. She is an Honorary Professor at the International Observatory on End of Life Care at Lancaster University and holds an Honorary Senior Lectureship at the University of Auckland. She was appointed Dame Commander of the Order of the British Empire in the Queen's Birthday Honours List 2010.

Dr Bill Noble

MD FRCP FRCGP (b. 1956) trained in Sheffield, including a hospice junior post on the GP vocational training scheme. He was a principal in general practice while working as an associate specialist at St Luke's Hospice in Sheffield between 1983 and 1996. His doctorate trialled cue-based interviews in hospice home care patients. He was appointed Macmillan Senior Lecturer in Palliative Medicine at the University of Sheffield in 1996. He helped evaluate the Gold Standards Framework in its early phases. His clinical work as a consultant in palliative medicine is combined with research on palliative care in the community. He helped to set up an oral history service of patients at the Sheffield Macmillan Unit for Palliative Care. Research projects include a new integrated care pathway for cancer of unknown primary, testing an holistic needs assessment called SPARC and a national survey of palliative care in general practice. He is past-president of the Association for Palliative Medicine of Great Britain and Ireland and Editor-in-Chief of *BMJ Supportive & Palliative Care*.

Dr William Notcutt

FRCA FFPMRCA (b. 1946) qualified at Birmingham University in 1970 and after working as a flying doctor in Lesotho, took up anaesthesia. He worked at the University of the West Indies, Kingston, Jamaica (1975–1979), became a Senior Registrar in the Nottingham area (1979–1982) and then consultant at the James Paget Hospital, Great Yarmouth. He was appointed Honorary Senior Lecturer at the University of East Anglia, Norwich (1997). His main interest is pain relief and he started a palliative care service in 1985 and introduced patient-controlled analgesia for acute pain in 1986. He is Chair of the ethics group of the British Pain Society (since 2005).

Dr Colin Murray Parkes

OBE MD FRCPsych (b. 1928) trained in psychiatry at the Institute of Psychiatry (1956–1959). He worked for 13 years at the Tavistock Institute of Human Relations (1962–1975) and edited books on the nature of human attachments and cross-cultural aspects of death and bereavement; he was then Senior Lecturer in Psychiatry at the Royal London Hospital Medical School (1976–1993). He was Director of Harvard Bereavement Project, Boston, Massachusetts (1965–1969) and Visiting

Psychiatrist at St Christopher's Hospice since its inception in 1969. He is Life President of Cruse Bereavement Care and Editor of the journal *Bereavement Care*. He was consultant following five disasters in the UK, helped set up 'Trauma Recovery programme' in Rwanda in April 1995, and a programme of support in New York to families from the UK following the terrorist outrages on September 11, 2001. In April 2005, with Ann Dent, he was sent by Help the Hospices to India to assess the psychological needs of people bereaved by the tsunami. He has recently worked on traumatic bereavements (with special reference to violent deaths, the cycle of violence and armed conflict) and on the roots in the attachments of childhood of the problems that can follow bereavements in adult life. He received the OBE for his services to bereaved people in June 1996. See *Bereavement: Studies in grief in adult life* (4th edn, with Holly Prigerson, 2010); with Robert Weiss, *Recovery from Bereavement* (1983); *Love and Loss: the roots of grief and its complications* (2006); and with M Relf and A Couldrick, *Counselling in Terminal Care and Bereavement* (1996).

Dr Julia Riley

MRCGP FRCP MD (b. 1960) is head of the Department of Palliative Medicine at the Royal Marsden and Royal Brompton NHS Trusts. She is a Senior Research Fellow at Imperial College London. She is a member of the executive committee of the Association for Palliative Medicine, Editor of the *European Journal for Palliative Care* and is the Clinical Lead for Coordinate My Care, the clinical service that coordinates end of life care for patients who receive multiple services and care from multiple providers, allowing them to have choices and improved quality of end of life care. Her research interests include the inter-individual variation in patients' response to opioids and the development of models of end of life care that include the seamless transition between the acute and the community sector, improve quality of life, decrease in the number of unnecessary hospital admissions and increase the number of patients being cared for, and dying, in their preferred place.

Professor Clive Seale

PhD (b. 1955) is a sociologist who has carried out surveys and other studies concerning dying and care at the end of life since the 1980s. Initially (1986–1990) working with Ann Cartwright on a survey

of relatives and friends of a large sample of people who had died, he then lectured at the University of East London (1990–1993) and at Goldsmiths, University of London (1993–2003), where he was appointed Professor of Sociology in 2001, moved to Brunel University (2003–2008) and to Queen Mary, University of London (2008–2012) as Professor of Medical Sociology. In 2012 he was appointed Professor of Sociology at Brunel University.

Professor Jane Seymour

PhD RGN (b. 1958) trained in general nursing at the Princess Alexandra School of Nursing, the London Hospital, Whitechapel (1979–1982) following an undergraduate degree in social sciences, University of Exeter (1976–1979). She worked as a nurse in Essex (1982–1984; 1986–1987), London (1984–1986) and Sheffield (1990–1996) mainly in critical care settings. She gained a Master's degree in social sciences from Sheffield Hallam University (1991) and a PhD from the University of Sheffield (1998) funded by a scholarship from the Trent Palliative Care Centre in Sheffield. Her PhD focused on the challenges of end of life decision making in critical care. She worked as a member of the research staff for the Centre between 1996 and 2003. In 2003,

she moved as a Senior Lecturer to the School of Nursing and Midwifery at the University of Sheffield and, with Professor Sheila Payne, developed a research group dedicated to palliative and end of life care. She moved to the University of Nottingham and has held a Chair in Palliative and End of Life Studies and Directorship of the philanthropically funded Sue Ryder Care Centre for the Study of Supportive Palliative and End of Life Care since 2005.

Professor Tilli Tansey

PhD PhD DSc HonFRCP FMedSci (b. 1953) is convenor of the History of Modern Biomedicine Research Group and Professor of the History of Modern Medical Sciences at Queen Mary, University of London.

Dr Robert Twycross

DM Oxon FRCP FRCR (b. 1941) trained at Oxford University Medical School (1959–1965), and then worked mainly in general medicine for several years. He was Research Fellow in Therapeutics at St Christopher's Hospice, London (1971–1976), where he completed studies of diamorphine, morphine and methadone in the management of cancer pain. He was Clinical Reader in Palliative Medicine, Oxford University (1988–2001) and Consultant Physician in

Palliative Medicine, Sir Michael Sobell House, Churchill Hospital, Oxford (1976–2001). He was also Head, WHO Collaborating Centre for Palliative Care (1988–2005), and for about ten years was the Academic Director of the Oxford International Centre for Palliative Care. He has written some 300 articles, chapters and editorials, and is the author of several books, including *Pain Relief in Advanced Cancer*. Edinburgh: Churchill Livingstone (1994); (with Andrew Wilcock and Claire Stark Toller) *Symptom Management in Advanced Cancer*, 4th edn, Nottingham, Palliativedrugs.com Ltd (2009); *Introducing Palliative Care*, 4th edn, Oxford: Radcliffe Medical Press (2003). He has been Co-Editor-in-Chief of the *Palliative Care Formulary* (www.palliativedrugs.com) since 1998. He is a founder member of the International Association for the Study of Pain, the Association for Palliative Medicine (UK), the British Lymphology Society and the European Association for Palliative Care.

Dr Bee Wee

Dip Pall Med (Wales) MRCP FRCP PhD (b. 1964). Originally from Malaysia, she trained at Trinity College Dublin. Following a period in Hong Kong, she became Consultant in Palliative Medicine

at Countess Mountbatten House, Southampton. She was Deputy Director of the Medical School at University of Southampton. She moved to Oxford in 2003, as Consultant and Senior Lecturer in Palliative Medicine at Sir Michael Sobell House, and Associate Director of Clinical Studies at Oxford University Medical School. She developed the e-ELCA e-learning programme in end of life care for the Department of Health in 2010 and chaired the topic expert group for the NICE Quality Standard for End of Life Care in 2011. She became President of the Association for Palliative Medicine of Great Britain and Ireland in 2010, a three-year term ending in 2013. She has been Visiting Professor at Oxford Brookes University since 2011. She chairs the NICE Standing Committee on quality standards.

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Back cover, left to right

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Professor Rob George

Dr Christina Faull

Dr Paresh Gajjar

Professor Jane Maher

Professor Clive Seale

