End of life care is an important part of palliative care for people who are nearing the end of life which aims to help people live as well as possible and to die with dignity (Marie Curie, 2016).

People are ‘approaching the end of life’ when they are likely to die within the next 12 months (See the North West Model below). This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events (General Medical Council, 2010).

In addition, end of life issues affect health and wellbeing in many ways including illness, disability, caring responsibility and social problems associated with experiences of death, dying and loss (National Council for Palliative Care, 2015).

### The North West End of Life Care Model

**Stage 1: Advancing Disease**
- 1 year

**Stage 2: Increasing Decline**
- Months

**Stage 3: Last Days of Life**
- Weeks

**Stage 4: First Days after Death**
- Days

**Stage 5: Bereavement**
- 1 year

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**Key messages**

Cheshire East is performing better than the England average in supporting people to die in their usual place of residence, however, this is still less than where people say they would like to be at the end of life and we need to continue to work to improve this.

Locally, we have many different ways to listen to and find out what is important to people who are dying and the people who are around them. However, there are gaps in our understanding around some geographical differences, such as the reasons why the highest proportion of people who died in their usual place of residence lived in Knutsford (55%) while the lowest proportion (40%) lived in Crewe and why there are variations in the percentage of people dying in a hospice.

In Cheshire, we are working closely as a partnership towards a more seamless approach to end of life care that meets the individual needs of our population. We have developed many local initiatives that have gained National recognition and these will continue to be developed and improved.
Around 550,000 people die in the UK each year. The total number of annual deaths is expected to rise by 17% by 2030 to almost 590,000 deaths per year. In Cheshire East, the number of people who died in 2015-2016 is 3,824. This is expected to increase along with the national average. There are inequalities by deprivation, gender and ethnicity across England. For example, men in the least deprived areas in England can expect to live around 9 years longer than men in the most deprived areas, and for women this difference is nearly 6 years.

Where people choose to die is clearly a significant factor of end of life care. A survey by the National Council for Palliative Care (2014) found that 72% of the general public would want to die at home, 10% would want to be in a hospice, 6% in hospital and 2% in a nursing home. However, people’s preferences can vary considerably over their final months, with fewer people wanting to die at home and more people wanting to die in a hospice (Sue Ryder, 2013). Furthermore it was highlighted that hospitals are the preferred place of death for some people and not all hospital admissions at end of life should be viewed as negative (Boase, 2014). The following tables consider where people are dying within Cheshire East and how it reflects against the national average.

**Chart 1** - This chart shows the number and percentage of deaths that occurred in the usual place of residence (i.e., the recorded address for that person). It compares Cheshire East and its’ associated Clinical Commissioning Groups (CCG) to the England average since 2012.

**Chart 2** - This chart shows the percentage of deaths that occurred in the usual place of residence during the most recent quarter, by GP clusters.

**SMASH** - Sandbach, Middlewich, Alsager, Scholar Green and Haslington

Since the start of the data collection in 2012, there has been an increase in people dying in their usual place of residence (i.e., the registered address for that person) both nationally and locally. By 2014, collectively our local areas increased against the England average with a greater proportion of people dying at their registered address in South Cheshire compared to Eastern Cheshire CCG area. The latest figures show that although the figures fluctuate, we continue to achieve a higher rate than the England average although this is still lower than the 67% in the national study who would prefer to die at home. There is also a wide variation between GP clusters demonstrating a disparity in where people die locally; the highest proportion of people who died in their usual place of residence lived in Knutsford (55%) while the lowest proportion lived in Crewe (40%). There are also smaller proportions of people living in Nantwich and rural, Crewe and SMASH who died in hospices (less than 5%) compared to the people living in other areas (between 7% - 10%).
The following information considers how well are identifying people at the end of life prior to death. Identifying as many people as possible in order to provide the most appropriate support and encourage early conversations about choice at end of life is essential. A significant way of doing this is by the use of practice based end of life registers. We can use these to compare whether people dying in their usual place of residence are on the register, enabling us to see how well we are identifying people at the end of life. It is expected that 0.8% of a practice population will be recorded on an end of life register (0.8% is an estimated figure based on the general acknowledgement that approximately ¾ of deaths are likely to be anticipated, i.e. excluding trauma, sudden deaths, etc.).

**Chart 4** - By taking the 0.8% figure of a practice population that would be expected to be on an end of life register, this chart shows the actual numbers on a register (observed) as a proportion of the number expected (See chart 5). The solid lines show the averages of the clusters within each area (either by CCG or Council area).

**Chart 5** - This chart provides a breakdown of how the data in chart 4 has been calculated. Column 2 shows the actual numbers of the list sizes of the practices in the clusters/CCG areas. Column 3 shows the numbers of people who are on the end of life registers. Column 4 shows this figure as a percentage. Column 5 calculates the expected numbers based on 0.8% and column 6 shows what percentage each cluster/area has achieved.

The key to caring well for people who will die in the (relatively) near future is to understand how they may die, and then plan appropriately. It is estimated that 0.8% of a practice population will be in their final year of life and it would be appropriate for that person to be on an end of life register. Across the breadth of Cheshire East, nearly half of the number of people who would be expected to be on an end of life register are currently recorded, with people in South Cheshire more likely to be on a register than in Eastern Cheshire. Breaking this down into GP clusters, there is a wide variation between the different areas. This data provides an overview of the end of life register size, but does not provide enough information to determine how it is being used, (i.e., is it used for people with specific diagnoses or illnesses) and therefore further work is required to understand the wider implications. It is also noted that when comparing the data on page 2 (where people die) to the data on this page, that SC CCG have more people recorded on end of life registers, but there is a smaller proportion dying at home compared to EC CCG.
What are people's needs and preferences?

A local Needs Based Assessment was carried out in 2015 to understand the local experience of death and dying. Identifying 12 areas that presented challenges at the end of life:

- 'Emotional support' - 'Coordination'
- 'Practical support' - 'Navigating the system'
- 'Communicating' - 'Access to equipment and medication'
- 'After death' - 'Managing expectations'
- 'Advocacy' - 'Care in institutions'
- 'Recognition of dying' - 'Skills and knowledge'

A number of Significant Event Analyses (SEA) have taken place. SEA is a way of formally analysing incidents that may have implications for patient care. Learning from what went wrong or right helps to improve practice. Recent SEAs have involved aspects such as communication and the coordination of care.

The national VOICES survey identifies that 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good. 1 out of 10 (10%) rated care as poor. 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital.

All feedback from questionnaires in our local Bereavement booklet is listened to. Although the number of forms returned are small (average 6 per year), the majority of feedback (90%) is positive. However, the key areas for dissatisfaction relate to lack of privacy and poor communication:

“At final stage a separate private room would have helped” [re being given information] “If I asked - the information was not volunteered”

Cheshire Living Well, Dying Well held a Community Partnership "Let’s Do It!” Event in January 2016 with 90 attendees. Aspirations from the event included:

“To recognise how we can help/support those close to us and our communities”

“To feel confident and be supported to make a difference in our communities”

For ALL members of our communities to be supported, to ensure support is inclusive and accessible
To support people to talk about and make plans for getting older and dying
Information that is easy to find and easy to understand

Over the last 9 years, there have been a considerable number of national reports and documents beginning with the DoH ‘End of Life Care Strategy’ in 2008 culminating with the ‘Ambitions for Palliative and End of Life Care’ in 2015 (see page 6). The government response (2016) identified 6 commitments which are:

Having honest conversations……Being able to make informed choices……Having a personalised care plan……Sharing the personalised care plan with professionals……Involving family, carers and important others……Delivering seamless care with help and advice available

Both local hospitals have taken part in the national Acute Hospitals Audit- Care of the Dying Evaluation (CODE). The national findings were:

76% of those completing the questionnaire reported being very or fairly involved in decisions about care and treatment of their family member; 24% did not feel they were involved in decisions at all.

63% reported that the overall level of emotional support given to them by the healthcare team was good or excellent. 37% thought it only fair or poor.

Overall, 76% felt adequately supported during the patient’s last 2 days of life; 24% did not.

Based on their experience, 68% were either likely or extremely likely to recommend their trust to family and friends. 8% were extremely unlikely to do so.
The End of Life Partnership is a collaborative to lead, educate, and facilitate excellence and best practice in palliative and end of life care; and to influence and enable our communities to live and die well, supported by the health, social and voluntary workforce. It supports stakeholders to deliver their outcome frameworks and local priorities, supported and informed by strong community, patient, public, clinical influence and engagement.

Care Homes. Most people living in care homes will die there, so are a significant place of care for people at the end of life.

East Cheshire Hospice (1) and St Luke’s Cheshire Hospice (2) both offer a range of services to those with a life limiting illness. They provide medical, psychological and spiritual support to promote the best possible quality of life.

Mid Cheshire Hospital Trust (3) and Macclesfield District General Hospital (4) provide end of life care. This can be provided by the hospital ward staff who may be supported by a specialist team as needed.

Befriending Schemes are services in the community where volunteers visit a person once or twice a week.

Palliative Care/Macmillan Teams are based in either the hospital and/or community and provide information, advice and support.

Hospital at Home/Integrated Community Teams (District Nursing, Allied Health Professionals and Social care staff) may all be involved in end of life care depending on a person’s needs.

Third sector agencies (Carers Trust4All, Marie Curie) provide a range of different end of life care services.

Strategic Clinical Networks do not provide direct care but bring together those who use, provide and commission services for development and improvement.

Community Partners & Public: Health and social care organisations, housing organisations, local businesses, Cheshire Police, Cheshire Fire and Rescue Service, church and faith groups, community and voluntary organisations/groups, CLWDW Community Ambassadors and bereavement services.

End of Life Care for Adults (page 5 of 8)
The Ambitions framework was developed by a partnership of national organisations across the statutory and voluntary sectors. It sets out a vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England. On the next page, we show some of the things that we are doing to achieve these.

<table>
<thead>
<tr>
<th>Ambition Number</th>
<th>Description</th>
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| 1               | 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. |
| 2               | Each person gets fair access to care  
I live in a society where I get good care regardless of who I am, where I live or the circumstances of my life. |
| 3               | 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. |
| 4               | 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. |
| 5               | 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 |
| 6               | Each community is prepared to help  
I live in a community where everybody recognises that we will all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to support each other in emotional and practical ways |
A local Advance Care Planning Campaign
This campaign is about enabling and supporting Partner organisations to establish and embed clear processes that help to empower individuals (with the support of those important to them) to make informed choices about the care and treatment that they would like to receive at the end of life.

Supporting End of Life Care in Care Homes
Workplace based training, coaching and education alongside those working in care homes to support them in their delivery of end of life care. Additional benefits of this approach include signposting to resources and support, and facilitating a problem solving approach when any issues and barriers arise.

Advanced Dementia Support Team
This specialist team supports professionals and informal carers with the challenges presented when caring for someone with advanced dementia. This includes supporting decision making for those that have lost capacity to make decisions for themselves as well as advising around the non-pharmacological management of challenging behaviours.

Development of a care co-ordination model for palliative and end of life care for South Cheshire and Vale Royal CCGs
Work with patients and staff is underway to develop a model that joins up and co-ordinates care and services so that patients and families receive what they need in a prompt way. There is a plan to submit a bid to Macmillan Cancer Support to fund a project worker to lead the development and implementation of the model.

Transforming End of Life Care in Acute Hospitals
This is a national programme involving over 70 hospitals across England. It focuses on the sharing of best practice in 5 key areas:
• Recognising people who are dying
• Supporting them to make informed choices
• Recording and sharing key information electronically with those involved in their care including out of hours & ambulance services
• Care during the final days and hours of life
• Supporting people to be discharged home to die if this is their preference

Electronic Palliative Care Co-ordination Systems
Facilitating the sharing of information electronically (e.g. via EMIS Web, Cheshire Care Record) across services to ensure timely communication of a person’s condition, treatment plan, and of their preferences. This ensures that the care of those approaching the end of life is well coordinated.

Education including communication skills development
There is a wide range of education/training opportunities for the health and social care workforce to equip them with the knowledge, skills, and confidence to care for those who are nearing the end of life. 3,587 delegates participated in sessions delivered by EoLP in 12 months. The range of topics include Advance Care Planning, Priorities for Care of the Dying Person, Dementia Care, Loss, Grief and Bereavement. Communication Skills Training for staff is a priority and delivered at 3 levels: Introductory, Intermediate and Advanced.

Community Volunteers
Developing and implementing formal community volunteer models to support and care for those with advanced frailty, advanced dementia and/or nearing the end of their life, including those who are important to them.

Carers Support
Education, training and resources including practical support/guidance for informal carers of those with advanced dementia, advanced frailty and/or nearing the end of their lives, including bereavement support.

Five Priorities for Care of the Dying Person
This national guidance developed by a collaboration of leading organisations and members of the public (outlined in One Chance to Get it Right) is being used to inform local education and training and to guide those who care for people in their last days and hours of life of their key responsibilities.

Public Health Approach to Ageing, Dying and Loss
Working with the public and anyone who works with the public (staff or volunteers) to enable action in relation to Five Key Steps which are:
• Support Others, Talk to Loved Ones: Wills and Financial Planning
• Plan Future Care: Funeral Planning
• Work incorporates Asset Based Community Development, Co-ordination of a Community Partnership, Training, Resource Development, Community Ambassadors Programme

Resources, Support and Advice
Developing and signposting to key resources that support informal and formal carers, members of the public, and health and social care professionals on a range of end of life matters. For example: websites, leaflets, films, and specialist advice/guidance.

End of Life Care for Adults (page 7 of 8)
Opportunities for improvement / future developments

- Feedback mechanisms in place to support the people who use services to shape and change them
- Developing and implementing care and service coordination, including improving our understanding about why some geographical areas utilise services differently (e.g., the variation in people dying in hospices)
- Increased and coordinated use of outcome measures demonstrating impact and cost effectiveness
- The better availability and sharing of local data which can then be mapped to national data sources
- Increased links with other teams working in Cheshire, such as those working with older people and frailty and ensure that this provision continues to include but extends beyond those with cancer
- Establish and enhance community development opportunities to support the needs of our local communities

Further information:

- A Community/Needs Based Assessment - [www.cheshire-epaige.nhs.uk](http://www.cheshire-epaige.nhs.uk)
- The End of Life Partnership - [www.eolp.org.uk](http://www.eolp.org.uk)
- Cheshire Living Well Dying Well - [www.eolp.co.uk/CLWDW](http://www.eolp.co.uk/CLWDW)
- Ambitions for End of Life Care - [www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)
- Collaborative Strategic Plan for Palliative and End of Life Care 2016-2019 - [www.eolp.org.uk](http://www.eolp.org.uk)

Deaths in Childhood JSNA – currently in progress

What we don’t know but would like to know...

- An analysis of which diseases cause people to be entered on a palliative care register to identify potential gaps
- General Practice (GP) level data, (rather than cluster), that is able to take account of different practice populations to enable better comparisons and identification of gaps, especially relation to the geographical variations of where people are dying
- A better understanding of why Cheshire East has a higher number of hospital admissions and a longer length of stay for people with conditions other than cancer at the end of life than other CCGs with similar populations
- To understand how effective end of life registers are at leading to people’s preferences regarding their being identified and/or implemented
- A better understanding of how well end of life care services are coordinated?
- A review of where services are based and how this reflects equitably across the geographical areas?
- Do protected characteristic groups have any specific and currently unmet needs?

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<th>Publication date</th>
<th>Changes made</th>
<th>Content sponsor</th>
<th>Sign-off</th>
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<tbody>
<tr>
<td>April 2017</td>
<td>Combined and updated existing “End of life” and “Living well, dying well” JSNA sections.</td>
<td>Lynne Partington (for The End of Life Partnership)</td>
<td>Tracey Wright / Emma Dixon</td>
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</tbody>
</table>