END OF LIFE

knocking gently on the door:
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Why discussing and planning for death is an important part of living

Toby Scott from The National Council for Palliative Care and Dying Matters Coalition discusses the importance of embracing the topic of death and expressing end of life wishes.

PACE (Palliative Care for Older People in care and nursing homes in Europe)

Eleanor Sowerby from Lancaster University introduces a research project called PACE and its work to improve the quality of palliative care received in nursing homes.

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Welcome...  

Editorial foreword

Welcome to the 14th issue of Innov-age which focuses on end of life care. End of life care does not necessarily mean a person is going to die tomorrow but refers to the care that is provided when there is no curative treatment for a life-limiting condition. Focus of care is on ensuring the patient is as comfortable and active as possible, for as long as possible.

This issue stresses the importance of letting loved ones and carers know of end of life care wishes. Seeing a close relative or friend approaching their end of life can be a very distressing and difficult time but can be eased by knowing their preferences and wishes are being fulfilled. In his article, Toby Scott highlights the work of the Dying Matters Coalition to make the topic of death more acceptable and to encourage people to get talking about their wishes. Michael Connolly discusses Advanced Care Planning and strategies designed to help clinical staff engage in end of life care conversations whilst Professor Trisha Dunning gives an overview of palliative care with a specific focus on people with diabetes.

We also learn of some of the projects taking place to enable us to better serve people’s needs. Most people, who express a preference, say that they would prefer to die at home rather than in hospital. Professor Barbara Black gives an overview of the ‘Hospice at Home’ service and we hear from Airedale NHS Foundation Trust about the Gold Line Service, both of which are helping more patients to remain in their own preferred place of care. We also hear from Eleanor Sowerby who introduces a European funded research project called PACE which aims to improve the quality of palliative care in a care home setting. Two different hospices enlighten us on some of the work they are doing to help patients receive high quality care and live as fully as possible. Finally, our resident contributor Tracey Howe gives us an interesting insight into the literature surrounding the topic.

I hope you enjoy this issue and can begin to see that the topic of death is not one to shy away from but instead one that should be comfortably discussed, to enable us to fully support one another and give the individual a good end of life experience.

Jackie Oldham
Honorary Director, Edward Centre for Healthcare Management Research
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Every death is different. Some die suddenly, in an accident or a sudden medical event. A few die violently, at their own hand or under assault by another. But many deaths, and an increasing percentage, take place over a period of time. Increasingly, that period of time is lengthening, as diagnoses and treatments improve.

About 450,000 people die in England each year – roughly 1% of the population. That number is forecast to rise to over 500,000 over the next 15 years, reversing decades of falling annual deaths. Individuals and society have benefited enormously from many things that have improved life expectancy: pharmaceutical, medical and surgical developments, improved safety in the workplace and the home and better understandings of the impact of lifestyle on longevity. There are many people alive today who have already exceeded the life expectancy they had at birth, and we are better for this.

Furthermore, people are not just living longer but living better and remaining active. Conditions such as heart disease or accidents such as broken hips that would have previously meant a change to a quieter, more sedentary lifestyle can now be overcome to give many more years of active life.

Nevertheless, death will come to us all. Increasingly, it comes slowly but within a known time frame. Some diseases follow such predictable courses that a terminal diagnosis comes with a sadly accurate prediction of expected life span. Others are known to bring death sooner that it would otherwise occur, but with no good idea of when.

Palliative care is changing to keep pace with all of these changes. In the past, it was mostly associated with cancer and focussed on pain management.

Today, only 29% of terminal diagnoses are cancer-related and palliative care encompasses much more. Pain relief is still part of it but so is symptom management, responding to emotional and spiritual needs, and also enabling the person to have as good and as active a life as possible before death.

The key to good care is person-centred care. Good quality palliative care starts with the needs and wishes of the person involved. What do they want? Equally importantly, what do they not want? What’s important to them?

Opinion polls, undertaken by research consultancy ComRes (http://www.comres.co.uk/), show that people rate pain relief as the most important factor in having a good death. But this overall figure hides some interesting variations. People aged between 18 and 34 rank being with family and friends as the most important factor: it is older age groups – arguably with more experience of living with pain – who rate pain relief as the most important factor.

The Ambitions Framework for Palliative and End of Life Care, created by a coalition including Dying Matter’s parent organisation the National Council for Palliative Care, came up with six key ambitions. The first of these is that “Each person is seen as an individual.” This means that there is no one-size-fits-all approach to end of life care. Every person’s illness will take a different course, each will have his or her own thoughts and concerns, and each person has a right to have their end of life care wishes respected.

For treatment to respect the wishes of the person involved, those wishes need to be known and clearly expressed. This means they must have been decided ahead of time, which in turn requires them to have been discussed.
The Dying Matters Coalition aims to encourage people to discuss their end of life wishes in England, and works with partner organizations in the other parts of the UK. Although the work goes on year-round, the main public focus is the annual Dying Matters Awareness Week, which this year ran from May 9-15 with the theme of the Big Conversation.

The main things Dying Matters asks people to do are:
• Make a will
• Make your funeral plans
• Make an advance care directive
• Make arrangements for lasting power of attorney
• Write all this down and let loved ones know where to find it.

These are not simple things to address. Making a will includes making sure finances are in order and documents such as life insurance policies are accessible. The advance care directive is a potentially complex one. This can include what sort of treatment is wanted but also where someone would prefer to die. Today about half of people die in hospital, but most people who express a preference say they would rather die at home. Some people want to receive every effort to keep them alive whilst others want no attempt to be made to resuscitate them. There’s no right or wrong position to take but unless an individual’s wishes are known, they will receive the “default” approach for whichever setting they are in.

It’s important for people to discuss and make their decisions. But it’s also important for the structures, policies, resources and support to be in place to enable these wishes to be respected. For example, if the many people who say they would rather die at home are going to have their wishes met, there needs to be a lot of things in place for this not only to happen, but to happen well. There are medical requirements and possibly social care requirements. But there will also be a need for support from the community. If a person has chosen to die at home, is there anything a neighbour could do to help? Fetch some shopping, or walk the dog?

Death will always be a disruptive event. However, for everyone to have their end of life wishes fulfilled many people, beyond professionals, are going to have to help. If people are more comfortable talking about death – if they’ve had their own big conversations – it’s easier for them to help others as they deal with the loss of someone they care for.

It’s never too early to have these “big conversations” and start getting plans in place. People don’t know the circumstances they will be in when they face the end of their lives. They may not be conscious, or have the mental capacity to make these decisions. It’s far better to get these things sorted out ahead of time and put plans in place. If things change, they can update their plans if they wish.

This year hundreds of events took place, involving thousands of people. There were death cafes, theatre, graffiti boards to record bucket list items, videos, drop-ins, outreach and so much more. There was a massive engagement on social media and great media coverage.

Death is a natural part of life, and discussing end of life care should be no more unusual than discussing maternity services, day surgery or dentistry. Care providers should offer good quality end of life care to all. However, everyone has an obligation to put their own plans in place, and get their own affairs in order, so that they receive the care they wish for.

For further information and data, please see:
Palliative and end of life care - older people with diabetes

Professor Trisha Dunning is Chair in Nursing and Director for the Centre for Nursing and Allied Health Research at Barwon Health and Deakin University in Geelong Australia. She is a registered nurse and accredited diabetes educator. She recently completed two consecutive 3-year terms on the Board of The International Diabetes Federation and is a member of the Board of Diabetes Victoria. Trisha is a distinguished Life Fellow of the Australian College of Nursing. Her research focuses on personalised care of older people with diabetes and diabetes palliative and end of life care. She is widely published in journals and books.

**Definition of Terms**

- **Palliative care**: An approach where dying is regarded as a normal process. Palliative care focuses on comprehensive assessments and engaging with the individual and their family to plan care and improve quality of life by relieving suffering, promoting comfort and managing symptoms. (World palliative care Association/World Health Organisation (WPCA)/WHO, 2014).

- **End of life care**: This term refers to the care of people who are likely to die in the following 12 months including imminent death, death in a few hours or days, and progressive incurable life-threatening illnesses (Gold Standards Framework (GSF), 2011).

- **Terminal care**: Describes care required in the last few days or hours of life (Palliative Care Outcomes Collaboration (PCOC), 2014).

**Introduction**

Diabetes is the most prevalent, costly and complex chronic disease and is associated with several complications, including some cancers that can affect functional status, quality of life and life expectancy. Usual diabetes care focuses on keeping the blood glucose control close to the normal range (tight control) in order to prevent complications. However, tight control may not be appropriate as people age and develop functional limitations that affect their safety, quality of life and the likely treatment benefits. Palliative care can be integrated with usual diabetes care at any stage (Dunning, 2016). Most benefits, including those associated with cost (Morrison et al., 2008), accrue when palliative care is introduced early in the course of the disease (Advisory Board, 2013). In addition, outcomes are better in people who receive palliative care compared to those who receive usual care (Temel et al., 2010) and people report greater satisfaction and feeling respected and understood by their clinicians (Gade et al., 2008).

International policy advocates early identification of people with life threatening illness who could benefit from palliative care (GSF, 2011). In reality, however, many people who might benefit are not identified or are not offered palliative or end of life care (Zheng et al., 2013) because clinicians are often reluctant to initiate conversations about such topics (Claessen et al., 2014). Understanding common disease trajectories could help clinicians and people with diabetes make decisions about the benefits of tailoring services and care to match their trajectory. A proactive approach to conversations about changing care needs might be more acceptable than sudden, unexpected changes.

**Disease trajectories**

Glaser and Strauss (1965) identified different patterns of dying: sudden death, lingering, certain to die ‘on time’ and a vacillating pattern. Lynn and Adamson, (2003) described disease trajectories relevant to people with progressive chronic illnesses, such as diabetes, which can be used to prospectively consider when to discuss and initiate palliative and end of life care. However, trajectories also need to include healthy people and sudden death. In any trajectory the ‘surprise question’ can be asked i.e. would I be surprised if this person died in the next year? A ‘no’ response suggests discussions about palliative and end of life care are warranted (GSF, 2011).
Disease Trajectories:
1. Healthy people with stable chronic disease where the aim is to maintain health and prevent complications.
2. Sudden death. Little can be done for the individual but it is important to support surviving family.
3. Steady progression and usually a clear terminal phase. Cancer is an example of this; however, many people with cancer can survive for long periods of time and are increasingly known as cancer survivors.
4. Gradual decline with episodes of acute deterioration followed by some recovery and then eventually a sudden, seemingly unexpected death e.g. heart failure and renal and respiratory disease. Episodes of acute deterioration/recovery usually increase in frequency in the year prior to death.
5. Prolonged gradual decline (prolonged dwindling). This is common in frail older people and people with dementia and is accompanied by uncertain prognosis. Many people on this trajectory are likely to be unable to self-care long before they die. It is important to help the individual plan how they want to live and eventually die.

Trajectories and diabetes
People in trajectory one are likely to benefit from tight blood glucose control for long periods of time before the trajectory changes and the situation needs to be reassessed. Regular monitoring can identify changes in health status and the disease trajectory.

Periods of unstable diabetes (hyperglycaemia), consistent with trajectories 3 and 4, are common in older people with diabetes. Unstable diabetes leads to glucose variability, which is associated with inflammatory processes that have negative effects on tissues and organs such as the heart, independent of other risk factors (Zhang et al., 2012).

Glucose variability is also associated with a high risk of severe hypoglycaemia (low blood sugar) (Weinstock et al., 2011). Hypoglycaemia increases the risk of falls, cardiovascular events and sudden death. Hypoglycaemia can occur in all five trajectories. It affects key cognitive functions such as memory and learning, making decisions and problem-solving and is also associated with dementia over time. It is imperative to proactively plan for end of life care and how to manage deterioration while the individual is able to make informed decisions.

Importantly, such conversations should take place when the cognition is not affected by high or low blood glucose levels i.e. when diabetes is ‘stable’ (Dunning et al., 2010).

The importance of discussing palliative and end of life care early
Understanding disease trajectories can help clinicians and people with diabetes understand the likely disease course and prognosis. However, diabetes-specific signs that indicate a change in trajectory have not been clearly described. Thus, costly, burdensome care often continues unnecessarily and does not lead to a ‘good death.’ A ‘good death’ encompasses having some idea when and how death will occur so that people can plan for the rest of their life.

Primary care nurses and doctors are in an ideal position to identify when older people with diabetes would benefit from palliative care, discuss care options, and help develop and document advanced care plans. The annual diabetes complication assessment is a key time to identify whether palliative and end of life care are indicated and discuss care options and benefits with the individual and/or their family. However, every clinical contact represents an opportunity to discuss the focus of care, goals and plans.

At present, most of these opportunities are missed because many clinicians are reluctant to discuss such issues (Zheng et al., 2013; Claessen et al., 2014) and they are not generally incorporated in clinical guidelines or diabetes quality measures. Older people with diabetes want to discuss palliative and end of life care but indicate clinicians do not ask them about these issues (Savage et al., 2012). Thus, a fundamental shift in clinicians’ understanding and acceptance of palliative and end of life care is required (Advisory Board Company, 2013).

Communication strategies
It is important to gauge the extent to which people want to discuss and make decisions about their long term and day-to-day care. Communication about palliative or end of life care must be respectful, sensitive and undertaken in private. Once documented, end of life care needs to be revised regularly because preferences change with changing circumstances and people have the right to change...
their mind. Provisions also need to be in place for times when decisions need to be made unexpectedly.

Key strategies for successful communication include:

- Deciding whether a case conference is warranted and if so, deciding who should be included. Case conferences with the family might be indicated if the individual is unable to make decisions and has not documented their care preferences.
- Clinicians reflecting on their values, preferences and how they could influence the conversation.
- Understanding any legal obligations, organisational polices and ethical principles that apply and being able to explain them to people with diabetes.
- Preparing for the conversation by having all relevant information to hand, ensuring the environment is appropriate and inviting family, with the individual’s consent.
- Assessing the individual’s readiness and capacity to have conversations about palliative and end of life care.
- Building rapport with the individual/family using attentive listening, relevant probing and clarifying questions, and being truly present in the encounter. This is more likely to elicit individual’s values and preferences and help the clinician gauge how much information and the type of information likely to be useful to the individual/family.
- Provide relevant information in a suitable format and inform the individual/family how/where they can obtain more information and document their care preferences.
- Document and communicate the conversation to relevant others.

Advanced care planning

Advanced care planning involves people planning an individual’s future care, whilst they remain able to make informed decisions about the type of care they want when their health deteriorates. If people document their care preferences, they are more likely to receive care that is consistent with their values and preferences, to die in their place of choice (usually at home) and achieve a ‘good death’. People worry about having an ‘undignified death’ and losing autonomy in the terminal stage (STEM-MARK, 2011), especially when they die in hospital. Only 14% do die at home, although the proportion increases when people receive palliative care (Swerissen & Ducket, 2014).

People value having reasonable control over their dying, who is present at their death, being able to choose where they die, to be comfortable and have time to complete unfinished business such as making wills and funeral plans and saying goodbye to loved ones (Swerissen & Ducket, 2014).

It is very important that the older person communicates their values and preferences to their family to avoid unnecessary stress and conflict. The individual’s values and preferences must be respected when they are documented.

References

Advisory Board Company. (2013). Realising the full benefit of Palliative Care. Available at: www.advisory.com
Gold Standards Framework. Available at: www.goldstandardsframework.org.uk

Resources

The following resources contain information on many related topics. Some include printable resources and decision aids.

CareSearch (Palliative Care Knowledge Network). Available at: www.caresearch.com.au
Gold Standards Framework. Available at: www.goldstandardsframework.org.uk
Residential Aged Care Palliative Care Approach Toolkit. Available at: www.caresearch.com.au/PActoolkit
Respecting Patient Choices. Available at:www.respectingpatientchoices.org.au
Royal Australasian College of Physicians End of life Care. Available at: https://www.racp.edu.au/fellows/resources/curated_end-of-life-care
Hospices play key role in Rehabilitative Palliative Care

Garden House provides specialist care for people with life limiting illnesses living in North Herts, Stevenage, Royston and surrounding areas. It provides inpatient care, a hospice at home service, a day service, 24 hour advice line and bereavement support.

The Hawthorne Centre at Garden House Hospice Care comprises a number of different team members including nurses, physiotherapists, complementary therapists, spiritual care and a team of volunteers.

Hospices have long been seen as offering gold standard palliative care at the end of life. Changing needs of the population mean that they are widening access and delivering a new model of service delivery aimed at integrating rehabilitation, enablement, and self-management. This isn’t a new concept; Dame Cicely Saunders talked very much about living until you die, maximising potential and having control and independence wherever possible.

Rehabilitation is often seen in the context of recovery and hope whilst palliative care is associated with dying. Consequently, at first glance, the two wouldn’t appear to fit together. That said, rehabilitation aims to improve quality of life by enabling people to achieve their goals with minimal dependence upon others (Maddocks and Payne, 2015 & NICE, 2004). This fits very well with the aim of palliative care to help people to achieve a good quality of life by helping them to live as actively as possible until death (Platt-Johnson, 2007). There is a significant body of evidence to suggest that the priority of palliative patients is to focus on life and living, maintaining continuity of daily life for as long as possible to enable individuals to maintain a sense of who they are and what is important to them (Tiberini and Richardson, 2015).

There is also a growing evidence base demonstrating rehabilitation does not just delay or prevent deterioration in function but in some patients it actively improves physical function, irrespective of advanced disease.

In recent times there is work to prove that, alongside maximising function and independence, reaching people earlier in the pathway gives a chance to plan and maintain control which results in an improved end of life experience.

As a result of all of the above, some hospices are developing centres which aim to support people earlier in the disease trajectory with the aim to provide a holistic multidisciplinary approach, enabling and empowering people to live well for longer.

The newly launched Hawthorne Centre at Garden House Hospice Care is striving to achieve just this. It offers a diverse spectrum of support and rehabilitation to maintain wellbeing, not just for the patient but also for those who are important to them. The focus is very much on the individual and their circumstances. A unique action plan is produced in collaboration with each person to meet their individual needs and situation.

The team at the Hawthorne Centre have found that wider communication and education is required in order to change public perception of hospice services, which may deter potential patients accessing rehabilitative palliative care in their community.

The diversity of challenges that patients face and symptoms they wish to manage mean that the team are in the process of developing a range of workshops, courses and groups;

- A successful ‘Fatigue and Breathlessness’ management workshop. This runs over 5 weeks and looks at practical tips to manage fatigue, ideas to help maintain physical activity, suggestions to improve sleeping patterns and ideas to enable improved nutrition.
- ‘Sharing stories’ will commence shortly and is delivered based on the work of author Miranda Quinney. Miranda has been working with hospices to develop workshops which provide a space for groups of people to share their life stories and reflect upon them in order to improve self-esteem and well-being. More information on this can be found at: http://www.sharingstoriesforwellbeing.co.uk/Home
- A drop-in session gives people the opportunity to come to meet the clinical team and volunteers at the Hawthorne Centre and find out what goes on. From this informal visit many realise that the hospice has more to offer than they first thought and start to engage with the centre.
- For those who currently have stable disease and would like to catch up for a social coffee, a volunteer led session on a Friday gives a chance for patients and carers to share their experiences and gain much valued peer support.

Abby McCarthy, Day Services Manager, Hawthorne Centre comments: “The team are working hard to enhance the excellent care already being delivered at the Hawthorne Centre by implementing a philosophy embracing self-management and rehabilitative palliative care. I am very proud of the early developments, the new range of services is receiving a large amount of interest and we have noticed an increase in patient referrals, enabling more people to receive specialist palliative care support.”

Patients are very positive about the new developments, one said: ‘When I first came to the hospice I was so low and ready to give up. The staff at the hospice brought me back from the road to destruction and made me feel like a real person again’.

Garden House Hospice Care is able to provide advice and training on how hospices can provide a day service programme integrating rehabilitation, enablement, and self-management.

For more information on the work of Garden House Hospice Care visit www.ghhospice.co.uk or call 01462 679540 or email enquiries@ghhospice.co.uk

References:
Knocking gently on the door: Advance Care Planning (ACP) and end of life care conversations

Michael Connolly (MPhil, BSc, RGN) worked in the fields of HIV/AIDS, in London during the late 1980s and then in hospice care followed by hospital palliative care in 1993. He developed the nationally recognised communication skills workshop that uses the mnemonic SAGE & THYME to guide practitioners through active listening (SAGE), and simple patient-centred problem solving (THYME). SAGE & THYME is taught under licence by UHSM to more than 50 other healthcare organisations across the UK and is the focus of research and dissemination projects.

In the final phase of life, people commonly lose their capacity to speak clearly for themselves. This increases the risk that they will undergo investigations and treatments to extend their lives, which they may find distressing and personally undignified (NCEPOD, 2012).

Over the last ten years therefore, policy makers have asserted that such people should be given opportunities to plan their future care before they lose capacity to express their wishes (DOH, 2008). The responsibility to provide such opportunities falls to the senior clinical staff who are expected by the policy guidelines to draw up Advance Care Plans. This can include the creation of a record of the treatments a patient wishes to refuse (Advance Decisions to Refuse Treatment) or a more general discussion of a patient’s preferences at the end of life (GMC, 2010). The conversation includes highly sensitive content; the risk of death, and the risk of loss of mental capacity at some point prior to death. It is perhaps unsurprising that in routine clinical practice, such discussions and such written care plans remain rare (Newbould et al., 2012, Abarshi et al., 2011). Clinicians report lack of training and confidence in this area (Almack et al., 2012). They also describe such conversations as challenging and uncomfortable (Pontin et al., 2013).

This article describes two recent systematic reviews of the literature on this subject and a communications skills training workshop which includes a ‘conversational framework’ to help clinicians with this new and challenging task.

The first review (Lunt et al., 2015) concluded from a review of 13 studies on the implementation of ACP, that implementation is difficult in busy clinical practice outside of specifically resourced research and implementation studies. Many factors undermine the delivery of ACP. Firstly, the weight and volume of other clinical and organisational demands on clinical staff appear to relegate the level of priority attached to advance care planning discussions. Secondly, patient trajectories are uncertain making it difficult to choose the right time for the discussion and requiring a proactive strategy to make ACP routine to practice. Thirdly, the discussions themselves can be emotionally complex for both patient and the clinician and the outcome of the discussion is difficult to predict. Finally, the decisions and plans made in the ACP may not be acted upon for reasons of communication, coordination or of changing context. Lunt et al describe the combined impact of these challenges as substantial.

In the second review, Parry et al (2015) report on the actual conversations with patients. They describe the impact of words, the way they are used and the sequence of questions in conversations about end of life care and advance care planning. They describe how some approaches can allow patients to deflect the conversation if they are not ready or willing to discuss difficult future issues. Parry et al call this ‘indirect talk’ which uses language such as ‘getting very ill’ or ‘something serious’ or referring to people in general rather than the patient themselves. This appears to allow a discussion about the future without ‘bringing death into full view’. Other approaches such as posing hypothetical questions about the future are, they report, more likely to result in a direct discussion about the difficult issues. These insights can perhaps help clinicians judge each patient and each conversation. Parry et al advocate that clinicians knock gently on the door rather than pushing it, until they are able to assess whether this is a good moment to address difficult future issues directly.

Clinicians who feel that they avoid such discussions with patients may take some comfort from the reviews described above, particularly the acknowledgement that this is organisationally and conversationally complex work. Patients also describe feeling reticent to initiate such discussions with clinicians. Indeed, the reticence of some patients negatively influences discussion of these issues with other patients (Almack et al., 2012). Policy and guidelines clearly need to be followed with caution and sensitivity.

If Advance Care Planning (ACP) is not to be discredited and discontinued as was the experience with the Liverpool Care Pathway for the Dying (DOH, 2013), then training is very important. ACP must not be applied routinely; individual patient differences and nuances must be allowed to influence the discussions and the processes. The current
Evaluation from nearly 400 participants suggests that they left the workshop with significantly increased confidence in starting an end of life or advance care planning conversation, and responding to the patients’ concerns during such a conversation. Participants reported significantly increased levels in their perceived competence in this regard and 74% said that they would definitely use the conversational framework of SAGE & THYME in practice. In addition, 88% reported that they would definitely recommend the workshop to their colleagues (Coppeard, 2014).

This educational intervention does not address the organisational factors described by Lunt et al (2015) but it does address elements of the conversational factors described by Parry et al (2015).

The first decade of ACP in the UK has involved a number of specifically funded programmes to introduce and evaluate the effectiveness of ACP and the difficulties and barriers are now becoming clear. If Advance Care Planning is to become established into routine clinical practice, then the clinical staff who take it on deserve training and organisational support. The SAGE & THYME for ACP and end of life care workshop appears to be a practical element of that training.

For more information about SAGE & THYME for ACP and end of life care conversations go to www.sageandthymetraining.org.uk

References


Should Palliative Care be rebranded?

A study exploring patients and caregiver’s perceptions of palliative care has found that the term carries negative implications associated with imminent death, hopelessness and a bedridden, dependent state. Such a stigma is said to lead to fear, resistance to and avoidance of palliative care.

The study, conducted at Princess Margaret Cancer Centre, Toronto, Ontario, included 71 participants (48 patients and 23 caregivers) in a randomized clinical trial. The intervention group received early referral to palliative care (in addition to standard cancer care) whilst the control group received standard cancer care alone. Participants had advanced cancers with an estimated survival (by their oncologist) of 6-24 months. At the end of the trial, researchers interviewed the patients and caregivers about their attitudes and perceptions to palliative care.

During the trial, those in the intervention group developed a broadened understanding and more positive conception of palliative care. However, many still felt that the term itself carried a stigma. A prevailing theme was that rebranding or renaming of palliative care could be helpful to address the conflict between the early palliative care they had received and the instilled association with end of life. They emphasised the need for it to be better explained so that it was not presented as a last resort, but something introduced early in the pathway, a more long-term, on-going intervention that could increase their quality of living and provide resources and support to make the most of life. A suggested term of “supportive care” was well received by those in the intervention arm.

The authors highlight that although a name change may be considered, nothing will be achieved without a fundamental shift in the manner in which palliative care is practised and portrayed. They emphasise that education of the public, patients and healthcare providers is crucial to ensure a more widespread understanding of what palliative care represents and involves. They also caution that the manner in which physicians communicate information about palliative care can affect the patient’s perception and decision-making about receiving such support.

To find out more please visit:
http://www.cmaj.ca/content/early/2016/04/18/cmaj.151171.full.pdf+html

Hospice UK report: ‘A low priority? How local health and care plans overlook the needs of dying people’

Hospice UK has released a report that explores the disparities between local organisations with regards to end of life care.

Freedom of Information requests were sent to each of the 152 health and wellbeing boards (HWBs) and 209 clinical commissioning groups (CCGs) in England, with responses received from 94% and 95% respectively. The results found that the local priority given to palliative and end of life care, as evidenced by its inclusion in needs assessments and strategies, varies widely across England. In almost 1 in 3 (31 per cent) cases, HWBs include palliative and end of life care in their population-based joint strategic needs assessment (JSNAs) but it then does not appear in their joint health and wellbeing strategy (JHWS).

Almost all (96%) CCGs stated that they have a nominated lead for palliative and end of life care for adults but more than 1 in 4 (27%) do not have a strategy in place, with an even worse outlook for children [7 in 10 CCGs (71%) without a strategy]. The report emphasises the crucial role that local health & social care leaders can play in improving access to and delivery of quality end of life care and suggests some opportunities to explore in order that the needs of everyone in the local community are appropriately addressed.

To find out more, please download the report here:
https://www.hospiceuk.org/what-we-offer/publications?cat=39a94612-4ccd-608d-ad24-ff0000fd3330
Encouraging findings in new End of Life Care Audit

Results of a national clinical audit, commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and run by the Royal College of Physicians, were released in March 2016.

The audit comprised of two elements; an organisational audit of services and protocols and a clinical case note review, depicting the end of life care of patients who died during May 2015. It was built to reflect the recommendations of the Neuberger review, namely to phase out the Liverpool Care Pathway and introduce individualised care, as well as the ‘five priorities of care’ set out in the Leadership Alliance for the Care of Dying People report named ‘One chance to get it right’.

It found that there has been steady progress made in nearly all aspects of end of life care in hospitals since the previous audit in 2013. However, it also identified that in many areas there is still wide variation between organisations and huge room for improvement, particularly concerning 24/7 access to palliative care specialists.

The full audit report is available to download here: https://www.rcplondon.ac.uk/news/new-rcp-end-life-care-audit-shows-steady-progress-care-dying-people

Upcoming Events...

**Strathcarron Hospice Annual Conference** 29th-30th September 2016
This two day conference in Scotland will focus on ‘Living with dying: challenges towards the end of life’.  
http://strathcarronhospice.net/annual-conference-2016/

**World Hospice & Palliative Care day** 8th October 2016
This is a unified day of action to celebrate and support hospice and palliative care around the world. The theme for 2016 is ‘Living and dying in pain: It doesn’t have to happen’.  
http://www.thewhpca.org/about

**The Marie Curie Annual Palliative Care Research Conference 2016**  
19th October 2016
Entitled “Round the clock: Making 24/7 palliative care a reality”, this conference takes place in London and aims to support the translation of research findings into practice. It is open to other healthcare professionals, academics and any others with an interest in palliative care research.  
https://www.mariecurie.org.uk/research/annual-research-conference

**Kicking the Bucket Festival** 24th October – 13th November 2016
This multi-media festival takes place around Oxford with a series of small intimate events to reflect, inform, explore and engage in the subject of death. This year’s theme is “Conversation-Information-Celebration!”  
https://kickingthebucket.co.uk/

**Hospice UK’s Annual Conference** 16th-18th November 2016
This three day conference takes place in Liverpool with the title “People, Partnership’s and Potential” to share and celebrate the work within hospice and palliative care.  
https://www.hospiceuk.org/what-we-offer/courses-conferences-and-learning-events/hospice-uk-annual-conf
Caring for and supporting the elderly to die at home – the impact of a bespoke Hospice at Home Service

Professor Barbara Jack is Head of Research, Director of the Evidence-based Research Centre and a member of the Postgraduate Medical Institute at Edge Hill University in Ormskirk, Lancashire. She is also visiting Professor at Hospice Africa.

Dr Karen Groves MBE is Medical Education Director for Queenscourt Hospice in Southport and Consultant in Palliative Medicine for Southport and Ormskirk Hospital NHS Trust.

This article acknowledges all the staff, both from Edge Hill University and Queenscourt Hospice, who were involved with the development and evaluation of the service.

Supporting dying at home
The last few decades and advances in medicine have resulted in hospitals being the preferred site for end-of-life care with 48% of deaths still occurring in hospital (Public Health England 2014). Despite these statistics, 50-83% of people with cancer, when questioned, reported a wish to die at home (Gomes et al., 2012).

Promoting death at home moves the focus of care onto that provided by families and is not without its challenges. Interrelated factors can impact upon a home death for example clinical symptoms, marital status, living alone, age and, vitally, support of the family carer (Gomes and Higginson 2006). Changes in household composition, geographical mobility and rising retirement rates have reduced the pool of people available to provide care. Additionally, many family carers are themselves ageing, with an increasing number of older carers (Office for National Statistics 2013).

Supporting end-of-life care at home has seen the expansion of palliative care home services. However, there are wide variations in configuration of services, including mixed healthcare professional teams, rapid response teams and out-of-hours services generally staffed by unqualified staff. Broadly they can be defined as hospice care in the home setting (Stosz 2008). The evidence of the effectiveness of hospice home care is generally positive, albeit limited, due to challenges of undertaking robust trials in this setting.

Queenscourt Hospice
Queenscourt Hospice covers a mixed urban and rural locality of West Lancashire, Southport and Formby in the North West of England, with a high elderly population. Prior to the development of the Hospice at Home service, an extensive stakeholder exercise identified gaps and what was needed to support those who wanted to be cared for and to die at home. This resulted in the development of a service comprising three elements:

1. Queenscourt Aides where health care assistants and registered nurses are identified to deliver the service,
2. Accompanied Transfer Home where an Aide accompanies the patient home from hospital or the hospice
3. Crisis Intervention Team where a multi-professional team from the hospice support the primary health care team and visit the patient at home to carry out short specialist palliative care management.

The service is available for patients with life-limiting illnesses who are eligible for non-means tested benefits at the end of life and who are already receiving care from district nursing teams and other agencies. The service was launched in 2009 and has provided care to over 1500 patients to date (Baldry et al., 2009).

Evaluation of the service
An independent mixed methods evaluation was undertaken by a team from Edge Hill University to see if the service was effective and meeting the needs of the local population. This focused, in particular, on that of the elderly, who are acknowledged as being at higher risk of not achieving a home death. Seventy-five healthcare professionals provided feedback on the impact and value of each of the three components of the service contributing to
helping patients to remain at home, by providing individually tailored care. The accompanied transfer home was noted as having a positive impact on helping patients to be discharged home. The crisis intervention service was found to be extremely useful in supporting healthcare professionals for complex cases and the Aides were widely identified as being invaluable (Jack et al., 2013).

From this initial phase, it was agreed that a study focusing on the bereaved carers was needed, to explore their perceptions and experiences of caring for a recipient of the service. Twenty family carers participated in semi-structured interviews and reported personal positive impact of the service. The ‘valued presence’, being in ‘good hands’ and how the service helped in ‘supporting normal life’ were reported with the overarching conclusion being that the service helped them to cope and care for their loved one (Jack et al., 2014).

Unexpectedly, several of the family carers, who took part in the interviews, made comments that their loved one would have appreciated the opportunity to share their views of the service and what it meant to them. They did not feel it would be an intrusion but instead a very acceptable and valued exercise. This resulted in the decision to take on the challenge of a third element of the evaluation; to interview patients and family carers who were in receipt of the service. This required careful planning to ensure that all potential issues that a research ethics committee may raise were considered. Listening to the clinical team’s concerns resulted in the development of a deterioration procedure. This was for the research team to follow, if the patient’s condition deteriorated during the interview. A clear system was instigated to minimise any distress involving close communication with the hospice in case the patient had died and contacting the families two hours prior to the interview in case the patient had deteriorated. This consultation exercise and close working with the clinical team resulted in the successful recruitment of 41 participants (16 patients and 25 family carers) in a prospective phase of the evaluation.

In this phase, 14 (88%) of the patients were aged 71-90 years but despite the known risk for the elderly of not achieving a home death, the support from the service was enabling them to remain at home. The overarching theme to emerge was that of ‘embracing holism’ and acting as a bridge from the hospice to bring the ethos of palliative care in to the home (Jack et al., 2016). Indeed, of the more than 1500 patients who have received the service, 84% have since died at home (or care home if this is where they live) which is higher than the 2014 national average for England of 45.4% (NHS England 2014).

This Hospice at Home evaluation was undertaken in phases over time. The evaluation has shown that this is a model that is clearly having a positive impact on healthcare professionals, patients and family carers and is helping to allow patients to remain in their own home. It is also meeting key UK policy drivers of promoting patient choice around end-of-life care. With the projected increase in the elderly population, there are some clear lessons to be shared around the targeting of specific interventions that are important to the elderly. This model of Hospice at Home service, built upon consultation with local stakeholders and with a programme of staff development (including all the Aides having thorough education and regular experience working in the hospice), has resulted in a service that is providing holistic care in the home, acting as a bridge from the hospice. The provision of hospice at home care is not available in all areas of the UK and so as new services are being planned, there are valuable lessons to be shared from this successful and sustainable model.

This research was supported by the Cheshire and Merseyside Palliative and End-of-Life Care Network.

References


Palliative Care for Older People in care and nursing homes in Europe (PACE) Project

Eleanor Sowerby is a Registered Nurse and the PACE Country Trainer for a cluster randomised controlled trial. The study aims to investigate the delivery of a facilitated intervention for staff in care homes so that they can improve palliative and end of life care in the North West of England. The PACE UK team is based at the International Observatory on End of Life Care at Lancaster University.

The purpose of this article is to introduce a research project called PACE which is funded by the European Commission and provide an overview of the benefits of facilitating development and educational interventions within care homes. By 2030, the UK population is expected to be living well into their late 80’s (Bennett et al., 2015). An increasing life expectancy is something to celebrate as it allows people the necessary scope to plan ahead and forge generations that not only live well but hopefully die well. However, increasing longevity can also raise issues such as frailty, debility and other life limiting conditions. It can also place greater emphasis on others to help provide the necessary support and care that may be required to help people to age well in their own communities. The balance of living with increasing frailty and being dependent on others to help support those needs and wishes can be unsettling; especially if the needs outweigh the practical support that is available within the individual’s home environment. A significant change in an individual’s health needs and social circumstances can dramatically unbalance the equilibrium, resulting in a move into a care home so that ongoing care needs can be better overseen and managed.

What is the PACE project?
The PACE 2014 project is a large five-year research study funded by the European Commission’s seventh framework programme which involves six other European countries. The overarching aim of the PACE study is to ‘develop tools to assist practitioners, policy and decision-makers to make evidence-based decisions regarding best palliative care practices in long-term care facilities in Europe.’ By working in collaboration with European partners, staff at the International Observatory on End of Life Care at Lancaster University will generate greater insight, understanding and appreciation of current practices across Europe. The work aims to help contribute to the future provision of palliative care in care homes for older adults and be a catalyst to help empower individuals, families and staff working within care homes across Europe.

PACE Steps to Success
Integral within the PACE study is a cluster randomised controlled trial investigating the delivery of a development and education intervention called ‘PACE Steps to Success’. The study aims to compare healthcare in care homes with and without formal end of life care services in homes across seven countries: Finland, Belgium, The Netherlands, Italy, Switzerland, Poland and the UK. The intervention has been adapted from the ‘Route to Success’ programme which was developed by the End of Life Care Programme in the UK. It aims to help staff caring for frail older people in care homes to deliver high quality palliative and end of life care (DoH, 2010). Twelve nursing homes in the North West of England, who are willing, will be invited to participate in a twelve month palliative care programme called ‘PACE Steps to Success’. Six of the homes will receive the full programme and six homes will act as a control group and continue to deliver their usual care to residents. The homes that are randomised into the control group will be provided with all the course materials and a consolidated training programme at the end of the study.
Support and Education
Support and Education is a key component of the PACE study. The care home sector seems to endure many prolonged and recurring problems of low morale and high staff turnover, which can be exacerbated by a lack of support, responsiveness and professional respect (Hussein et al., 2015). Care homes provide care for an ever increasing number of frail older adults, who have a host of complex medical conditions. A culture of continuing education and development is important to not only help support staff but also to ensure that care is responsive, person centred and optimised to meet the needs of each individual. The diversity and skill required to provide this care effectively can prove challenging as it places a great onus on the care staff, often with minimal external support. Development and education frameworks are a prerequisite to help nurture, support and create a culture of change in attitudes and behaviours within care homes. However, it requires an effective figure head or leader, such as that of a Care Home Manager, along with a responsive team that are willing to help establish a clear vision of change. By developing a culture where staff are valued and supported in their contribution to the delivery of ongoing safe and effective care.

Conclusion
The PACE project seeks to test a development and education intervention in care homes across Europe. The project offers palliative and end of life care education and aims to empower staff to deliver this care confidently within the care home setting. The care home sector is a rich and wonderful learning environment where the essence of ‘hands on’ care, basic human kindness and communication should be valued and exemplified in their own right. By establishing a robust facilitated intervention, the project will seek to support staff and help create a catalyst for positive change to allow new attitudes and behaviours to be developed. It is hoped that by establishing clear educational and developmental channels it will create a nurturing environment recognising the lifelong learning of staff. The establishment of cohesive and sustained support networks to embrace a vision for seeking best practice, which is embedded in an educational culture of on-going learning with integrated alliances, will uphold the continuing work of care homes to provide high quality palliative and end of life care, now and into the future.

For further information please visit www.eupace.eu

References
End of Life Care is Changing

Julie joined Wirral Hospice St John’s as Chief Executive in 2005, after nine years as Director of Hospice services at Willowbrook Hospice in Knowsley.

Her career began as an Intensive and Coronary Care nurse in Walton. Her particular interest in palliative care developed when she moved to Broadgreen Hospital and she undertook a ‘Care of the Dying’ course. Then came the radical decision to move away from hospitals, and she joined a hospice in Southport as principal nurse, remaining there for over three years.

The delivery of quality end of life care to everyone, wherever they need it, is key to her work.

What is End of Life Care?

So many people misunderstand what end of life care actually means. It does not necessarily mean an individual is going to die tomorrow or next week. It means that there is no curative treatment for a life-limiting condition, but maybe it can be managed so that the patient is as comfortable and as active as possible, for as long as possible. This could be days, weeks, even years. Whatever the patient’s prognosis, the presumption should be that everyone requiring care during the end of life phase should both expect and receive the highest quality care possible.

This is the standpoint from which hospices begin their care these days. However, it is not just the responsibility of hospices: people might receive end of life care in hospital, be treated in the community or maybe just need social care.

Wirral believes that collaboration between the health and social care providers, throughout the locality, is crucial to an overall quality provision. Inevitably, the various services are coming from a slightly different viewpoint, depending on what they are providing but all are agreed that quality is paramount. For that to be achieved, there must be as near seamless as possible transition between providers.

To that end, a set of quality expectations were devised and launched last year as the Wirral End of Life Care Charter. Using the strapline ‘Care, Kindness and Understanding’, the Charter’s statements seek to provide reassurance for everyone facing this difficult time.

The Charter was not just imposed on the area’s health and social care providers. Its twelve expectations were the result of a Wirral-wide consultation, and were distilled out by the partners of the Wirral Palliative and End of Life Care Partnership Group. These included; Wirral Clinical Commissioning Group, Wirral Hospice, Wirral University Teaching Hospital, Wirral Community Trust, and Wirral Borough Council, among others.

For this set of standards to be successful, it was essential that everyone – care providers and recipients – knew about them and understood what they mean. In an effort to achieve this, when the Charter was launched, all interested organisations were asked to actively pledge their support. Signatories were also asked to train and support colleagues in the delivery of the standards, inform their service users by word of mouth and to display the Charter and the signed Pledge in their workplaces.

A public information campaign was also launched, which asked general members of the public to sign a Supporters’ Roll, to indicate their recognition of the Charter and its aims. This campaign continues, with the intention that the taboo surrounding end of life care will ultimately just vanish and everyone will know what support and help they can expect as a matter of course.

One year on from the Charter’s launch, Wirral Hospice have now entered the next phase which is making end of life care services easily identifiable and accessible. This is being done through a new online resource, www.endoflifecarewirral.org, which went live on 11th May 2016.

The information accessed through this website is freely available to both members of the public and also professionals; in fact anyone who needs guidance or support. It details the organisations involved in end of life care delivery, and also links to charities who can offer support. It details policies and guidelines specifically designed to help people in this phase of their lives.
The topics of end of life care, hospices and death are ones which people still find difficult to talk about but this is another aspect that the creation of the Charter might help overcome. Personal experience is also hugely beneficial and, on the occasions when people come to visit the Hospice, they find it is not the dark, forbidding place they imagine. The building itself is full of light, where interesting, positive things go on. Patients are encouraged by their visits, and others often leave inspired by the caring atmosphere and the dedication of the staff and many volunteers they encounter.

The reality is that many people are not admitted to the inpatient ward of hospices and are instead treated as day-patients or the professionals might visit them in their homes. Furthermore, in-patients usually stay only as long as it takes to stabilise their condition and once that has been achieved, they return home where possible.

Huge amounts of effort go into helping the families and carers of Hospice patients, in the knowledge that they are under great strain as well. Just as a patient might require help to relax and feel good about themselves, so may their carer, who can be very distressed and strained. Family members and carers are encouraged to take advantage of opportunities to meet with one another and relax together.

Wirral are trying to bring the end of life out of the shadows. It is such a cliché to say that everyone is going to face it, but why is it so hard to talk about? All these initiatives, within the Hospice itself and across the area, are designed to make people feel better and less afraid. Palliative Care is a specialism in its own right and its highly sophisticated strategies can help people cope during a very difficult time, relieving complex symptoms, discomfort, pain and worry.

End of life care has had a very bad press through national media but the work being undertaken is striving to present the reality that the deliverers of end of life care can see: end of life care, available right now, is high quality, caring, kind and understanding, where the needs of the patients, their families and carers are paramount.
The Gold Line Service for End of Life Care

Dr Helen Livingstone and Linda Wilson are the clinical leads for the Gold Line service. They have both worked at Airedale NHS Foundation Trust since 2003 and are interested in providing coordinated, high quality care for all patients that are approaching the last year of their lives.

Most people prefer to die in their home and yet the reality is, in England, around 50% currently die in hospital (DH, 2008). A support and care coordination hub, dedicated to patients who have a serious illness and may be in the last year of their lives, was launched two years ago. For patients registered to that service, only 14% die in hospital and patients and carers report feeling very well supported.

This Gold Line service provides one point of contact for patients and their carers for help and advice, 24-hours-a-day, seven-days-a-week, to support them in their preferred place of care wherever possible.

Colleagues from across the local health community including consultants, GPs, district nurses, a local hospice, patients and carers helped to develop the Gold Line project.

It was developed as a result of a successful bid for £420,000 from the Health Foundation – an independent charity working to improve healthcare in the UK – as part of its ‘Shared Purpose’ programme.

The service is used by patients across Airedale, Wharfedale, Craven and Bradford, from care homes or their own homes, who are on the Gold Standards Framework and have agreed to be referred to the service by their healthcare team.

Calls are answered by a team of experienced senior nurses based in a Digital Care Hub at Airedale Hospital who are linked up to community-based teams, who can visit patients if necessary. More than a third of calls are resolved without any additional referral.

Dr Linda Wilson, Palliative Care Consultant at Airedale NHS Foundation Trust said:
“Having to tell their story ‘over and over again’ has been described by carers as one of the most draining parts of caring for someone in their last year of life.

“Our hospital staff, community nurses and GPs share the same electronic palliative care coordination system to avoid a patient or carer having to tell their details to a number of different people, several times.”

“Gold Line is about providing compassionate care to a group of people who are probably at their most vulnerable. We only have one chance to help people make their death as good as it can possibly be.”

Most use it as a telephone service but 40 patients have an iPad so they can use a secure video link to have a face-to-face consultation with a nurse on screen.

The project is supported by Immedicare – a partnership between the Trust who provide the clinical expertise and a technology company called Involve.

Phil Parkinson, Managing Director of Immedicare said:
“Gold Line, whether used via a telephone or iPad, gives patients and their carers quick and easy access
to experienced nurses who can offer advice and support and coordinate the most appropriate response to their needs. One lady described it as ‘a friend in the corner of her room’ and many care home staff say that even if they don’t use it often, they find it so reassuring that it is there.”

The service is not expected to replace patients’ use of their GP and other community healthcare services during normal working hours but aims to enhance their care when daytime services have closed.

External qualitative and economic evaluations have been completed. These show a high level of satisfaction with the service and support. Other data suggest a reduction in admissions to hospital, A&E visits and GP and community nurse visits with a return on investment of up to £2 for every £1 spent on the service (YH EC, 2016).

The Gold Line service features in the Airedale and Partners enhanced health in care homes vanguard programme as part of the national Five Year Forward View new models of care programme.

Dr Helen Livingstone, Palliative Care Consultant based at Sue Ryder Hospice Manorlands said:

“We know that our patients want to spend as much time at home as possible and by providing easy access to extra support from experienced nurses who can coordinate the best response to their needs, the Gold Line helps this to happen. However, hospital admissions can also be arranged if required.”

“Our service has helped us to allow more people to die at home or in their care home - which is what most people want - and reduced the number of service users who die in hospital.”

To make someone’s preferred place of death a reality requires a coordinated effort across the health and social care system. Gold Line has the potential to significantly improve people’s end of life experience and release resources for investment to support this and other new initiatives.

Case Study
Concerned care home staff used the service when one of their residents was having a stroke. The telemedicine sister, Rachel, could see her via an electronic tablet and ascertained that she might be having a transient ischaemic attack (TIA). She reassured them that an ambulance would be called if necessary. Over the next few minutes Rachel stayed in constant visual and audio contact with both the patient and care home staff and could see that things were improving. She talked the care home through all of the signs and an unnecessary “999” call, and possibly a hospital admission, was prevented. The patient continued to be cared for by the people who know her best, in the place she calls home.

An Inspirational Film
Gold Line was the subject of an inspirational film - ‘Bringing Healthcare Home’ – launched nationally at Sadler’s Wells Theatre in London and then premiered locally at The Picture House cinema in Keighley.

It was commissioned by the Health Foundation, an independent healthcare charity, as part of a series of mini documentaries. These aim to bring healthcare improvement to life and show healthcare professionals and patients working together to tackle the challenges faced by the NHS via innovative ways. They were launched in October 2015 and can be seen at: www.health.org.uk/powerofpeople

The film featured Stephen Lock who used Gold Line to help fulfil the dying wishes of his wife Bea, who died from cancer.

He said: “I knew I could ring Gold Line any time, about anything. I’d not seen anyone die before and didn’t know about how their condition changes, so the nurses explained things so that I wouldn’t panic…For so many services to come together and make it feel totally integrated and focused on you is an incredible achievement. Everyone I spoke to knew about Bea, our two children and what was going on. I didn’t have to keep explaining my situation to different people.”

References
End of life care

Four Cochrane systematic reviews address the subject of end of life care.

Continuity of care in the follow-up of patients with cancer.

Cancer is a complex disease and often has multiple treatment phases. A Cochrane review in 2012 examined continuity of care i.e. the quality of care a patient experienced over time and whether it was seen as coherent and linked as a result of good information flow, good interpersonal skills and good coordination of care. The results of 51 research studies found three main models of care; case management, shared care and interdisciplinary team. However, there was no evidence that any one model was better than another or improved or worsened patient health.

Another Cochrane review 2015 found limited evidence concerning the clinical, physical, psychological or emotional effectiveness of end-of-life care pathways.

Supporting informal caregivers of patients in the terminal phase of a disease.

Patients in the terminal phase of a disease often have complex needs. Frequently family and friends play a central role in providing support, despite health professional input, regardless of whether the patient is at home or elsewhere. This informal caring often involves considerable physical, psychological, and economic stresses. A Cochrane review in 2010 examined 11 research studies involving 1836 caregivers. It found that interventions that directly support caregivers help them to cope emotionally, and may help them to cope with their role in caring and to improve their own quality of life. The impact on their physical health is not known and one study found overall no difference in sleep improvement.

Home palliative care services.

It is known that, when faced with a choice, well over half of people would prefer to be cared for and to die at home. However, only one-third, or less, of all deaths take place at home. The results of a Cochrane review in 2013, involving 23 research studies including over 37,000 patients and 4,000 family caregivers, found that when someone with an advanced illness receives home palliative care, their chances of dying at home more than double. Home palliative care services were also found to help reduce the symptom burden people may experience as a result of advanced illness, without increasing grief for family caregivers after the patient dies. In these circumstances, patients who wish to die at home should be offered home palliative care. There is still known scope to improve home palliative care services and increase the benefits for patients and families without raising costs.

Another Cochrane review 2015 found that people who receive end-of-life care at home are more likely to die at home but is unclear whether this reduces or increases caregiver burden.

References:

What is your current position and what was your career path that took you there?

Consultant nurse in supportive and palliative care at University Hospital of South Manchester. Four year degree at London University, MPhil at Manchester University. Experience in general medicine and hospice care. Previous roles include hospital Macmillan nurse, consultant nurse and Specialty Lead for palliative care, leading a 7 day multi-professional hospital and community palliative care service. Principal investigator and co-investigator in research designing, researching and disseminating the SAGE & THYME communication skills training programme which is now in 55 health care organisations in the UK.

What challenges do you face in your current position and which has been the greatest one?

Being proactive rather than dealing with the issues that endlessly need reacting to.

In your opinion, what are the top three issues affecting the care of older people?

Poverty, loneliness, defence of the public services and society that their generation established.

What changes in elderly care do you anticipate in the next few years?

I anticipate improvements in teamwork from and between the professionals and the informal carers. Older people will demand it.

If you hadn’t become a nurse, what might you have done?

I’d have liked to be a politician and I still might. I thought I should do a real job first and I’m still doing it.

What experience has influenced your career the most?

Working in the late 80s on a ward in London for people with AIDS. The ‘penny dropped’ in my head: each patient is an expert in themselves and my job is to make the service fit the patient and not the other way round.

What advice would you give to someone contemplating following in your footsteps?

Take part in research. It’s a group activity and being amongst thoughtful people is inspiring. It lifts your brain above the daily pressures of healthcare.

Where do you go for advice and information?

We have a national group for consultant nurses in palliative care. We are few in numbers but highly informative and very encouraging to each other.

Who would you most like to work with?

A nurse I once worked with. When I saw how she spoke to patients I realised that I’m still learning about how to do that.

What do you enjoy doing when you are not working?

Drinking real ale in real pubs.

What do you do in a typical working day?

Cycle, talk, email, manage, meet, eat, nurse, teach, type, talk, cycle.

If you were stranded on a desert island what would be your one luxury?

A book: The Ragged Trousered Philanthropists by Robert Tressell. It was my grandmother’s favourite book and now mine. It is our link and it taught me how to spot injustice in every day life.
In our next quarterly issue of Innov-age we will be looking at Older People and Mental Health, with a particular focus on Loneliness and Depression.

Nearly half of those aged 65 and above say that television or pets are their main form of company. Loneliness can have a serious impact on both mental and physical health. It can be as harmful for health as smoking 15 cigarettes a day and people with a high degree of loneliness are twice more likely to develop Alzheimer’s than those with a low degree.

Depression is also associated with worse general health. In England depression affects 22% of men and 28% of women aged 65 or over. (Age UK, 15/16). It is important to identify common risk factors and know how to help overcome these debilitating conditions.

Join us for the next issue of Innov-age where our contributors share their knowledge and experiences of these and other important eldercare issues...