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apm POST

The Newsletter of the Association for Palliative Medicine of Great Britain and Ireland

IN THIS ISSUE

Shape of Training. A New Direction for Palliative Medicine

Background
As many members will be aware the Shape of Training review has been underway for some time (link 1). It now appears likely that Shape will happen. It will create an entirely new landscape for training and for how trainees and future consultants in palliative medicine work.

We must ensure that training equips doctors for the job they will be doing. We must also maintain the relevance and the ethos of our specialty in the new world. Hard work over the past twenty years to ensure palliative medicine is recognised as being essential across all care sectors must not be wasted. We now have 550 consultants across the UK, a robust training programme and an ability to effectively influence national policy agendas.

Proposed JRCPTB Framework for New Training Model
In the summer of 2015 we circulated a briefing paper about Shape and the potential impact on palliative medicine (link 2). At the same time the APM conducted a survey of members which highlighted concerns about aspects of Shape including our future role in acute take. The survey formed the basis for discussions with JRCPTB who then produced a framework describing how the 29 medical specialties would operate within the new model of training (link 3).

This new framework left us sitting apart from all of the key and relevant medical specialties. It was clear that we were in real danger of losing our ability to directly influence patient care. This position generated real concern for many, including training leads and those representing our specialty.

Options Appraisal
An options appraisal was generated to facilitate further discussion. The two options are summarised in Figure 1 (*on page 2*). There was widespread constructive debate within the APM, the JSC the SAC and with trainees, supervisors and consultants across the UK. Notwithstanding the concerns, the consensus was that the specialty needed to change position and to support Option 1 in order to avoid being marginalised. This has also been the conclusion reached by many of the other medical specialties such as medical oncology. This relates to training and it does not mean that future consultants would be expected to routinely be part of acute medical takes in hospitals. We do need to be able to assess an acutely unwell patient in any care setting to reach the best management plan; in this way we play a part in the acute care pathway but in the context of our services.

Way Forward
The RCP and JRCPTB understand our reservations but have welcomed our decision to join with other key specialties in focusing on the development of a new internal medicine curriculum to link with a new curriculum for specialty training. Both of the new curricula will be concise with a focus on defining what a competent physician can do. There will be approximately 10-14 Competencies in Practice for each curriculum with key descriptors for each competency. How we assess competency is being reviewed with a real determination to move away from box ticking and multiple assessments.

Embedding a competency in palliative and end of life care in the new internal medicine curriculum will help to ensure that all future physicians, whatever their specialty, have appropriate training, experience and competence in looking after patients at the end of life. The new curricula will require pilots. These could start as early as 2017 with 2019/2020 suggested as the target for rolling out the new model of training.

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New Committee Member

Esraa Sulaivany
– SSAS Co-Chair
I am a Senior Specialty Doctor in Palliative Medicine working in Merseyside and Cheshire. I joined the APM SSAS Committee in 2014. I have represented the SSAS on the Professional Standards Committee. As SSAS Co-Chair, I look forward to continued development of my skills to enable me to support my fellow SSAS colleagues.

President's Report

You will see from this month's post that it is all meat, so the less I occupy of your reading time the better.

The PCC in Glasgow is now only (www.pccongress.org.uk/index.php?pageid=18) 3 weeks away and the opportunity is there both to hear and question experts on the principal articles in this post: discussion on the Shape of Training will form part of the AGM and we will offer a breakout session on Friday lunchtime parallel to the lunch, poster and exhibition viewing for more detailed discussion. The NICE guidelines session is on Wed 9 March in the early evening, and a masterclass on e-ELCA on the morning of Friday 11th. These articles are briefings to inform you ahead of the event so that you can be well prepared to benefit.

The AGM on the Thursday is equally important. We have spent the last year considering and discussing in the executive team and committees how we can launch and brand a refreshed Association for this next period of challenge as we refine our counter narrative to the media's forensic pursuit of how bad and not how good a person's death can be. There is a chance in our AGM for you to hear and reflect on this and our strategy for 2016-7.

The PCC this year is therefore particularly important. The programme ranges across our specialty and palliative care in general, so If you have not done so already, then please book in via the website whilst places remain. Remember this is your Association and it can only survive and flourish with your active engagement and support of our events.

We also have the opportunity in this edition of the Post formally to honour our friend and colleague Fiona in her obituary. Should you wish still to contribute to our fund for the Fiona Hicks Memorial Lecture, please let Becki know.

I look forward to seeing many of you in Glasgow.

Rob George
President

Shape of Training... continued

We know that there will be further changes and some uncertainty remains. The APM, JSC and SAC will work together to ensure that palliative medicine is represented, influential, protected and developed. We will continue to provide members with regular updates via this newsletter and the APM website. Training Programme Directors will remain a key contact point in each locality

Figure 1: Summary of Options Appraisal

	Option 1	***Option 2***
Input to acute medical care	Yes. May include direct contribution to acute take	No contribution to acute take
CMT training	Three years using new internal medicine curriculum	Two years. Curriculum unclear
Specialty training	Four years. 12 months would focus on internal medicine	Four years. Only focused on palliative medicine
Dual accreditation	Yes	Unlikely
Future Consultant role	Negotiated according to local need e.g. level of input to acute take. More flexibility in career development	No option for negotiation. Potentially few employment options in acute trusts. Focus on community and hospice settings. Less flexibility
Selection criteria	May make MRCP the desirable entry pathway	Could remain broad to include MRCGP etc
Potential to change specialty during training	Yes	Unlikely
Position of other medical specialties	Respiratory, cardiology, geriatrics, medical oncology	Audio vestibular medicine, ophthalmology, genetics

There are real opportunities and exciting times ahead. We are confident that as a specialty we are now in a better position to influence both patient care and the training of doctors in all medical specialties.

Dr Alison Coackley
Chair of Palliative Medicine Specialty Advisory Committee

Dr Idris Baker
Member of Palliative Medicine Specialty Advisory Committee

Dr Stephanie Gomm
APM Executive Member and Chair of Workforce Committee

Dr Wendy Makin
Chair of the Joint Specialty Committee for Palliative Medicine

The Science Committee's articles of the month from the APM journals.

Palliative Care Screening and Assessment in the Emergency Department: A Systematic Review George N, Phillips E, Zaurova M, et al. J Pain Symptom Manage. 2016;51(1):108-119
This systematic review included 7 articles addressing palliative care interventions in the emergency department. The interventions assessed in all studies increased palliative care referral, but the study outcomes varied widely and six of the seven studies required additional staff to perform screening for palliative care needs in the emergency department. Standardization of palliative care screening in the emergency department is recommended.

Variations in specialist palliative care referrals: findings from a population-based patient cohort of acute myeloid leukaemia, diffuse large B-cell lymphoma and myeloma. Howell DA, Wang HI, Roman E, et al. BMJ Support Palliat Care. 2015;5(5):496-502.
This cohort study collected information on patients with three haematological malignancies. Of the 323 included patients, 155 (48%) were referred to specialist palliative care, with patients living longer or having myeloma being more likely to be referred. People dying at home or hospice were more likely to have been referred to specialist palliative care services compared with those dying in hospital. The authors suggested further research to explore the reasons for specialist palliative care referral and non-referral, and differences in the preferred and actual place of death.

Prepared by **Elaine Boland**, *on behalf of the APM science committee*

Fiona Hicks

Born *24th September 1962*
Qualified *Nottingham University 1986*
Died *23rd October 2015 from breast cancer*

Consultant and Senior Clinical Lecturer in Palliative Medicine, Leeds Teaching Hospitals Trust. A passionate teacher and excellent clinician, with deep humanity and gentle humour, Fiona led curriculum development and higher specialist training in palliative medicine nationally. She led Marie Curie's Delivering Choice Programme across Leeds (2006-9), and collaborated with commissioners and all palliative care providers in the city to ensure integrated services. Married David Barrow, one daughter, two sons.

Fiona Hicks knew she wanted to be a doctor from the age of three. Her gentle quiet determination combined with an inquiring mind took her into medicine at Nottingham University, graduating in 1986. She became one of an early small group of registrars in 1990 in the newly formed specialty of palliative medicine and within months was appointed as senior registrar in Leeds. Leeds was to be her professional home and base from which she worked as a skilled and respected clinician, and contributed to education and training in palliative medicine across the UK.

She was elected to the executive committee of the Association for Palliative Medicine in 1993. From that position she chaired the curriculum working group to produce specialist and generalist curricula in palliative medicine. She went on to serve on and then chair the specialty advisory committee at the Royal College of Physicians, a contribution that was recognised by the special President's award of Certificate of Merit. She loved to teach and she knew how to teach well.

Fiona's personality was a great asset. She was always warm, welcoming and considerate of others, with a friendly smile for all she met and with a great sense of humour. Differences of view never stopped her seeing the merit in people and her strong moral compass led her to question things in such a way that people didn't even realise they were being challenged. When colleagues needed support she was quietly but selflessly available, frequently inviting them to share supper at home. She enjoyed playing saxophone with anyone of musical disposition.

As Regional End of Life Care lead, she led on many of the strategic developments across Yorkshire and the Humber, always working in consultation with colleagues and crediting others. Working at Leeds Teaching Hospitals and providing on call to the Leeds' hospices she could see the need for rapidly responsive transport for seriously ill and dying patients without distracting from the emergency services. She pioneered a novel palliative care ambulance service with Marie Curie, to ensure appropriate transport was timely. She was passionate about person centred care.

Fiona contributed not only locally and nationally as a doctor, she provided clinical services also to Martin House Children's hospice and went on to serve as a trustee. She was an active member of her church and had organised Fairtrade locally for many years.

When her own breast cancer was diagnosed she viewed it as 'a bit of a nuisance'; that was her view of its recurrence and advancing metastatic disease. She had excellent care every step of the way, but her disease failed to respond. With her family, she spent most of her last months at home. She adored her three children Naomi, Jonathan and Edward, and both she and her husband spoke openly with them about her illness and prognosis, wanting to prepare them for life without her. On 23rd October 2015 Fiona died with her husband at her side.

She died as she had lived, with serenity and calm generosity to all she encountered.

NICE guidelines for care of adults in the last days of life: implications for palliative medicine

The dominant model in the UK of delivering high quality care to people in their last days of life was influenced, in the latter part of the 20th century and the first decade of the 21st, by a concept of a 'good death' emanating from the hospice model which had been formulated almost exclusively for cancer patients. This lead to the introduction of the 'Liverpool Care Pathway' (LCP) which was an attempt to transpose this model to the wider reaches of the NHS. After initial acceptance, Department of Health (DH) endorsement and widespread adoption, serious failings in its implementation and its fundamental lack of research evidence led to its abolition by the DH in 2014.

The National Institute for Health and Care Excellence (NICE) was commissioned to produce guidelines to give an evidence-based framework for caring for adults in the last few days of life. This was developed by a multiprofessional committee representing acute and chronic care in the NHS, community and hospice services and was published as NG31 in December 2015. A large number of co-optees provided expert perspectives on management of dying in specific diseases and diverse aspects such as swallowing assessment, pain management and cultural/religious influences.

The NICE guidance is primarily aimed at 'generalists' but also applies to specialists such as palliative medicine doctors. It provides clinicians with recommendations on: Recognising dying, but also the potential for recovery and the uncertainties surrounding these; Communication; Shared decision-making and individualised care planning; Maintaining hydration; Pharmacological interventions including the management of pain, breathlessness, nausea and vomiting, anxiety, delirium and agitation, noisy respiratory secretions; and Anticipatory prescribing.
In many of these topics the evidence base was severely lacking and the guideline committee made expert consensus clinical recommendations.
Research recommendations were also made on: Reducing impact of uncertainty about recognising dying on clinical care and communication; Managing delirium – with or without agitation – without unduly sedating the dying person or shortening life; Role and side effects of pharmacological treatments for noisy respiratory secretion over and above nursing interventions alone; Clinical and cost-effectiveness of anticipatory prescribing for patients in the community.

The new NICE guideline provides a structure for holistic and individualised care for the dying person and those important to them. It will help services move away from a dogmatic and idealised concept of a good death from the 20th century to acustomisable model which responds to modern modes of dying, regardless of the underlying condition, and wherever NHS care is given.

There will be numerous challenges and potential barriers to its implementation. These include the availability of specialised

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NICE guidelines... continued

palliative care 24/7 wherever people are dying; re-training of staff to embrace uncertainties and to share them honestly to patients and families; making clinical interventions such as assisted hydration available in all settings; an increased emphasis on individualised care planning and avoiding the 'blanket' approach to prescribing.

It is unlikely that any new funding will follow the guidance so realistically, commissioners and providers will have to work together to agree what re-design and re-allocation of funds will be needed to implement the recommendations. Palliative medicine should play key role in advising both on how to make the guidelines work in specific localities.

At the PCC in Glasgow this month there will be a discussion led by medical and nursing members of the NICE guideline committee, who between them represent the acute and community sectors. Questions will be encouraged about the evidence base – or lack of it; and suggestions proposed about how the recommendations can be put into practice given the current multiplicity of post-LCP locally developed solutions. Opportunities to re-discover the holistic roots of palliative care, through the NICE guidance, will be explored.

Sam H Ahmedzai FRCP
Emeritus Professor and Chair of NICE guideline NG31 committee

e-ELCA: Completely updated

The review and updating of all 156 e-ELCA sessions will be completed by the end of March. A big thank you to all who have supported me in this. It's been a fascinating 18 months really getting to grips with the amazing breadth and detail of content. Some sessions won't need updating again for several years but some will need a much more regular review to keep them as valuable as possible for users.

There are now over 54,000 registered e-ELCA users! 22,000 joined right at the start but over 7,500 new users registered last year. Nearly half of the registered users are actively using e-ELCA with 86,400 session launches last year and over 80 million seconds of view time! That can't just be my editorial reviews!

The top 10 sessions accessed are:

- 00_01 Introduction to e-learning for End of Life Care (16,236 launches)
- 00_02 Relationship Between Palliative Care and End of Life Care
- 01_01 Introduction to principles of ACP
- 01_02 Cultural and Spiritual Considerations in ACP
- 01_03 Benefits and risks of ACP to patients, families and staff
- 01_04 ACP in practice: using end of life care tools
- 01_05 Advance Decisions to Refuse Treatment: Principles
- 02_01 Introduction to principles of assessment in end of life care: Part 1
- 03_01 The importance of good communication
- 03_02 Principles of communication

One session I really enjoyed recently was Spirituality and the Philosophy of End of Life Care. To me this is really core to best practice in palliative care. You can access it here:
http://portal.e-lfh.org.uk/Component/Details/364896

Christina Faull
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Internationally groundbreaking work

Improving the care and the experiences of families and health professionals when a patient with Motor Neurone Disease (MND) requests withdrawal of their ventilation.

When breathing problems occur many patients with MND choose to use non-invasive ventilation (NIV) to improve their quality of life. The NICE guidance in 2010 identified the lack of evidence on providing information to family and patients using NIV in relation to end of life and that more research is needed on the rare scenario of withdrawal of NIV at the request of a patient who has become very dependent on it.

Over the past 3 years, supported by funding from LOROS and the Motor Neurone Disease Association, Professor Faull has lead a team to explore the experiences of close family and health professionals. All the participants identified that this is a very challenging part of the journey of care for a person with MND. The project identified examples of where things had gone well and also examples of where outcomes were not satisfactory.

The findings of this work have lead to National Guidance for professionals published by the APM in November 2015.

There is a multi professional group continuing to collate information about withdrawal of ventilation to make further recommendations for the care of patients and their families. Please consider submitting anonomised data if you are involved in withdrawal. The audit proforma is on the APM publications web page. *For more information see the study webpage.*

Christina Faull
APM e-ELCA Lead