Ambitions for Palliative and End of Life Care:
A national framework for local action 2015-2020

The six ambitions for palliative and end of life care

01 Each person is seen as an individual
I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what’s possible.

02 Each person gets fair access to care
I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

03 Maximising comfort and wellbeing
My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

04 Care is coordinated
I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

05 All staff are prepared to care
Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

06 Each community is prepared to help
I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

The National Palliative and End of Life Care Partnership
4 Domains Public Health (NMC 2004)

1. Search for Health Need
   - Surveillance and assessment of the populations / communities health and well being
   - Data collection, identify inequalities, community profiling.

2. Stimulation of awareness of health needs
   - Work with and develop capacity and confidence of individuals, groups, and communities to influence and use available services.
   - User voice, community & stakeholder engagement. Eco-mapping

3. Influence on policies affecting health
   - Identify and evaluate service provision and support networks for individuals, families and groups in the local area
   - Contribute to policy development and or agenda setting (professional networks, lobbying)

4. Facilitation of health enhancing activities
   - Work with others to plan, implement and evaluate programmes and projects to improve health and well being
   - Increase Social Capital/ Community Development and Empowerment.
Ending inequality at Eol

A different ending
Addressing inequalities in end of life care
Overview report

- Homeless
- Prison
- Dementia
- Learning Disability
- Live alone

CQC May 2016
St Luke’s Hospice
Community development Strategy – we have started!

Gail.Wilson
gwilson@stlukes-hospice.org.uk
Inequality of Service provision: Hospice care EOLC to chosen few – expand community provision

Sandy Knowles / G Wilson
Developmental Conceptual Framework July 2016
Our Care Home Communities: Making a real difference

EOL Champions – Six Steps +

This organisation has been awarded St Luke’s accreditation following successful completion of the Six Steps to Success End of Life Care Programme

2012-2013

‘Plymouth, a beacon of excellence’

ABC, ACP and the Six Steps programme

On the next two pages we showcase education and training initiatives in Plymouth, East of England, Suffolk and West Sussex aimed at helping care home staff to provide high quality end of life care.

“It’s great that despite this, most respondents felt their loved one had died in the right place. But until we have those conversations with the residents themselves how do we know?”
Post Death Audit, Improving quality – 1451 deaths analysed

Died in hospital

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Died in Hospital</th>
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<tbody>
<tr>
<td>Pre course</td>
<td>18%</td>
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<tr>
<td>During</td>
<td>16%</td>
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<tr>
<td>1 year</td>
<td>10%</td>
</tr>
<tr>
<td>2 years</td>
<td>8%</td>
</tr>
<tr>
<td>3 years</td>
<td>6%</td>
</tr>
<tr>
<td>4 years</td>
<td>2%</td>
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</table>
Engaging & supporting other professionals in our community

**ADVANCE NOTICE DATE FOR DIARIES**

‘FACING THE SUNSET’ CONFERENCE
20th July 2011
Future Inn Hotel, Plymouth.
9am-5pm

AN INTEGRATED APPROACH: ENSURING QUALITY END OF LIFE (EOL) CARE FOR THOSE WITH DEMENTIA

**KEY NOTE SESSIONS:**
- Facing the Sunset: perspectives on dying
- EOL care and what challenges does this present for the person with dementia
- The Carer’s Perspective
- The importance of an early dementia diagnosis in supporting EOL choices
- The Irish Model: A Best Practice Example
- Using Prognostic Indicators to determine EOL in patient with dementia
- Mental Capacity, Consent and Best Interest meetings
- Pain Management and Symptom Control
- A case study: The role of CNS in dementia & EOL

FREE End of Life Care Workshops
Funded by Health Education South West
“Let’s Start the Conversation”

Supporting patients and families to have open and honest conversations about progressive illness and Advance Care Planning (ACP) and Treatment Escalation Plans (TEP)

15th October – Cophorne
12th November – China Flee
19th November – Buckfast
21st January – Buckfast
7th March – Cophorne

**Workshop 1 – 09.00 - 12.30**
- Find your 1%
- Exploring the communication issues in Advance Care Planning: Benefits & Potential pitfalls, CAPPP programme
- How to use materials, provided tools and information to help you

**Workshop 2 – 13.15 - 16.30**
- Review of Devon ACP tools
- Overview - How to complete a Mental Capacity Assessment
- TEP - Interactive scenario with an individual without capacity
- Advance Decisions to Refuse Treatment

Open to GPs and Nursing Professionals who have EoLC conversations in the home.
Level 3: Creating EOL Champions
Learning Disability Community

St Luke's Hospice Plymouth
NHS

Easy Read Care Plan
My Future End of Life Care Plan

This Advance Care Plan (ACP) has been developed to support people to think and talk about how and where they would like to be cared for in the future and will help to inform future decision making, if they are not in a position to either make and/or communicate their health or social care choices at that time.

Talking about care choices in advance helps to reduce stress and anxiety for individuals, their families and carers as it enables decisions to be carefully considered and based on the individuals wishes and beliefs. Everyone can use the plan but it has been particularly designed for people with a communication or learning disability, who often are not given the opportunity to discuss these issues.

The plan has been designed and developed in partnership with Plymouth People First Self Advocacy group through End of Life Ambassador and ACP Engagement Workshops 2015 - 2016.

With the support of NHS New Devon clinical funding this plan will be made available and used across Devon.

The plan, guidance and feedback forms can be downloaded from:
https://www.stlukes-hospice.org.uk/information-for-healthcare-professionals
Regional Updates

HMP Dartmoor Prison working in partnership to improve end of life care for all - St Lukes Hospice, Plymouth began a prison project along with Macmillan at Derriford Hospital and myself at HMP Dartmoor to improve end of life/life limiting disease care in prison. The outcome is that here at HMP Dartmoor we have a Macmillan Nurse and a nurse specialist from St Lukes Hospice who see all our patients who are living with cancer or who have a life limiting disease or are end of life on a monthly basis. We also have quarterly MDT's with these nurses, prison family liaison officer and chaplaincy and social work. This service is constantly evolving.

Sheridan McGinlay, Deputy Healthcare Manager
Hazel Roberts from The Livewell Southwest Drug and Alcohol Team

“We have noted an increase deaths of service users related to drug and alcohol use. The End of Life Care Champions project has given me the confidence to raise the profile of end of life care within the service and what's more, help us with those very difficult end of life conversations and consider greater opportunities for advanced care planning.”
End of Life Ambassadors Project for the Homeless

St Luke’s Hospice Plymouth wishes to work with a range of partner organisations in the city that are providing support for the homeless. So that staff and volunteers can recognise when the physical condition and behaviour of a homeless person is deteriorating and that end of life may be approaching. This programme is free to those who work or volunteer within the homeless community.

This is a free programme for people who either work or volunteer within the homelessness sector. These individuals will become end of life ambassadors.

Course Delivery: There will be 3 different cohorts each with four 4 hour workshops (12:30-16:30). The sessions will run from March through until June, and there will be an evaluation workshop at the end of the programme to summarise learning.

The programme will contain:
- Recognising of End of Life Care in the homeless population – Workshop 1
- Primary causes of death in homeless population – Workshop 1
- End of Life discussions with hostel residents – Workshop 2
- Planning ahead for End of Life Care - Workshop 3
- Information on drugs and alcohol in EoL – Workshop 3
- Understanding the impact of loss – Workshop 4
- Bereavement support for residents and staff – Workshop 4
- Spiritual care in EoL – Workshop 4

What is expected of ambassadors?
- Be able to recognise that someone may be at EoL
- Be able to signpost to end of life services and support
- Hold supportive conversations
- Support people general well being through compassion

EOL Ambassadors for the Homeless

12 organisations
55 people
“I was doing the soup run and I was concerned about a sex worker who had a growth or something near her eye. I knew I had to say something, so I went over and said you can tell me to go away and mind my own business if you like, but I am really concerned about your eye. I spoke to the lady and she was concerned too, but did not have a GP. I told her about the drop in centre and she said she would go. The following week I saw her and she said the doctor made an urgent eye hospital appointment that day. The eye hospital doctor said if she had left it for just one more day she would have gone blind. She started treatment – she came to find me to say thank you.

I feel I made a real difference”          Soup Run Volunteer

1. Hostels are not classed as home.
2. Inequity of choice at EOL.
3. EOL seen as a failure/blame culture.
4. Emotional support.
5. Lack of co-ordination between statutory / VSE
6. Lack of knowledge re services.
Representation from:

- SLH
- Health & Social Care
- Community & Voluntary Sector
- Legal Sector
- Funeral Sector

Cost SLH approx £1500

Sponsored by co-operative funeralcare

120 booked
117 turned-up
90 external delegates
Turning Conversation to Action!
<table>
<thead>
<tr>
<th>Organisation</th>
<th>What would you like help setting up</th>
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<tbody>
<tr>
<td>The Churches In Plymouth</td>
<td>Supporting carers/patients at home – CC</td>
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<tr>
<td>The Red cross</td>
<td>Supporting carers at home CC</td>
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<tr>
<td>Timebank South West</td>
<td>SLH Volunteer Timebank CC</td>
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<tr>
<td>Plymouth Dementia Action Alliance</td>
<td>EOL Ambassadors people with dementia</td>
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<tr>
<td>GP Macmillan Facilitator</td>
<td>ACP for people with dementia</td>
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<tr>
<td>Plymstock School</td>
<td>EOL education / compassionate communities in schools- CC</td>
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<tr>
<td>Wolferstons Solicitors</td>
<td>EOL Ambassadors</td>
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<tr>
<td>SLH Turnchapel</td>
<td>Child bereavement support &amp; Jeremiah’s Journey</td>
</tr>
<tr>
<td>Age UK Plymouth</td>
<td>EOL Ambassadors for people with dementia</td>
</tr>
</tbody>
</table>
Each Community is Prepared to Help:
Community Development in End of Life Care – Guidance on Ambition Six
6 Key Aims

- Building the communities capacity to care for those at end of life – volunteer networks
- Ensuring Plymouth’s Health & Well being Board recognise end of life needs as part of a healthy city approach.
- Raise awareness and understanding about why dying well is important.
- Create EOL Ambassadors to Promote ACP to Promote open discussions about death, dying and loss
- Address Inequality in EOL care
- Compassionate Workplaces & Schools
Compassionate Neighbours Networks

“People Helping People”
4. Promoting Compassionate Neighbours Networks –

THE MAN IN THE VAN!

5 Neighbours
4. Compassionate Neighbours

Real Challenges

1. Relationships with professionals (us & them) – practical info & advice required
2. Expectations of cared for person
3. Finances
4. Co-ordinators Role
5. Honesty – Ok to say no
6. Handling falls
7. Handling Guilt
8. Choices & Consequences
9. Communication

• Domestic Help – Cooking, shopping
• Emotional support- listening, chatting
• Spiritual support.
• Advocacy, co-ordination.

Not prepared to do: Physical care
Coming together is a beginning; keeping together is progress; working together is success.

“People Helping People”
THANK YOU 😊