New film from the General Medical Council

The Dorothy House Hospice Story

The Future of Nursing

Palliative Care Archive

August 2017
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Hello

Welcome to your latest copy of Inside Palliative Care. I hope you enjoy and find it useful – either way, you’re always welcome to let me know what you think of it.

As I hope you know, on 1 July the National Council for Palliative Care merged with Hospice UK. The merged organisation is carrying on with the name of Hospice UK and takes forward many of the goals and initiatives of NCPC, including the Dying Matters coalition and Building on the Best project. By pooling the knowledge and resources of the two organisations, we will be able to further strengthen the voice for excellent palliative and end of life care for all, continuing to support all those working in palliative and end of life care, and pressing government and other organisations to ensure that everyone receives the best possible end of life care in a place of their choosing.

As you can imagine, the practicalities of merging the activities and services of two organisations takes a bit of time, including the details of benefits for previous NCPC subscribers and Dying Matters member. Please bear with us as we finalise these details in the coming weeks. In the meantime, please be aware that, as a result of the merger, the NCPC website will remain online but will not be regularly updated. If you wish to purchase any items, the online shop is still available. It has a new look and easier to use interface, but all the items are still available.

The Dying Matters site is still active, and both the Hospice UK site and the Ambitions Knowledge Hub are regularly updated with useful information and case studies.

I hope to see many of you at the Hospice UK annual conference later this year (22-24 November, Liverpool). This flagship event for the hospice and palliative care community and for those interested in Leading, Learning and Innovating. Finally, don’t forget that Dying Matters Awareness Week next year runs from Monday May 14 to Sunday May 20.

Best wishes,

Tracey Bleakley, CEO, Hospice UK
Stronger relationships with the public -
the Dorothy House Hospice story

Professor Mark Gamsu and Jennie Chapman (in collaboration with Dorothy House)
Leeds Beckett University

In 2016 Dorothy House Hospice Care invited Leeds Beckett University to help them review their approach to involving and engaging with the public. As part of its strategic planning process the hospice recognised that, to meet its future challenges, it would need to better understand and involve the community it serves.

Background

Over the last few years there has been a growing interest in the relationship between the public and the wider health and care system. This has been for a number of reasons, including recognition that:

- services can be improved if the views of the people who use them are heard more systematically and powerfully.
- enabling people to take more control over their own health can be as important as clinical interventions - in particular the growth of the Compassionate Communities movement
- services need to be accountable to their funders who are primarily members of the public as taxpayers or donors.
- some services are better delivered by volunteers and by so doing this extends the reach and efficacy of clinical services.
- services need to be inclusive and respond to changes in the composition of populations

In addition to the above a recent report by Hospice UK identified:

“too many people do not get the care and support they need at the end of life. Improving access to palliative and end of life care can only be addressed if it is considered to be a priority at a local level”

One important way to address this is through hospices and other institutions having substantial and meaningful relationships with the public so that the needs of dying people and their families and carers are championed appropriately with local commissioners and providers.

Of course, the hospice movement has a long history of using volunteers and of placing the people at the heart of their services:

“Hospice Care seeks to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal illness, helping them live as fully as they can for the precious time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs”

In fact a guiding statement for Dorothy House are the words of Cicely Saunders:

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

For understandable reasons (such as scale and central government performance management) much good practice guidance on public engagement has tended to focus on statutory services.
It may also be the case that until recently some of the factors that have driven this agenda in the NHS and Social Care have been different in the hospice sector - for example:

- There is a strong ethos of collaboration in this sector
- The strong value base in the hospice sector helps attract committed staff
- For many people the term hospice is synonymous with care, respect, kindness - many Hospices have continued to be attractive to people who want care and support as they approach the end of their life.

Nonetheless, the hospice landscape is changing

- More people would like to die at home
- While the hospice ‘brand’ has been very successful in attracting many people to their services there are now different communities and populations - such as those from minority ethnic populations who also need care and support but who do not have the tradition of using hospices as they are currently configured
- Many people may now live for a long period of time with a terminal condition - many hospices are now reconsidering how their expertise might help here.
- People are living longer, and consequently more people will be living with long-term disability, chronic conditions and multiple health conditions which will put pressure on all health and social care providers – hospices included
- The NHS Five Year Forward View projects that in the current policy environment the NHS in England faces a deficit of £30bn by 2020/1 that will require new service models and further efficiencies.

In response to this changing agenda we are also seeing a growing interest in public engagement and palliative care - such as the work of Libby Sallnow and Sally Paul

**What we did**

Dorothy House is a well established hospice serving a population of 550,000 people who live in parts of Bath and North East Somerset, Wiltshire and Somerset. The community management team invited Leeds Beckett University in to look with them at how they currently engage with the public and to consider which areas they could focus on to improve this work.

This was a quick review - so the review team placed an emphasis on talking to the service managers, the executive team and a small number of external stakeholders such as the CCG and local authority. We built on these interviews with two workshops, one with staff and one with executive members to discuss our findings and develop ideas for actions.

**What we found**

Three key points that we learnt from this process were:

**Strategic**

Engagement is often seen as an essentially operational function - for example consulting members of the public or service users on specific changes or services. While this is important, engagement has to start at the top of the organisation and broader engagement with the wider public is essential in strategy development - it helps to test out ideas, sense check analysis of population change and expectations and build alliances.

Hospices need to identify and mandate champions at senior management and trustee board level who can challenge and drive forward engagement within and outside the organisation.
Communities

While there remains a strong public perception of hospices as somewhere people go at the end their lives, the development of the Compassionate Communities agenda is an opportunity for hospices to contribute their expertise to a wider arena of supporting independence and wellbeing in larger populations. Hospices are often not expert at this wider community engagement, the opportunity and challenge is to develop collaborations with organisations who are such as neighbourhood based voluntary organisations and community anchor organisations as well as others such as Age UK, Cruse and Mind. A strong relationship with local public health leads is also important.

Volunteers

Hospices have a long track record of attracting and recruiting volunteers - many of these work in shops or help with fundraising. Volunteers are involved in some caring roles however, this is not systematic - one of the reasons for this is due to concerns from clinicians with regard to safety and confidentiality. More work needs to be done to support hospices developing service models that build on the contribution that volunteers can make to service delivery both in the community and in the hospice setting.

Going Forward

As acknowledged at the beginning of this article, this short piece of work aimed to provide a platform for future work and collaboration locally. Hospice UK has initiatives and strategies which will set the example and tone of future work. Dorothy House have already begun the process of investing in and embedding the recommendations of the work undertaken by Leeds Beckett University and will review the impact of this a year from now. It has however raised the prospect of greater shared learning in this new and exciting area.

We are proposing that Dorothy House host an event facilitated by Leeds Beckett University to share knowledge, strategies as well as successes and failures in this vital area of work. In today’s healthcare market and system hospices can only continue to deliver outstanding quality of care to more people through partnership with its local citizens.

References

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2) A low priority? How local health and care plans overlook the needs of dying people
3) What is Hospice Care? - www.hospiceuk.org
5) NHS 5 Year Forward View Executive Summary https://www.england.nhs.uk/ourwork/futurenhs/nhs-five-year-forward-view-web-version/5yfv-exec-sum/
Best Practice in care coordination for palliative and end of life care services: information for commissioners

Alec Williams, Policy and Advocacy Officer, Hospice UK

Keech Hospice, in Luton, has been highlighted as a good practice example in ‘Best Practice in care coordination for palliative and end of life care services: information for commissioners’ – an information resource to support commissioners in designing and contracting optimal care coordination systems for their local areas, released in June by the National Council for Palliative Care prior to the merger.

The guide highlights how Keech Hospice’s Care Coordination Team, coordinated care around an individual: arranging for Palliative Care Support Workers to give personal care twice a day, linking the wife and family to local support networks and organising an assessment for equipment to help with the individual’s mobility needs.

Coordinating care around the individual is essential to good end of life care. It ensures people receive the right care, at the right time and in the right place. It means that people feel listened to, that they have greater choice and control over their own care, and that there are fewer unwanted hospital admissions.

Following on from a desktop review carried out by NHS England, NCPC reviewed 66 palliative and end of life care co-ordination systems with the aim of identifying good practice systems for providing effective care coordination in this area of care.

Each system was rated on whether it met the five building blocks within the fourth ambition in the Ambitions framework (for care to be effectively coordinated) and to what extent it had been evaluated - the systems that scored highest all shared a number of core features (all of which are outlined in the publication).

Building on the good practice examples, the resource provides a step-by-step practical approach to support commissioners to plan, design, commission and evaluate optimal end of life care coordination systems for their local areas.

The guide – which was developed through consultation with a wide range of stakeholders, including commissioners, health care professionals, and people working in the voluntary sector and social care – is now available on the Ambitions Knowledge Hub. www.endoflifecareambitions.org.uk/

The document will help identify and develop optimal systems for providing effective care coordination that will improve people’s experience, choice and quality of care at the end of life.
Nursing and Midwifery Council consultation: What will we need from nurses in 2030?
Grace Weaver, Senior Stakeholder Engagement Officer, Nursing and Midwifery Council

Setting standards of education

The Nursing and Midwifery Council regulates nurses and midwives in the UK. Our core purpose is to protect the public.

We set standards of education, training, conduct and performance so that nurses and midwives can deliver high quality care throughout their careers.

Adapting to change

The health and care landscape moves quickly, with constant advances in technology, changes to the population of the UK, and transformations to the way that care is delivered.

There is a growing emphasis on providing care in community settings and caring for those with complex needs, those living with dementia and those at the end of life. The ability to think critically, apply their knowledge and skills and provide expert direct nursing care therefore lies at the centre of all registered nursing practice.

We want to enable nurses and midwives to adapt to these changes. We are undertaking a radical review of our education standards, thinking about what the public will need from nurses and midwives in 2030. We are now consulting on our proposals for new standards of proficiency for registered nurses. These are the standards that students will need to meet before they can become registered nurses. We are also consulting on our education framework for nurses and midwives and standards for prescribing and medicines management.

Outcomes in palliative care

Our proposed new nursing standards are focused on outcomes rather than processes. Many of our proposed outcomes are relevant to palliative care.

For example, at the point of registration, we want nurses to be able to:

- Identify and assess the needs of people and families for care at end of life, including requirements for palliation and decision making related to their treatment and care preferences.

- Demonstrate the knowledge and skills required to prioritise what is important to people and their families to enable evidence based person-centred care at end of life.
In order to meet these outcomes, nurses must be able to carry out the procedures such as:

- Observe and assess the need for intervention for people, families and carers, determine the level of independence and self-management of care that an individual can potentially have.
- Assess and review preferences and care priorities of the dying person and their family and carers.
- Manage and monitor symptom relief medication, infusion pumps and other devices.

You can read more detail about our proposals in the draft standards document.

Have your say

As well as the full consultation, we are running a short survey to enable patients, carers and members of the public to have their say.

We want to hear from patients and healthcare professionals across the UK. We are running a series of workshops, webinars and Twitter chats so that everyone can get involved. More details can be found here: https://www.nmc.org.uk/education/education-consultation/engagement-events/
Since 1990 the History of Modern Biomedicine Research Group, based at Queen Mary University of London, has been recording the oral testimonies of those who have been at the forefront of biomedical developments post-1945 (predominantly in the UK but also internationally). Convened by Professor Tilli Tansey, these ‘Witness Seminars’ with more than 1200 contributors have led to over sixty publications, including Innovation in Pain Management (2004) and Palliative Medicine in the UK c.1970–2010 (2013). Indeed, this archive of oral history would have been incomplete without the voices of key figures in the specialty of palliative medicine.

Dame Cicely Saunders’ participation in the Innovation in Pain Management Witness Seminar in 2002 was a vital contribution to our historical records. Her crisp recollections of the early days of the UK’s hospice movement and her work as Medical Director of St Christopher’s Hospice from 1967 to 1985 can be read in full via our Group’s website, www.histmodbiomed.org.

Dame Cicely discusses, for example, her initial motivation in the 1940s to work with people who were dying:

“I was impelled by the stories of my patients that I had experienced first as a nurse, but most of all as a social worker. I knew I had to do something about end-of-life pain and I went, as a State Registered Nurse volunteer, to one of the early homes. There I found that the nurses seeing the prescriptions of morphine four-hourly ‘PRN’ [pro re nata indicates analgesic drugs to be administered as needed or as requested] by the doctors, quite quietly took ‘PRN’ off and gave the drug four-hourly, so as to prevent pain ever happening. This regular oral four-hourly giving of morphine dates back to 1935, fairly soon after the Brompton cocktail was put together.”

Dr Robert Twycross (Research Fellow in Therapeutics at St Christopher’s from 1971 to 1976), also known as ‘the man who destroyed the Brompton cocktail’, explains that the analgesic consisted of ... a mixture of morphine and cocaine in honey or syrup plus alcohol. [p. 26] He describes the pharmacological research journey that St Christopher’s participated in from that infamous cocktail to the ‘morphine by mouth’ therapy that supplanted it. Also on analgesia, Professor Sir Michael Bond (consultant psychiatrist) shares an extraordinary insight into social attitudes towards pain from his research with cancer patients at Sheffield’s Royal Infirmary during the 1960s:

“...on the ward for women all types of analgesics were available, including narcotic analgesics, but on the men’s ward narcotics were not available. I enquired why narcotics were not available to men and was told that men don’t need powerful drugs like that. It is hard to believe that such attitudes existed, but they did...”

The Witness Seminar specifically addressing the UK’s role in the development of palliative medicine was held in 2012 and chaired by Sir Kenneth Calman, the oncologist and former Chief Medical Officer for the UK (1991–8). Managing to elicit humour despite the often poignant and profound testimonies, Calman steers the complex conversation, with topics ranging from multi-disciplinary work to care at home; the role of the NHS; the foundation of the (UK) Association for Palliative Medicine and National Hospice Council, and the role of the charity Macmillan Cancer Support and voluntary staff. Within these broad topics, personal anecdotes suggest why the hospice movement has become such an internationally-recognised force in modern medical best practice.
Mrs Jean Gaffin (Trustee of St Luke’s Hospice, Sheffield), for example, recalls:

“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? 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.’

Despite the high esteem in which we now hold palliative care practitioners, Dr Mary Baines (physician in palliative medicine) points out how ‘a move to hospice was considered professional suicide’ during the 1960s; a comment she supports from the results of a questionnaire that was conducted in preparation for the Witness Seminar with 33 doctors. They moved into the specialty before the advent of formal training. ‘Why practise in a hospice?’ was a pivotal question. For many respondents, losing a parent to cancer had been a motivating factor. Others were inspired by hearing Dame Cicely Saunders speak with the London Medical Group in the late 1960s.

Controversies about hospices not admitting HIV/AIDS patients without cancer also feature as an uncomfortable part of palliative medicine’s history. Tribute, however, is paid to the important work of the Mildmay Mission and London Lighthouse in providing care to these patients; the latter specifically by and for the gay community. Dr Andrew Hoy (clinical oncologist) speaks candidly about his view on this period:

“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.”

Baroness Ilora Finlay elaborates, reflecting on the culture of ignorance that fed some of the prejudice towards HIV/AIDS patients in the 1980s:

“… when I was working for Marie Curie cancer charity …. 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.”

It is only through such frank testimonies that we can begin to revisit the emotional landscape of another era and, in doing so, to appreciate the vast progress that has been made by these outstanding individuals in the UK, and internationally.

**Acknowledgements**

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New framework to promote person-centred approaches in healthcare

Skills for Health

On 26th July 2017, Skills for Health, Health Education England and Skills for Care announced a new Framework to support person-centred approaches for the health and social care workforce.

This approach, outlined in the Five Year Forward View, puts people, families and communities at the heart of health, care and wellbeing. It encourages people to speak with staff about what is important to them, helping to develop a shared understanding of what matters to them.

The new framework, commissioned by Health Education England, helps workers communicate meaningfully both verbally and non-verbally, tailoring the care and advice they give to suit peoples’ needs. It supports individuals to better manage their own health and wellbeing through bespoke care, planning and support. Where appropriate, the framework encourages shared decision making, outlining all reasonable options and ensuring that all information is personalised, accessible and useful.

The framework was informed by health and social care experts and people who are experts by experience, drawing on existing person-centred approaches and applying them to today’s health and care landscape.

The value of a person-centred approach is increasingly recognised and for many health and social care workers, engaging in a meaningful way with people and communities is already part of their intrinsic motivation. This is also seen through practices like health coaching, motivational interviewing, co-production and care and support planning. However, it is often less clear how best to develop the workforce to enable them to put person-centred approaches into practice and to create sustained behavioural change, which is the purpose of this framework.

John Rogers, Chief Executive of Skills for Health said: “This is a really important piece of work and we were delighted to be commissioned by Health Education England to lead on its development and work alongside Skills for Care. The health and social care sectors have an opportunity with the new framework to create more personalised services, where individuals are actively included in decisions regarding their treatment and care and the way that care is delivered.

“Building on existing person-centred approaches the use of the framework has the potential to further develop and improve the responsiveness of the care that is offered and the way that it is experienced as well as the importance of a shared workforce around populations. I’m very proud that Skills for Health is able to play a part in that.”

Ged Byrne, Director of Education and Quality (North) for Health Education England said: “We recognise the importance of making sure that people feel included and in control over their circumstances and that their contact with the providers of their treatment and care is meaningful and constructive.

“We were delighted to work in collaboration with Skills for Health and Skills for Care to develop the new framework to try and make it easier for the workforce to develop genuine partnerships with people and families. The approaches outlined will help effectively plan, design and deliver care based on a person’s individual needs, giving them confidence to take actions to improve their own health and wellbeing.”

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About Skills for Health

Skills for Health is the Sector Skills Council for all health sector employers—NHS, independent and third sector. Since 2002 it has been working with employers to get the right people with the right skills in the right place at the right time. It is the authoritative voice on skills issues for the health sector and offers proven workforce solutions and tools, with the expertise and experience to use them effectively. To find out more, please visit: [www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk)
A new short film from the General Medical Council and the National Council for Palliative Care aims to help doctors talk to people and their families at the very end of life. The new film follows two successful and popular titles released last year. “Communication” features doctors in conversation with people with life-limiting conditions and someone who lost her partner.

The film covers how to share information, even when, as one participant puts it, “the news is rubbish.” Although developed for doctors to use, the film shares its time between doctors and patients or carers, and is designed to help medical professionals see how conversations about end of life issues can impact the relatives of those close to death. It shows how good communications is equally valued by both parties, and how body language and tone of voice have such a large impact.

Mary Agnew, the GMC’s Assistant Director of Standards and Guidance, said: “Discussing end of life care with patients who are dying, their families and their loved ones is something no one finds easy. The real life conversations in this short film show how clear, sympathetic and caring communication by doctors can help people at what is such a difficult time for everyone involved.

“The work of the NCPC and Hospice UK to lift the taboos around death and end of life care has real benefits for doctors and healthcare workers as well as for patients and their families. As with the previous films we’ve worked on together, we’re sure this will help everyone working in this challenging area.”

Claire Henry, until recently CEO of NCPC and now Director of Transformation and Improvement for Hospice UK said “when someone is close to dying, every moment is precious and mustn’t be wasted on unclear or awkward conversations. People and their families need clear, straightforward but caring information about what is happening.”
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