Cheshire Living Well, Dying Well Public Health Programme

To improve health and wellbeing by supporting a change in public knowledge, attitude and behaviour towards life, age, death and loss and through this make living well, ageing well, grieving well and dying well, the norm.

End of Life Issues affect health and wellbeing in many ways including illness, disability, caring responsibility and bereavement. The Cheshire Living Well, Dying Well Public Health Programme recognises that natural death is part of the human life cycle and that considering, discussing and recording end of life wishes throughout the life-course can help individuals, families and communities to make healthy choices and to live well and die well.

THE NEEDS: Our community has lost its familiarity with natural dying, death and loss, the consequences of which are a lack of family and societal openness and discussions. The dominant cultural approach to a predictable life event has a negative impact on the health and well being of our community.

“No matter how much effort is put into training clinicians in good communication skills, unless everyone in society – members of the public, the Press, clinicians, public figures – are prepared to talk more honestly about death, dying and bereavement accepting they are a normal part of life, the quality of care and range of services for the dying, their relatives and carers will remain inconsistent. The review panel strongly supports the work of organisations that promote public awareness of death, dying and bereavement”.

Extract from More care, less pathway; A review of Liverpool Care Pathway; July 2013, Chair: Baroness Julia Neuberger

STATISTICS FROM CHESHIRE EAST INFLUENCE SURVEY: Data from 1945 residents who have completed a section on “Your end of life wishes”:

- Talking about death, dying and loss; 22%- very comfortable; 58%- fairly comfortable/no strong feeling; 22%- very uncomfortable
- Discussion of end of life wishes - 31% of over 75 and 51% of permanently sick/disabled have not discussed those things that are of importance to them with anyone
- Written plans, including wills: 61% of all respondents and 38% of permanently sick/disabled have completed some form of written plans

The Six Priorities of the CLWDW Programme identified through consultation are as follows:

- Embed a public health partnership approach to death, dying and loss at a local/ regional/national level
- Motivate and assist people to make plans, record wishes and have more open discussions about death, dying and loss
- Create and develop a toolkit of resources to enable effective and appropriate Living Well, Dying Well Public Health Interventions
- Raise awareness and increase knowledge and understanding as to why Living Well, Dying Well is a public health issue
- Build community capacity for End of Life Care via informal help from relatives and friends or via formalised volunteering
- Encourage workplaces / businesses to review organisational approaches and recognise Living Well, Dying Well as a public health issue

Opportunities for improvement
Historically Public Health has focused on reducing preventable disease and death. However, it is now recognised that end of life and bereavement has associated morbidity and mortality that could be amenable to Public Health Interventions and therefore, should be viewed as a mainstream Public Health issue.

The Cheshire Living Well, Dying Well Public Health Programme aims to normalise natural ageing, death, dying and loss in society, break down taboos and support a change in public knowledge, attitude and behaviour.

As ageing, death, dying and loss is a cross-cutting issue it is important that a multi-faceted approach is developed and delivered in partnership.

Improving the health and wellbeing of Cheshire East Communities by working to help people to make healthy choices to live and die well, is a multi-agency issue and not singularly confined to those in the health arena.

Local Stakeholders and their Views:
The Cheshire Living Well, Dying Well Partnership has been established to enable effective multi-agency response and support for the Cheshire Living Well, Dying Well Public Health Programme of Work and the needs of local communities.

During 2012, Partnership Development Events were undertaken across Cheshire East and Cheshire West to consult and engage with Stakeholders and to encourage cross-sectorial representation at all levels (strategic, operational and community).

The CLWDW Partnership was officially launched in May 2012. The first official cycle of meetings within the agreed CLWDW Partnership Structure took place in November/ December 2012, although a number of the groups had been meeting in a shadow format prior to this.

Members of the partnership are wide-ranging and include health and wellbeing services, hospice, local authorities, housing, fire service, voluntary sector organisations, community groups, local businesses and church and faith groups.

In April 2014, The Cheshire Living Well, Dying Well Programme, Cheshire Hospices Education and the End of Life Care Service Model combined to form a new organisation called the End of Life Partnership on. The EOL Partnership is working together to transform End of Life experience and care

Assets:

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<th>Type</th>
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<th>Total</th>
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<td>CLWDW Partnership – Strategic Group</td>
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<tr>
<td>CLWDW Partnership – Cheshire East Operational Group</td>
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<td>CLWDW Partnership – EOL Financial Housekeeping Group</td>
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<td>CLWDW Partnership – Compassionate Communities Group</td>
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<td>CLWDW Partnership – Virtual Partnership Network</td>
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<tr>
<td>Total</td>
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*Note there are a minimal proportion of Champions sitting on more than one Partnership Group

**There are approximately 60 partner organisations represented within the CLWDW Partnership (excluding the membership of the Virtual Partnership Network)

Pledges from the Partnership Development Events included:

- To Champion CLWDW at Health and Wellbeing Board Level and with Clinical Commissioning Groups.
- To inform and communicate more with service users and their families.
- To support carers to consider and discuss.
- To use Chester Diocese website to promote and signpost to the programme.
- To raise awareness of the approach through meetings, newsletters, support visits and health awareness events with customers, staff and tenants.
- To build CLWDW awareness into the training programme for CAB Advisors.
- To update sub-regional solicitors network to inform practice.
Assets:
Highlights of the CLWDW Programme to date (May 2011- July 2013) demonstrate some of the community assets identified and developed in partnership with stakeholders and communities.

- Presentation to the All Party Parliamentary Group on Dying Well at the House of Lords to increase awareness and understanding of the programme
- Partnership Development Events undertaken in Cheshire East
- Supported Community Events co-ordinated by Stakeholders
- Identification of CLWDW Partnership Representatives (Champions)
- Identification of CLWDW Champion at Health and Wellbeing Board Level in Cheshire East
- Relationships developed with Cheshire East Ageing Well Programme
- Launch and implementation of CLWDW Partnership – including a dedicated Launch event supported by Local MP and Community Representatives
- Name and branding of Cheshire Living Well, Dying Well Partnership agreed as a result of consultation with stakeholders
- Work with Cheshire East Council InfluenCE Team – inclusion of 7 questions within Citizens Panel Survey (representative sample of 3000 members)
- Launch and implementation of St. Luke’s Community Support Alsager – Compassionate Community Volunteer Model
- Co-ordinated activity for National Dying Matters Week 2012, including; CLWDW Partnership Launch, Community ‘Circle of Life’ Event (with Co-operative Funeral Band), Piloting of Will Writing Workshops by local Solicitor in Extra Care Housing Venues, Outreach in partnership with CAB at local supermarkets Delivery of lectures and awareness sessions, Community ‘Circle of Life’ Coffee morning, Local funeral Home ‘Open Day’, Radio and Press Interviews and Coverage
- Co-ordinated activity for National Dying Matters Week 2013, including; CLWDW Partnership – Showcase Event, Delivery of CLWDW Programme Sessions – Community Sessions and Sessions for Staff and Volunteers, Radio and Press Interviews and Coverage, ‘Funeral Planning’ by students from University of Chester, Support for Advance Care Planning Conference for health and social care staff, Support for ‘Dying Matters’ Conference in Cheshire West and Chester
- Bespoke resource development including; dedicated webpage, ‘Setting the Scene’ Package, ‘Bill’s Story’ DVD Animation, ‘Wills Misconceptions’ Leaflet, Cheshire ‘Dying For A Laugh’ DVD, ‘Role Play’ DVD for Community Sessions, Supported development of a resource for engaging communities in end of life issues, produced on a regional level
- Two successful poster presentations at the 3rd International Public Health and Palliative Care Conference, Ireland
- Continued development of LWDW Volunteer Team
- Launch and implementation of the Middlewich Good Neighbour Scheme – Compassionate Community Volunteer Model (including a dedicated launch event)
- CLWDW Programme Lead shortlisted for Macmillan Professional Award in Innovation Excellence
- Supported the development of the report ‘An Overview of Compassionate Communities in England’ – Murray Hall Community Trust and National Council For Palliative Care Dying Matters Coalition
Assets:
Development and delivery of a range of awareness and training sessions for the public, community and wider public health workforce regarding considering, discussing and planning for the rest and end of life;
- Community Awareness Sessions (to increase understanding as to why living, ageing, grieving and dying well is a public health issue)
- Community ‘How To’ Skills Workshops (to motivate and assist the public to openly consider and communicate their wishes)
- Brief Intervention Training Packages for the wider public health workforce (to enable any staff / volunteers who are public facing in any community setting to enable them to motivate and assist the public)
- ‘Making the Professional Personal’ Sessions (to enable personal development sessions for staff and volunteers to enable them to consider their own wishes and consider, discuss and plan from a personal perspective)
- Community Wills Workshops (to increase understanding of the benefits and process of end of life planning and will writing)

Outcomes: Your Stories...
Mum was 85 years old when she died earlier this year, following a fall which resulted in a broken hip. Her death was very sudden and although she had been staying with me to recuperate from pneumonia it was quite a shock.
Mum was very philosophical about dying and accepted it as an inevitable part of living. Therefore we had a very open approach to her death and final wishes.
Mum has always wanted to be cremated and it was assumed this would be somewhere local. Following a chat about a neighbour’s funeral she informed us that she wanted to be cremated in Manchester where she was born.
When Mum died we as a family wanted to ‘do right by her’, we wanted to make sure she had the funeral she would have wanted as a way of expressing our love for her.
Mum had organised everything. In a bag where she kept important papers, such as her will, were her wishes for her funeral. She had decided what music she wanted with CDs, hymn, poem and final words. Mum had even nominated those of her family to carrying out the readings.
We tend to view people from our own starting point so Mum was always our Mum and we knew very little about her earlier life and aspirations. She had written down her memories which were really useful when my brother gave the eulogy at the funeral.
One of the other things Mum had done was to write individual letters to myself and each of my brothers. These letters were written 9 years before she died and will be treasured forever.
Mum had already opened an account with money to go towards her funeral costs. However, she left instructions for us to check with her work pension and see if they provide money towards her funeral costs.
We all want to do the best for our loved ones and although I miss Mum very much it is such a comfort that we were able to carry out Mum’s wishes right to the end.
She was always fiercely independent and maintained control over her life and I feel strongly that by planning her death she retained that independence.
In fact taking a leaf out of Mum’s book I am getting my paper work more organised. I am also planning putting together a scrap book for my grandson and hopefully further grandchildren as a memoire of their Granny. This will involve taking lots of photographs to look back on rather than relying on my phone.

J. Thornhill, Sandbach, July 2013

Further information:
www.cheshirelivingwelldyingwell.org.uk
www.eolp.org.uk
www.dyingmatters.org.uk

Guidelines:
- Department of Health, End of Life Strategy, 2008, Chapter 2, Death, dying and society
- Neuberger et al, More Care Less Pathway – A review of the Liverpool Care Pathway, 2013