Hampshire Health and Wellbeing Board

End of Life Care Seminar – Living Well, Dying Well

Tuesday 24 March 2015

Ashburton Hall, Elizabeth II Court, Winchester

REPORT

Programme

9.30 **Introduction and Welcome**
Nikki Griffiths, Head of Workforce Development, Adult Services HCC

9.35 **Opening and Scene Setting**
Cllr Keith Mans, Deputy Leader Hampshire County Council, Executive Member Childrens Services, Chair of Trustees of Oakhaven Hospice

9.45 **Understanding the population needs in relation to end of Life care**
Dr Marie-Claire Lobo Public Health Consultant, HCC

10.05 **Supporting choices in good end of life care**
Dr Lara Alloway Consultant in Palliative Medicine / Clinical director for Cancer, Hampshire Hospitals Foundation Trust

10.30 **The Power of Conversation in End of Life Care**
Dr Bridget Wood, Consultant in Palliative Medicine, Oakhaven Hospice
Tina Quinn, Clinical Nurse Specialist Oakhaven Hospice

11.10 **Coffee break**

11.30 **Developing the Workforce Skills - making good End of Life care a reality**
Nicola Andrews, PhD Student Southampton University / Clinical Nurse Specialist – Care Home Education, Countess Mountbatten House

11.50 **Facilitated Table discussion**
"What does good integrated care look like for an individual, and what is your commitment to making this happen in practice?"

12.30 **Reflection - The Personal Impact of Good Care at End of Life**
Nikki Griffiths
Introduction: Gill Duncan, Director of Adult Services

12.45 **Closing Summary**
Cllr Liz Fairhurst – Chair, Hampshire Health & Wellbeing Board

13.00 Close

Attendance

Delegates included Members of the Health and Wellbeing Board, representatives from the Hospices in Hampshire, Clinical Commissioning Group representatives, representatives from Adults Services at the County Council, Acute NHS Trust representatives, charities, carers representatives, and Community NHS Trust providers.

Executive Summary

The event was attended by representatives from a range of partner agencies including NHS provider Trusts, Hospices, carers and commissioners. The event explored population needs in relation to end of life care, supporting choice and good end of life care, the power of conversation in end of life care, and developing the workforce skills in end of life care. Delegates took part in a facilitated discussion on what good integrated end of life care looks like, and how we can make this happen in practice.

The seminar generated engagement from a wide variety of partners in the ambition to support a good end of life experience in Hampshire. There was consensus about the priorities that would support good end of life care. As the Health and Wellbeing Board provides strategic direction for health and care services, the Board is well placed to promote the messages that came out of the event.

Themes that came through the session were:

- The importance of person centred care, which recognises what is important to the individual, and gives them choice and control.
- Availability of carers and nursing staff 24 hours a day, to support end of life patients in their preferred setting
- The need to have conversations about end of life, to help individuals to plan
- The need for organisations to work smoothly together to provide well integrated care, including sharing information about the person's preferences, and being able to build on a shared care plan

Feedback from delegates indicates that the event was well received. There was a positive atmosphere of commitment to improvement. The Health and Wellbeing Board can pick up on the priorities identified through the event, and the suggestions from delegates feedback, to promote good end of life care in Hampshire.

Introduction and Welcome

Nikki Griffiths (Head of Workforce Development, Adult Services, Hampshire County Council), the facilitator, welcomed attendees to the session and introduced Cllr Keith Mans (Executive Lead Member for Children's Services, Member of the Hampshire Health and Wellbeing Board and Chairman of Trustees at Oakhaven Hospice) to open the session.

Setting the Scene

Cllr Mans reflected on the multidisciplinary background of the founder of the first hospice in 1967, and how multidisciplinary teams remained key today. He noted that the picture has become more complex since the opening of the first hospice, with 'hospice at home' services supporting people in the community and other settings. He highlighted the importance of a holistic, personal focus in end of life care. He noted that the majority of end of life care now takes place outside of hospices. He welcomed the session as an opportunity to consider how the various players can work well together to make end of life good in Hampshire. He encouraged an approach of taking actions that look after all of a persons needs without getting too 'hung up on process'.

Understanding the Population Needs in Relation to End of Life Care

Nikki introduced the first speaker, Dr Marie Claire Lobo (Consultant in Public Health, Hampshire County Council) who gave a presentation on the evidence relating to end of life care need in Hampshire (slides provided at Appendix 1).

- It was noted that there is higher disease prevalence in deprived populations, and yet lower take up of end of life care.
- It was noted there may be unmet need for end of life care among prisoners, the homeless, veterans, and those with mental health issues.
- Cancer accounts for around 30% of deaths and around 70% of deaths are non-cancer related.
- It was highlighted there were opportunities to improve the number of people on palliative care registers in Hampshire.
- From a survey of bereaved people, areas for improvement highlighted were: the impression of hospital staff for family and carers, and access to bereavement services.

The facilitator thanked the presenter, noting the presentation indicated the range of information available to help partners jointly plan services based on population needs, and to learn from practice changes that have worked well in some areas and determine how this could be applied across the board.

Feedback: It was commented that more and more, people have a combination of chronic illness when reaching the end of their life, and it's not as simple as 'cancer' and 'non cancer'. Interest was expressed in available data on multiple conditions at time of death (not just eventual main cause of death), to consider what impact this may have.

Delegates were invited to leave comments or questions for the speakers (see Appendix 2).

Supporting Choice and Good End of Life Care

The facilitator introduced Dr Lara Alloway (consultant in Palliative Medicine/clinical lead for EoL Care, Hampshire Hospitals NHS Foundation Trust), who gave a presentation on supporting choice and good end of life care (slides provided at Appendix 3).

- She had previously attended an event hosted by the County Council when there were issues relating to continuing healthcare funding. The impact of that event was to lead to significant change. She was attending this event to report on what is going well and to reflect and set the challenge for what more there is still to do
- Most people are still dying in hospital, even though people say that isn't their preference (though sometimes peoples views change closer to the time)
- She recommended a book by Atul Gawande – 'being mortal'. The message being that what's important to you as an individual is key – meaning professionals need to not just talk about the standard options. She gave examples of the important things that people nearing the end of their life had requested e.g. seeing their dog.

- Between 2005 and 2015 there have been lots of strategies and reports on end of life care produced. There have been improvements during this time e.g. there are now joint working groups across various organisations.
- Importance of advance care planning for end of life – so people can make, and communicate their informed decisions.
- Hospice at Home is currently filling a gap to help keep people at home at end of life as we don't have 24 hour nursing care and support available at home.
- Befriending exists is some places but is not universal
- Continuing healthcare – accessing the funding is easier for people at end of life through the fast track system – but there is a serious shortage of paid carers in the community to enable people to die in their preferred place
- Communication – the Electronic Palliative Care Register. There are 3 or 4 different versions, use of them is varied. Whilst a good tool it is reliant on professionals gaining consent and more critically having end of life conversations with individuals.
- Need to promote conversation about end of life matters as a society, not just about preferred place of death. It's about quality of experience, what people might want, sharing these wishes – the ensure that when someone is at end of life there is a better change of having, for example the right care/drugs/equipment in place to support their choices
- Barriers – problem is not all about the money – it's the availability of carers, and 24/7 availability of nursing. Access to hospice beds and support is also variable
- Issues – lack of home carers in the community– this is a big problem for all health and social care services. For end of life care we need to drive skills development and support to achieve a minimum standard of care and consistency
- It is critical to maximise the non professional support – as families and communities we should aspire to become a 'compassionate Hampshire'

Delegates were invited to leave comments or questions for the speakers (see Appendix 4).

The Power of Conversation in End of Life Care

The facilitator introduced Dr Bridget Wood and Tina Quinn from Oakhaven Hospice, and Dr Carol Davis from University Hospital Southampton, who enacted an interactive role play to explore end of life conversations.

Messages:

- the importance of being open, asking what the individual wants to talk about, not telling them
- How to navigate the conversation sensitively, and get to the important parts of what needs to be discussed
- Explore the individuals story and what they want – ask their expectations.
- Help them plan and feel they have control.
- Options can be left open, and preferences can be changed down the line if their feelings change.
- Need to be realistic. Need to be brave, but having the conversation is important

- Don’t avoid or block openings to have these conversations

Developing the Workforce Skills – making good end of life care a reality in care homes

The facilitator introduced Nicola Andrews (Palliative Care Nurse Specialist – Care Home Education, Countess Mountbatten House, PhD student, University of Southampton) who gave a presentation on developing end of life care workforce skills (slides provided at Appendix 5).

- 20% of deaths at present are in care homes, and this is likely to increase.
- It is important to get feedback from other residents about ways to deal with the death of another resident e.g. some homes have provided an area for a memorial to the person who has died. It is equally important to seek feedback from staff about what helps them deal with loss
- The healthcare culture and social care culture are different – we need to find a way to work together
- Challenges – having a whole system approach e.g. support for care homes so they don’t need to dial 999, which may result in a person being transferred to hospital to die – when their wish is to stay in their own (nursing) home
- There are staff recruitment and retention issues in the residential and nursing home sector – 42% of care staff leave within the first year, 61% within two years
- There is more work to do to improve and develop the leadership in these homes in order to drive quality of care, improve end of life experiences for people and their families and to help maintain greater stability in the workforce
- Importantly there must be a move to recognise and value the valuable skills care home staff have – they know their residents well and their role in supporting people to live and die well is critical

Delegates were invited to leave comments or questions for the speakers (see Appendix 6).

What does good integrated end of life care look like? - Table Discussion

The facilitator invited delegates to discuss on their tables “What does good integrated care look like for an individual, and what is your commitment to making this happen in practice?” and identify their priorities.

Notes from each table’s discussions are provided at Appendix 7.

Priorities from each table were fed back and summarised:

- Effective coordination of integrated care – key contact to lead and link with the family
- Individual to tell their story once, have it captured and shared, and be able to build on it over time
- One plan that all use, which is person centred
- 24 hour care availability (appropriately trained staff)
- Person at the centre and what they want. Being realistic and honest, not over promising. Compassionate communities – network of neighbours etc

- Good collaboration also including wider parties e.g. faith representatives, wider community

Reflections: a personal end of life care story

The facilitator, Nikki Griffiths, spoke of her experience when her husband died of a brain tumour in December 2012. Key points for them had been:

- Because of the early professional support and conversations from the palliative care team they were able to still do things they wanted, and were able to choose and have control over the last months of life
- They were supported in their choices, although they were not always what the professionals expected. Being listened to and choices respected was critical.
- Little things made a big difference.
- Time becomes important – for example having to wait 4 days for 'ear syringing' when you only have weeks to live becomes much more significant
- Choices were facilitated – it was as good as it could have been.
- Important to retain a clear focus on what works for people as individuals, not everyone will follow the standard process, in fact will anyone…?
- A good death is as important as a good life – our challenge is to work together and with people and their families to ensure we have the best possible chance of making this happen.

Closing Remarks

Cllr Liz Fairhurst (Chairman of the Health and Wellbeing Board and Executive Member for Adult Social Care and Public Health at Hampshire County Council) reiterated that it is our job to help people to die well, and to give people choice.

She encouraged delegates to fill in the feedback forms to give their views on what will help us to achieve this ambition. She thanked everyone for coming, and the speakers for their contributions, and Nikki for organising the event and sharing her story.

Feedback from delegates: Summary

Delegates were invited to indicate what they would do as a result of attending the session. The feedback suggested those attending would be using their learning to take back to their professional role, to consider end of life needs in their work, and promote end of life conversations.

Delegates were asked to indicate their priority for the Health and Wellbeing Board to support end of life care. Among the feedback was ensuring the availability of 24 hour care, to support an integrated approach across the agencies represented on the Board, and to provide leadership for/promote a person centred approach. It was also suggested that the Board nominate an end of life care lead on the Board.

General feedback indicated the event had been well received, and reflected the positive atmosphere of commitment to improvement evidenced on the day.

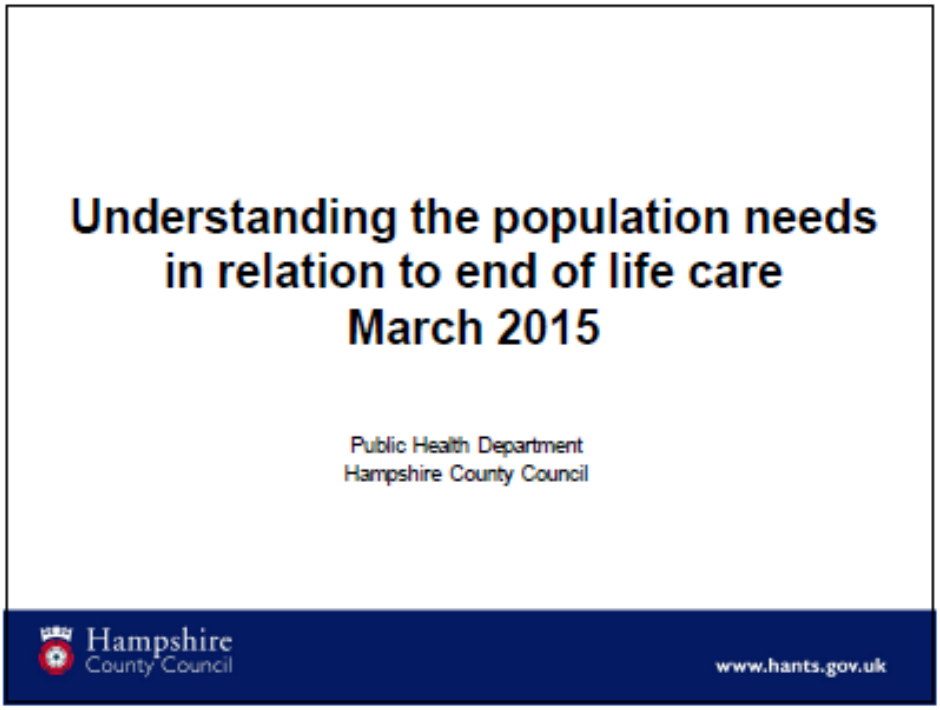
Full feedback comments are provided at Appendix 8.

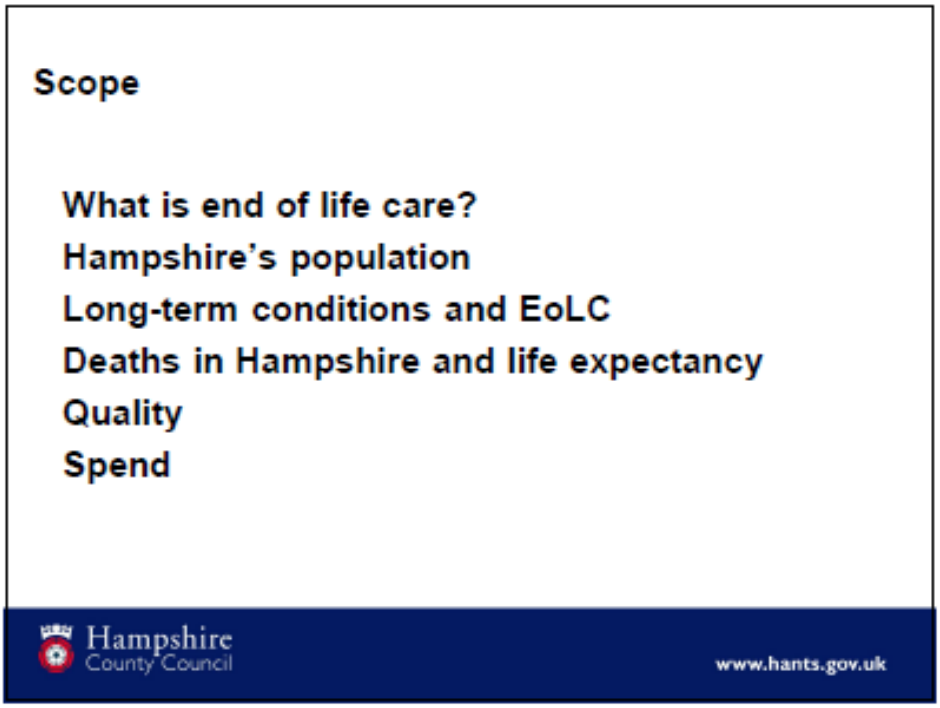
Conclusions

The Seminar generated engagement from a wide variety of partners in the ambition to support a good end of life experience in Hampshire. There was consensus about the priorities that would support good end of life care. As the Health and Wellbeing Board provides strategic direction for health and care services, the Board is well placed to promote the messages that came out of the event.

Appendix 1

Presentation Slides: Understanding the population needs in relation to end of life care





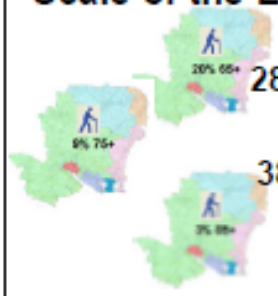
What is end of life care?

"People can be said to be 'approaching the end of life' when they appear likely to die within the next twelve months"

The General Medical Council and the National Council for Palliative Care

Hampshire County Council www.hants.gov.uk

Scale of the EoLC issue – Hampshire's population



Population

280,316 people were 65+ in 2014

128,814 were 75+

38,308 were 85+ or "oldest old"

Outmoded concept of old age, Hampshire self perception of ageing as 72+

Changing population

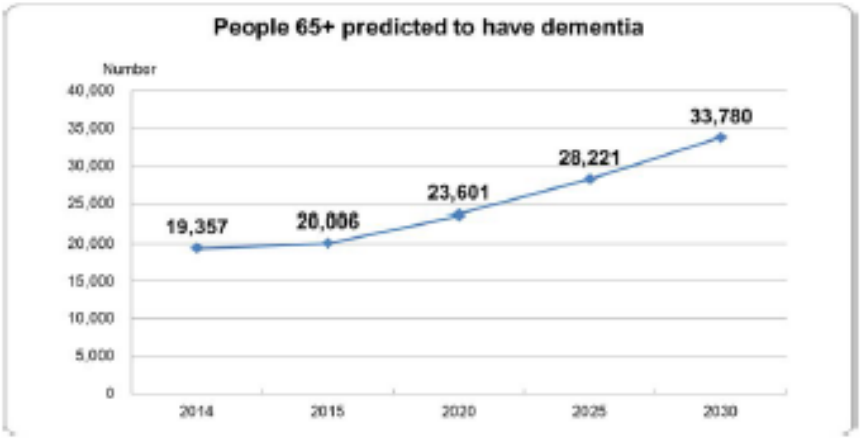
Growth in people 65+ between 2012 and 2022 27%

But growth in people 85+ in the same period 47%

Ageing phenomenon varies across Hampshire's CCGs both in terms of size and future projections

Hampshire County Council www.hants.gov.uk

Long-term conditions and EoL - Dementia



While we know that life expectancy is shortened in dementia it varies in different LTCs:

- About 4 years for people aged 75+ with renal failure on dialysis
- Less than 6 years in people with heart failure
- The 4 year survival of many people with stage IV COPD is <20%

Deaths in Hampshire – numbers, causes

Deaths in 2013

12,525 people died, 0.9% of the population
9,519 were palliative deaths (76%)

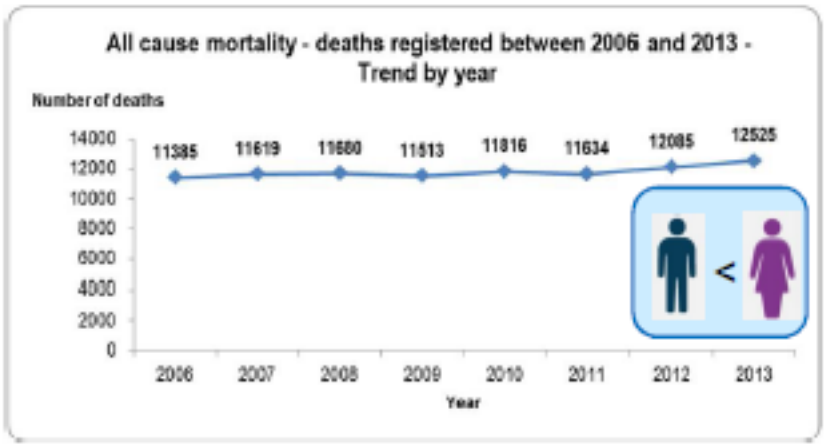
Palliative deaths

5,969 people died from non-cancer causes (63%)
3,550 people died from cancer (37%)

Hampshire County Council www.hants.gov.uk

In 2013 a total of 12,525 deaths, the highest since 2006

Vast majority (70%) were older people 75+



10% rise in deaths, although rise not consistent throughout

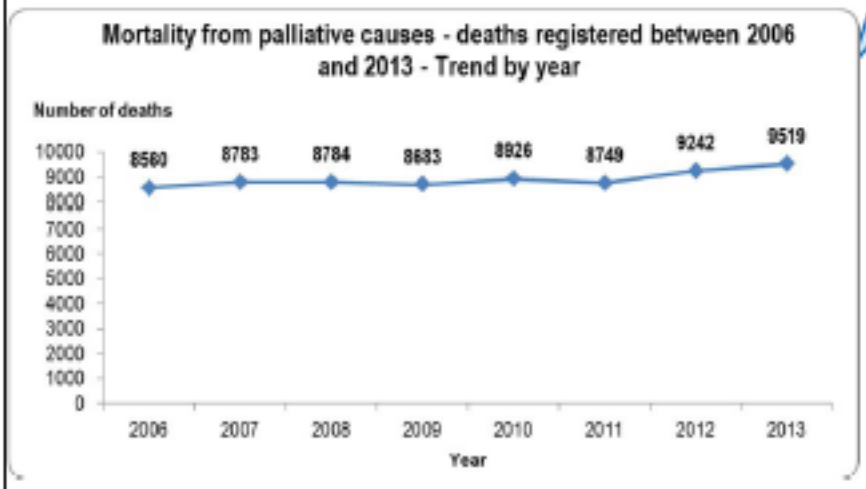
Hampshire County Council

www.hants.gov.uk

Palliative deaths

A total of 9,519 palliative deaths in 2013 the highest since 2006

On average, 8,906 palliative deaths a year



11% rise in deaths over the period, although fluctuations

Life expectancy at 65+

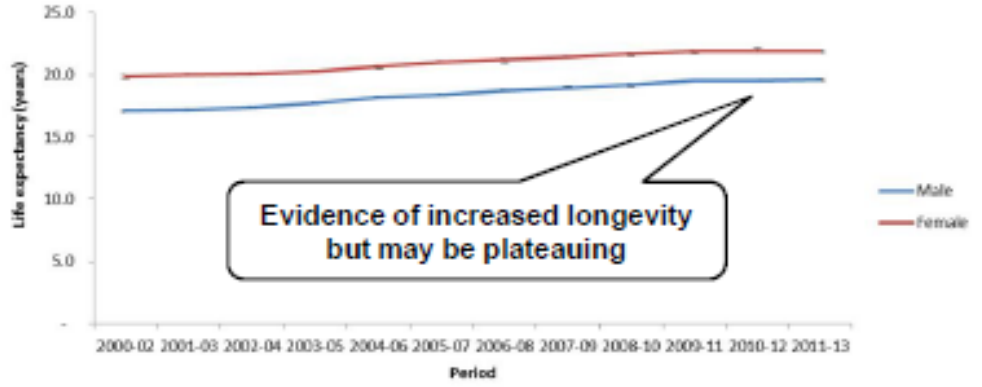
12.1 years

65 years

12.4 years

HLE

Male and female life expectancy at age 65+ for HAMPSHIRE



Source: Office for National Statistics via Public Health England. Note: confidence intervals are not available for life expectancy at age 85.

Hampshire County Council

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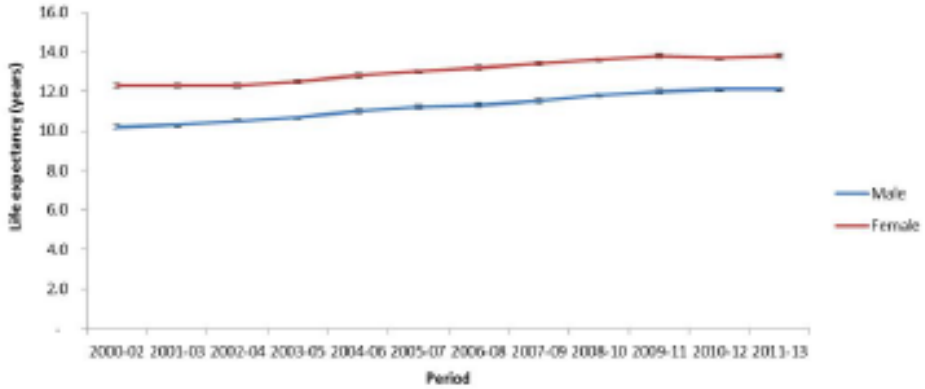
Life expectancy at 75+

Male and female life expectancy at age 75+ for HAMPSHIRE



Source: Office for National Statistics via Public Health England. Note: confidence intervals are not available for life expectancy at age 85.

Hampshire County Council

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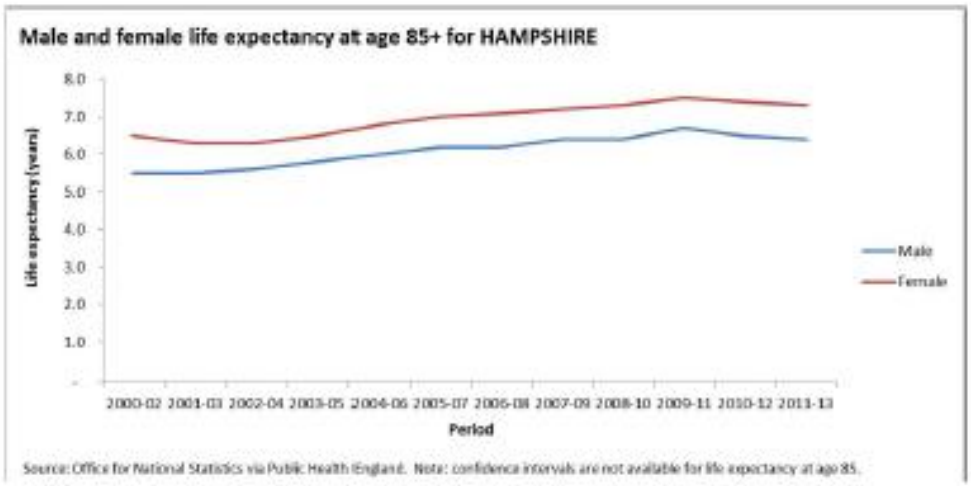
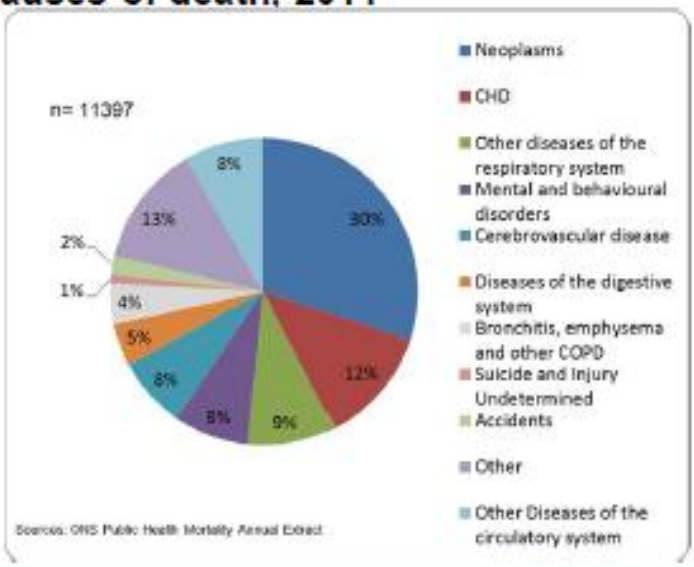
Life expectancy at 85+



Hampshire County Council www.hants.gov.uk

Main causes of death, 2011



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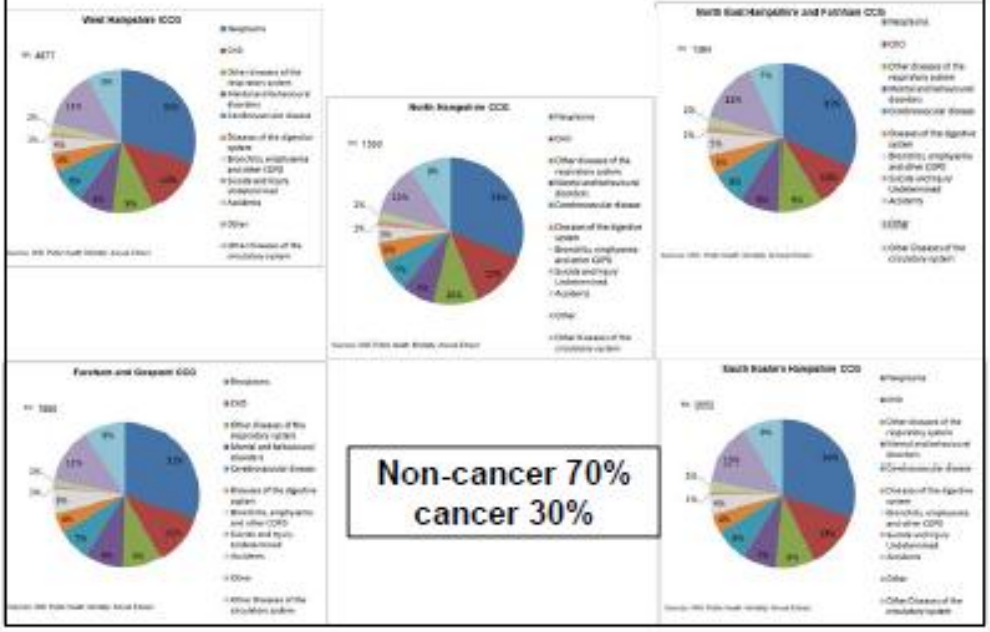
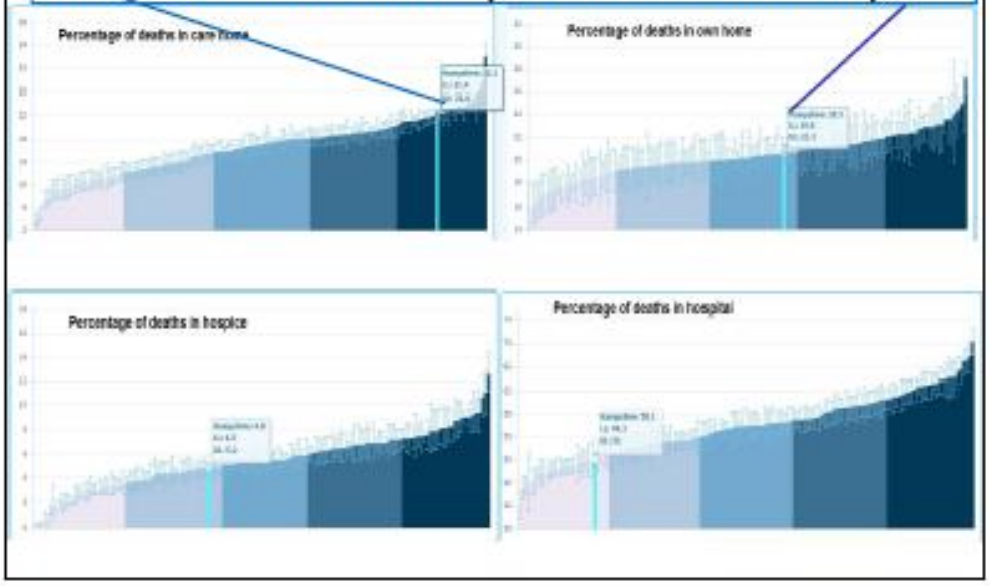
Main causes of death, by CCG



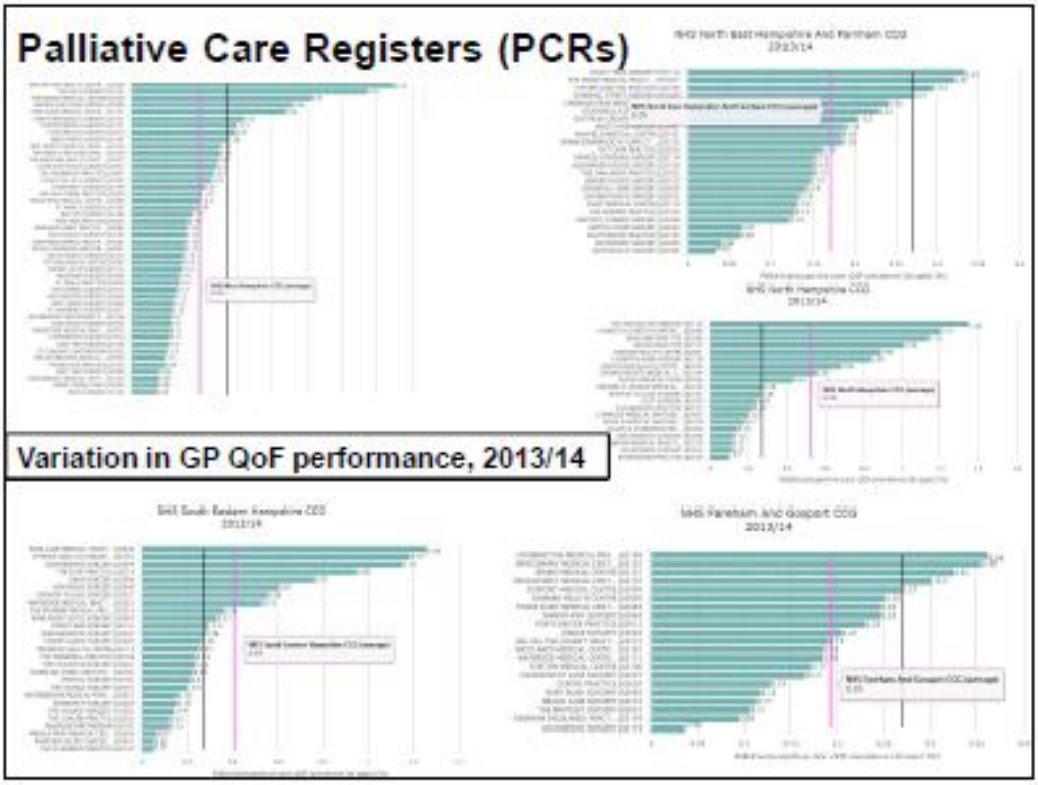
Non-cancer 70%
cancer 30%

Place of death, 2008-2010, PHE End of life profiles

Hampshire's data confirms we have come a long way in terms of deaths outside hospital but still needs to improve



Palliative Care Registers (PCRs)



Variation in GP QoF performance, 2013/14

Quality - The National Survey of Bereaved People VOICES

- Hospital staff received the lowest ratings
- Nurses were rated lower than doctors
- Need to improve patient experience and of family members and carers
- Access to bereavement services

Hampshire County Council

www.hants.gov.uk

EoLC Spend

Costs

Equivalent to at least a fifth of NHS costs

Social care costs per person = £3,486
Hospital costs per person = £6,644
Total costs = £10,130, -*Theo Georghiou et al.*

£96,427,470/- based on 9,519 palliative care deaths in 2013

Hospital care most significant service in terms of its costs but the least preferred location as a place of death.

Hampshire County Council www.hants.gov.uk

Reflections on EoLC Needs

With more people enjoying good health well into old age, substantial non-cancer palliative deaths, variation in practice and EoLC quality and significant spend, we need to ensure that they are supported to die with dignity in their preferred place of death.

Hampshire County Council www.hants.gov.uk

Appendix 2

Understanding the population needs in relation to end of life care

Post it Questions/Comments

- "How many people can access consultant support at end of life? What training/knowledge do GP's have in the challenging needs of end of life (EOL)?"
- "Care workers are not carers – training is an issue"
- "Need for caution re. place of death statistics – multiple confounding factors e.g. deaths at Southampton City residents at CMH not recognised. PHE data – 0.1% deaths at hospice vs. correct data of 8%"
- "If the average cost of a palliative care death is £10,000 in the final year, can we compare the cost of end of life care in hospice vs. community vs. hospital?"
- "Where is the £10,000 per death palliative cost from? What is the time period?"
- "What is the spend on community health vs. hospital and social care"
- "Is the cause of death just looking at Ia on the certificate or all diagnosis on the certificate?"
- " '72 years' self perception of aging – where is this from, what is the national data and what is the variation?"
- "Would you agree that hospice at home should be a stator service commissioned by CCG's as it seems such a vital part of end of life care?"
- "What end of life care research has been undertaken for Children and Young Adults?"
- "What is a 'palliative care' death? Do you mean it is an expected death that has been acknowledged?"
- "Can SEH CCG have their relevant slides around JSNA and individual practice analysis please?"
- "Will the slides be shared?"

Appendix 3

Presentation Slides: Supporting Choice and Good End of Life Care

Supporting choice
and good end of life care

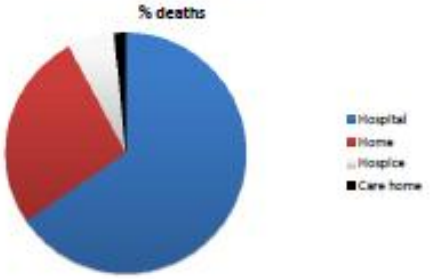
Dr Lara Alloway
Consultant in Palliative Medicine / Clinical Lead for EOL care
Hampshire Hospitals NHS Foundation Trust

Wessex Palliative and End of Life Network Specialist Palliative Care Lead

Supporting choice
and good end of life care

Where are we and what is still needed?

Death and dying
- everybody's business...

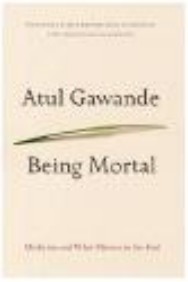


What is good end of life care?

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends
- Choice...

Hampshire Hospitals NHS

What really matters to you?

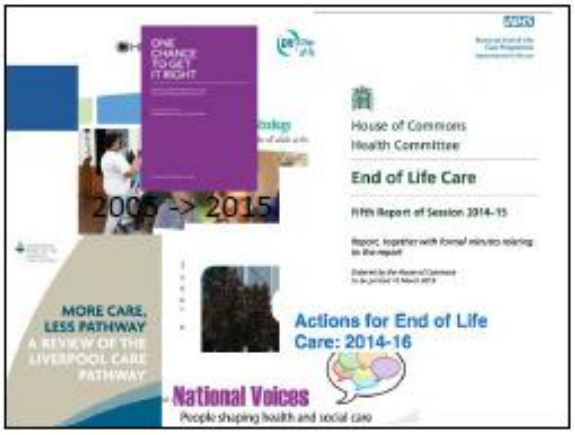


Hampshire Hospitals NHS

Dying from heart failure in 2005

Hampshire Hospitals NHS

Dying from heart failure in 2015



2005 -> 2015

Improved:

- Identification last 6-12 months of life
- Access to services
- Communication between services / organisations
- Workforce education
- Public awareness (positive and negative)
- Planning: individual / service / regional / national

-> More choice?????

Developments

- Working together:
  - Health and social care working groups / NHS and voluntary sector
  - Joint education
  - Feedback from carers / relatives: Voices / local bereavement surveys
  - Higher profile of end of life care
- Identification last 6-12 months
  - Primary care palliative care registers / meetings
  - Advanced care planning
  - Time to make better informed decisions
- Access to services
  - Increased access to specialist palliative care
  - Hospice at home services (in some areas)
  - Befriending services
  - Accessing fast track CHC funding
  - Hospital end of life work: transform programme

- Communication between services / organisations
  - Locality EOL registers (EPaCCs): HHR
  - Virtual wards and ward rounds
  - CCG / Wessex EOL groups
  - Unified DNACPR policy
- Better educated workforce
  - Hospital / primary care staff education
  - Care home staff
  - Care agency staff
  - Communications skills training: basic and advanced
  - E-learning packages (e-ELCA)
- More public awareness
  - Dying matters coalition
  - Media: positive and negative
  - Compassionate communities
- Planning:
  - Advanced care plans
  - Preferred place of care / preferred place of death
  - Treatment escalation plans / Amber
  - Just in case drugs
  - Palliative care community pharmacy list

What barriers?

- Choice?
  - Access to care at home
  - Community nursing not available to all 24/7
  - Variable access to hospice / hospice at home
- Communication?
  - Variable use of EaPCCs (electronic EOL register)
  - Information governance issues
  - Confidence in talking about death and dying
- Education?
  - Variable
  - Professionals / public

Next steps...

- Address lack of home carers
- Educate and support all staff
- Establish minimum standards across all services involved in care of dying
- Maximise non-professional support:
  - Hospice volunteer experience
  - "Compassionate Hampshire"
  - Befriending services

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

National Voices, "Every moment counts" March 2015

Lara.alloway@hhft.nhs.uk

Appendix 4

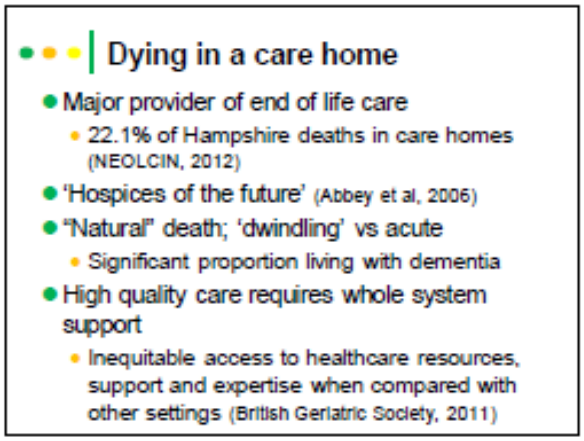
Supporting Choice and Good End of Life Care

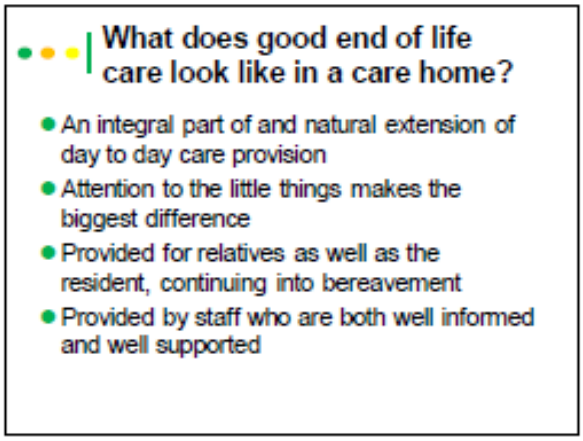
Post it Questions/Comments

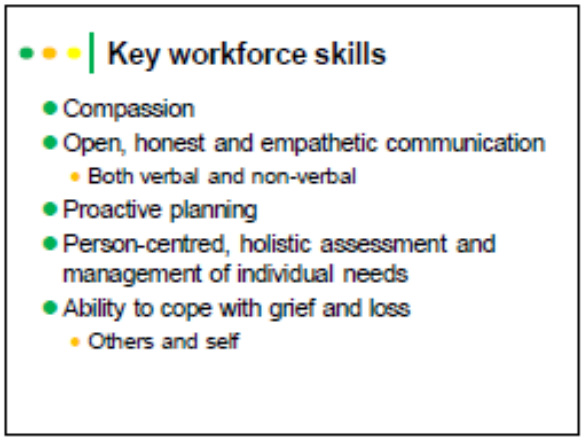
- "I am going to the 7 day service review tomorrow!"
- "Not only not enough carers but not enough carers with palliative care competencies – 4 a day means spread out Morning, Lunch, Tea and Bedtime"
- "Care Home deaths in West Hampshire are much higher than the pie chart – around 20% of all deaths"
- "QOF only 6 points – 'Having a Register' not putting your 1% expected deaths on the register OAZP – not electronic"
- "Why do we need to keep separate end of life teams from the virtual ward/GP teams already working in the community?"
- "Hospice or Home Pilot from CoB hospice – outcome data?"
- "Being able to offer something that can be achieved – do not promise what can't be delivered"
- "Carers are unpaid family and friends, Care Workers are paid staff to provide help. The confusion makes staff recruitment difficult"
- "Plans – if too good they may fail – like the 'laminated birth' plan"
- "Where is the evidence for 24/7 community nursing to support my perceived need?"
- "No mention of chaplains/faith - is the Church (mosque/temple) totally irrelevant to the patient and family?"
- "Can change your mind- but what about losing capacity? Hospice bed availability? Can't make promises. Them and us (Community vs. Hospital)"
- "End of Life care in Care homes is a key issue, should we be describing a model of care that is jointly commissioned through a 'pooled' budget?"
- "Increasingly I feel we should concentrate on wellbeing and life, make concrete plans (i.e. LPA, DMCPZ) will then other plans will emerge?"

Appendix 5

Presentation Slides: Developing the Workforce Skills – making good end of life care a reality in care homes







Organisational culture & processes

- Culture that supports privacy, dignity and respect for residents and their relatives
- Organisational processes to support proactive planning, multi-professional working and holistic care
- Resident and relative involvement in the decisions made within the home
- Processes to support staff and provide them with access to ongoing education
- Empowered and compassionate leadership

Empathetic communication

What care homes do well

- Many nurses and carers have good communication skills
- Manage cognitive impairment and other communication barriers on a daily basis

Key challenge

- Significant numbers of staff who do not speak English as a first language

Education and support

- 'Difficult conversation' tools for everyday use
- Advice on resources to support EoLC discussions

Proactive planning

What care homes do well

- Key worker system
- Planning for end of life care

Key challenge

- Involvement of healthcare staff in proactive planning

Education and support

- Implementing use of a supportive care register and tools to assist with identifying deterioration
- Advance care planning – processes & documents

Person-centred, holistic care

What care homes do well

- Know their residents well
- Pay attention to the little things

Key challenge

- Gaining respect for their knowledge from partner agencies

Education and support

- Tools to support their holistic assessment of resident needs
- Managing symptoms, medication and use of syringe drivers

Grief and loss

What care homes do well

- Engage with families from (pre-)admission

Key challenge

- Significant losses encountered by residents, relatives and staff

Education and support

- Approaches for dealing with distress
- Assisting staff to look after themselves and others
- Identifying resources available to provide support to relatives or staff

Supporting good end of life care in care homes - Education

- Gold Standards Framework
- Six Steps to Success
- Namaste Care Programme
- PaCT courses
  - Led consortia approach to hospice education
- Link nurse / EoLC champion groups
- Range of education sessions provided by hospice providers

Supporting good end of life care in care homes - Challenges

- Developing an integrated, whole systems approach
  - Ensure appropriate support provided
  - Support sharing of knowledge and expertise
- Recruitment and retention issues
  - High staff turnover
  - Need for stable home management
- Poor perception of care homes

Appendix 6

Developing the Workforce Skills – making good end of life care a reality in care homes

Post it Questions/Comments

- "How do we improve staff retention in care homes?"
- "How can key workers in care homes feed the care plan to share with Whole Integrated Community Teams, GP's, SCAS or acute hospital care (e.g. available on HantsHealth Record)?"
- "Care workers are in short supply, what is the solution – wages, career structure, opportunities?"
- " 'A good career with opportunities for promotion, qualification and support' – when care looks like that we will get good, well paid staff and keep them."

Appendix 7

Table Discussion Facilitator notes

N Andrews/Magenta table

- Inclusion of faith leaders – interfaith groups. Spiritual care as part of community support.
- Social/health/community organisations that collaborate well together
- Continuity of care
- Building community capacity
- Care that includes family carers and support for them

Priorities:

- Organisations/services that work together collaboratively and include not just health and social care, but community support including spiritual advisers/faith leaders
- Building community capacity

L Clarke/table 4

- Information shared across many organisations so questions note repeated and sharing computer systems
- Single point of access – contact number and appropriate staff member taking the role
- 24 hour nursing care for individual and family/carers
- Greater understanding and harmonizing the process
- Planning well in advance
- What's in the best interests of the individual and not best in terms of the process
- Continuity of care, starting with the GP

Priorities:

- 24 hour care (not necessarily nursing care) – access to care and support
- Continuity of care
- Training for care staff

Maria Hayward/tables green and orange

- Good care plan that is truly person centred and meets the individuals needs– shared, single plan, with consent to share, including with the ambulance service (with Multi Disciplinary Team approval). To include a balance of Health and Social Care need, and to include the small things that make a big difference. Trust and Co-ordination required. Individual/carer only has to tell things once.
- Link to MDT – quality of care plan, and coordination of the single care plan
- Ownership of the plan – one coordinating role
- Improving sharing information (and protocols to allow this to happen)
- HHR – everyone can feed into it and it can be a live document
- Early conversations with people with dementia – from point of diagnosis

Priorities:

- Unified care plan – across Hampshire, and one case holder
- Where are the gaps e.g. in 24 hour care

Gayle/blue table

- Say it once – telling your story once (avoid exasperation). Journey should be seamless for the individual. Start with the person – family, friends, community. Health and Social Care should only be part of life. Links to compassionate community/locality working. Remember the individual is a person not a patient.
- Person always seen as central and in control. Maybe key person to link professionals with. Each professional does own care plan so person doesn't have one plan. Need shared record that really works. Can't hide behind information governance anymore. Sharing information for the benefit of patients.
- Individual portfolio for all care and clinical to be held centrally and grown and changed as people change. Held in HHR? Have on a 'smart card' or paper. Personal profile already exists

Priorities

- Say it once and have individual health record owned by the individual e.g. personal profile on HHR system (not just about 1 assessment but a life story/profile with medical assessment included)
- Resolve information governance issues, and publicise to professionals, individuals and their families
- Availability of carers – a) family/friend/community carers, b) paid carer workforce/volunteer workforce

Barbara/purple table

- Coordination of care around the individual
- Integrated care is about having a lead team member responsible for the care and taking responsibility for co-ordinated care. They would be the go to person for the individual and their friends/family
- The lead worker would be the link person but the whole care team would take collective responsibility. Matrix management – send things out sideways to the various agencies rather than up a hierarchical line management of a single agency
- Choice – coordinating role not determined by professional background/qualification. Needs to be someone you can trust with sufficient authority to make things happen
- Placing the team around the service user focusing on their needs rather than potentially competing agency priorities
- Listening to and respecting the individual and their choices, not imposing our own agenda
- Need to maintain level of paid carers. Something needs to happen to increase their standing in the community. They need respect from the community – cherishing for carers
- Support for families

Catherine Pascoe/White table

- Care that is promised to be delivered. We offer things we can't realistically provide. Beds not available and waiting lists
- Need honest conversations about what resources are available, also at a political level regarding resources
- Person at the centre. Delivering a holistic 'comfort' are, where ever that is
- Conversations about death and dying to happen much earlier, shouldn't wait for eolc specialist conversations. Nicola – lots of little conversations
- Comfort care – symptom relief, medicines
- Support for carers essential – their own mental health
- Patient focus groups – what would they want in the community
- Developing the ? of the compassionate community. Neighbours who deliver food etc sitting etc
- Not always much choice
- Need for befriending services and churches
- Cultural shift. Empowering people to say what their needs are. Networking and sharing ideas of what works for them
- Workforce – need career paths and consider pay
- Ensuring a peaceful death
- The people who experience that death, these are the memories that people live with
- Also experience of dying
- Person at the centre
- Team approach – important how the person's wishes are shared
- Encourage early ? planning
- DH to come up with ? outcome?

Appendix 8 Feedback from delegates

As a result of attending today I am going to:

- "Continue to promote holistic and co-ordinated End of Life (EOL) palliative care"
- "Follow up with Health and Wellbeing Board (HWB) on how to support/work together"
- "Encourage all clinicians and social workers in my practice ICT to start having lots of little conversations with people they consider to be at the EOL"
- "Continue supporting people to plan. Say it once. Request funding to keep with encouraging people to communicate about EOL"
- "Ask our Day Care Team whether they have or could have a conversation with a focussed group to know what would be appropriate to remember/memorialise those who have died. Consider 'reflective debriefing' for Care Home staff, delivered by family service volunteers"
- "Help create 'Compassionate Hampshire' and nurture it"
- "Support staff in our care homes in terms of developing EOL care"
- "Raise the profile of integrated care within my organisation"
- "Feedback to LIT. Review current working practices re contacting health professionals for help OOH"
- "Reflect"
- "Find out more. Think about the needs of carers and care works and their recruitment and retention. Information Governance/systems – just why is it such a problem?"
- "Feedback all that I have learnt today to my DM, TM's and staff team on ensuring that the child/adult remains centre and that wishes and feelings are gained and promoted"
- "I will continue to provide good patient centred care, listening to and managing expectations trying to bridge the gap between expectation and reality on the ground"
- Do more to enable integration, but remain realistic and honest"
- "Focus on individual outcomes, although some processes are still important"
- "Ensure that Oakhaven is well placed to work with other agencies in providing a well coordinated EOL service."

My priority for the Health and Wellbeing Board to support good end of life care is:

- "For the board to appoint an end of life care lead to explicitly consider the needs of people with terminal or life limiting conditions in their strategies and to promote equity in provision of EOL services throughout Hampshire"
- "Explore how EOL needs can be met between health, social and society – work with difference groups including the population, home focus groups, GP's and providers (SH/Solent)"
- "To support the development of patient focus groups and establish/encourage 'Death cafes'. Local events (e.g. Dying Matters Awareness Week) to promote the concept of early planning for EOL years"
- "Think about supporting people in communities to work together to improve local support and working together in localities"
- "To consider having SPC social workers as part of an integrated care team or working in SPC units/hospices under contract. Access currently is very

limited. A good model is operated by the Rowans Hospice (TRH) under an agreement between HCC,PCC and TRH. Commission hospice at home services (CHC funded)"

- "Social care = care workers being valued, educated, trained, empowered and available"
- "24 hour care and support"
- "24 hour care easily accessed"
- "Communicate openly with all involved in EOL care and try not to allow 'border disputes' to have any effect. Do involve the charities and private care agencies"
- "Listen to the EOL person not the people in authority who, with the best intentions in the world, don't always know best"
- "Leadership for organisations working together. Facilitate a strategy for it"
- "Spreading the word within social care teams"
- "Out of hours GP services, availability of good care agencies with capacity. Support the voluntary sector who are providing services already"
- "Asking the question 'What matters to you' and being able to facilitate and articulate what that will mean for the individual"
- "Ensure integrated health care services for Care Homes"
- "Does the board have a named person responsible for representing end of life interests within the group. Also to ensure that end of life care is well coordinated across the patch particularly in relation to the barriers of health and social needs and to consider how best this barrier can be removed both from a financial and operational perspective."

Any other comments:

- "A very helpful and well organised event, highly current EOL issues. Implementation is the next challenge"
- Excellent meeting – HWV is the natural place for EOL to sit and all generalist/specialist/health/social/political/voluntary sector can feed in. Need to include primary and community care at the next meeting"
- "Good event, excellent discussions – well done Nikki"
- "Documents need to consider whether enough is paid to social Care Agencies to support access to high quality social care?"
- "Excellent morning – thought provoking even for someone in who specialises in this "sort of stuff". Nikki G – brave and true"
- "Very good"
- "Very good seminar"
- "Review continuing care funding? Need trained rather than agency workforce"
- "A very good morning"
- "Moving/inspiring presentation by Nikki – she should be proud"
- "Good morning"
- "Thank you for an excellent and informative seminar – especially to Nikki for her story"
- "Representation from spiritual care advisers/faith leaders and other community providers (as there were only a few) may have widened the views in the discussions"
- "all the presentations were great and there felt a real sense of wanting to improve things within the room."