

West Sussex Health and Wellbeing Board



End of Life Care and Pathways in West Sussex – What We Know Now

April 2015

Report by Director Public Health and Social Care Commissioner

Executive Summary

This report has been produced as a result of the work of the Health and Wellbeing Board Working Group on End of Life Care (EOLC) in West Sussex. This is a key issue of importance both nationally and at a County level. This report gives a summary picture of 'what we know now' about EOLC in West Sussex, through the eyes of national strategy, local information and feedback from the many different services providing palliative and EOLC to thousands of families every year. A combination of online research, bespoke demographic data from Public Health and face to face interviews with providers has been used to feed into the report, alongside an in depth case study with a West Sussex resident who has recently had two parents on the palliative/end of life journey.

National Picture:

Nationally, the research draws attention to the many strategies and guidance documents on providing EOLC. This includes the Department of Health's End of Life Strategy (2008), the annual 'What We Know Now' reports from the National End of Life Intelligence Network, the NICE guidelines (2011) and most recently the 'More Care Less Pathway' review of the Liverpool Care Pathway (2013). This highly publicised pathway, coupled with the introduction of End of Life registers has placed EOLC within the media spotlight over the last two years and increased national debate. It has now been removed in place of an obligation for local guidelines to be agreed by relevant health and social care agencies. Annual 'VOICES' surveys (part of the national Bereaved Survey) has focussed a need on how families and carers of those at end of life are being supported.

The evidence gathered here supports the fact that an overwhelming majority of people, given a choice, would want to be treated and die in their own home. In contrast, the most recent VOICES survey found that people's confidence and experience to of dying at home is lessening and the biggest fear is about coordination of services.

The cost implications of EOLC are huge. The research suggests that in the final year of life, a patient will spend an average of 30 days on an acute admission ward and be admitted 3 ½ times. In their last 90 days of life a patient will have an average of 4.6 consultations with their GP.

Local Picture:

In West Sussex, we have an older population than the national average (nearly 21% of our residents are over 65, compared to 16.3% nationally). We know that life expectancy is increasing-with the highest number of deaths now in the over 85's¹. This means in West Sussex we have a bigger issue, both in terms of death but also how EOLC is delivered. This research shows with an older population comes more complex healthcare needs, with many presenting with 'co morbidities'. It's estimated that 30% of people with cancer over the age of 85 will also have dementia. Illnesses such as COPD and organ failure are now better treated, although life limiting, and are presenting our hospitals, community services, hospices and care teams with bigger challenges. We know that in West Sussex only about 40% of our deaths happen in hospitals, below the national average (placed anywhere between 51-56%) but the percentage of deaths in a care home or hospice setting are higher. This highlights the greater reliance than other counties on this type of resource.

4 hospices serve the County, 4 acute hospitals each with a dedicated palliative care team and the 3 Clinical Commissioning Groups (CCG's) are incorporating EOLC in various ways into their work. The three CCG's are Horsham & Mid Sussex, Crawley and Coastal.

Identified local gaps:

The report has identified some gaps in care provision and knowledge, which appear to be reflected nationally.

- There is no shared and universal end of life strategy across the county.
- There is no agreed coordination point/collation of patient's information
- Different areas have different levels of service dependent on the organisations that work within it.
- There are examples of best practice and great work across the county but some agencies are sometimes unaware of others and signposting by any professionals appears to sometimes be dependent on the knowledge and willingness of that professional.
- There is currently no agreement on when End of Life conversations should happen and who should have these or any agreed outcomes as to what good EOLC should look like.
- Feedback demonstrates that 24 hour nursing coverage either through community teams or specialist hospice at home teams is piecemeal
- There are potentially some marginalised groups who are facing more than average inequalities in care and support-such as those who are homeless, with a learning disability or have HIV related complications.
- Adult's services could play a larger role and are asking for more guidance on the issues, but they are not the only ones to do so.
- GP's appear to be asking for guidance on their role and how the pathway links in.

The Health and Wellbeing Board is asked to:

1. Consider the information within the report, especially with more recent publications such as NHS England: Actions for End of Life Care 14-16² and

¹ PHE statistics for mortality rates within West Sussex in 2013

² <http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

National Council for Palliative Care: Every Moment Counts³

2. Keep End of Life Care as an area of importance and update within the Health and Wellbeing Board by reviewing the identified gaps in provision
3. Support the recommendations in the following report (page 21) to tackle the identified local gaps in care, provision and knowledge
4. Support the findings of the report by encouraging all stakeholders to work in a consistent way to achieve system wide integration and coordination across End of Life Care.

Overview

Background

This report has been produced for the Health and Wellbeing Board (HWB) in West Sussex as EOL has been identified as a priority area for the HWB and a key area of importance. EOL care will affect every resident of West Sussex at some point, either directly or indirectly.

EOL care and support is embedded in practice across many disciplines and this is further seen in the introduction of the Better Care Fund (BCF), placing a real focus on the integration of health and social care.

The BCF West Sussex submission states:

Adult Social Care Services supported by the fund will be part of a whole system integrated approach that ensures there is capacity to offer choice and availability of care at home and where necessary, care and nursing home placements, and an integrated approach to end of life care

The Care Act⁴ also places a responsibility on WSCC as a local authority to support all vulnerable residents, focus on the work of carers in the community and reinforces the idea of good quality care and choice for adults in the County. This is underpinned by the 'well-being principle'⁵. The Personalisation Framework⁶ for West Sussex further demonstrates the importance of choice. The choice of where to end your life and be supported to do so could be one of the most important choices to make.

Scope

This paper cannot be exhaustive-and will not provide the great level of detail which would be possible in each area. The intention is to give a 'Where We Are Now in West Sussex', a summary, touching on the major issues in EOL care. Further reading will be signposted at the end of this document-and a more detailed version of the research is available upon request.

The scope and purpose of this report is:

- to give a flavour of the care and pathways within West Sussex compared with national best practice,
- outline the choices available to those affected by EOL,

³ <http://www.nationalvoices.org.uk/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations>

⁴ <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

⁵ <http://www.legislation.gov.uk/ukpga/2014/23/section/1/enacted>

⁶ https://www.connecttosupport.org/Resources/Councils/WestSussex/downloads/operating-model/wscs_personalisation_framework_2014-19_summary.pdf

- show how providers of EOL Care services in West Sussex interact through a case study,
- identify what's working well in West Sussex and what development opportunities there are,
- make recommendations and propose next steps for the Health and Wellbeing Board (HWB) to consider and provide direction on to enable West Sussex to be able to respond to the 10 questions posed by Dying matters.

Summary of report to HWB January 2014

Previously presented to the HWB in January 2014, WSCC has looked at the '10 Questions' posed by Dying Matters⁷ - which is used nationally as a guide to take a temperature reading of how effective an area's EOL care is (these questions are available in full, alongside the answers WSCC gave in January 2014, in Appendix 1). These sparked the beginning of some exciting work and were used to guide the work of the HWB working group on the issue.

The answers to these questions looked at the work of the CCG's in proactive care and the formation of EOLC programme boards. They then gave information as to the work being undertaken by some employers to train their staff in EOLC, advance care planning and the role that carers play within EOLC.

1. When is End of Life?

The definition of when end of life begins varies, however the National Institute of Clinical Excellence (NICE) guidelines draw on the definition of the General Medical Council and define it 'beginning when it is likely a person will die within the coming 12 months⁸:-

This includes people whose death is imminent (expected within a few hours or days) and those with:

- *advanced, progressive, incurable conditions*
- *general frailty and coexisting 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.*

This definition has generally been adopted by CCG's and other organisations, such as Macmillan in their document 'A Rich Picture of End of Life'⁹.

2. The National Picture

Over the last year a lot of work has been undertaken nationally in the area of EOLC. The End of Life Care Intelligence Network¹⁰ is maintained by Public Health England and gives a central point of access in the UK for resources, statistics and signposting to services. This network leads heavy promotional work about the issues in EOL and collates the work and services of the NHS, other healthcare providers, local authorities and the 3rd Sector.

The Liverpool Care Pathway (LCP)

This pathway was introduced for cancer care in the late 1990's and became a 'beacon' of EOL care and support for the next 10 years.

⁷ <http://dyingmatters.org/news/ncpc-launches-guide-improving-local-end-life-care>

⁸ <http://www.nice.org.uk/guidance/cm42>

⁹

http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/PCCL/primarycareupdates/RichPictureforPeopleattheEndofLife.pdf

¹⁰ <http://www.endoflifecare-intelligence.org.uk/home>

Following negative publicity, an independent review of the LCP 'More Care Less Pathway'¹¹ found that whilst based in good theory, there were cases where the LCP was misapplied and a 'one size fits all' process in the EOL field was wrong. The Government took this on board and by July 2014 the LCP was phased out of all health care institutions.

One Chance To Get It Right

Following the removal of the LCP, the Leadership Alliance for the Care of Dying People (LACDP) was established as a coalition of major EOL support providers. Their recommendation 'One Chance to Get It Right'¹² put much more of an emphasis on each authority/CCG developing personalised care plans and pathways for dealing with EOL care, based on the following:

The Five new Priorities for Care are:

1. *The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly.*
2. *Sensitive communication takes place between staff and the person who is dying and those important to them.*
3. *The dying person, and those identified as important to them, are involved in decisions about treatment and care.*
4. *The people important to the dying person are listened to and their needs are respected.*
5. *Care is tailored to the individual and delivered with compassion – with an individual care plan in place*

This obligation permeates across all providers nationally, where they now must devise their own care planning and support process for EOL.

NICE

NICE released their guidelines in 2011 which have since been reviewed in light of the LCP decision. They authored 16 Quality Statements with the intention of encouraging collaborative work. Further information contained within Appendix 2:

Both the NICE guidelines and 'One Chance to Get It Right' should be utilised in creating and reviewing EOLC strategy.

What We Know Now 2013¹³

Published by Public Health England, this document gave an analytical overview of the services across the UK and what we know now in terms of where, when and how people were dying, where people wanted to die and how people felt about current EOL care. A full summary can be found in Appendix 3.

However the essence of the report identified:

- 1) More and more people over the age of 85 were dying and less and less people between 64 and 85 were dying.
- 2) The South East has the highest relative population of over 85's and also has the highest over 65 population.
- 3) 70% of people felt comfortable to talk about dying however most had not expressed these wishes to loved ones
- 4) Only 5% had some form of advance care plan if they could not make the decisions themselves

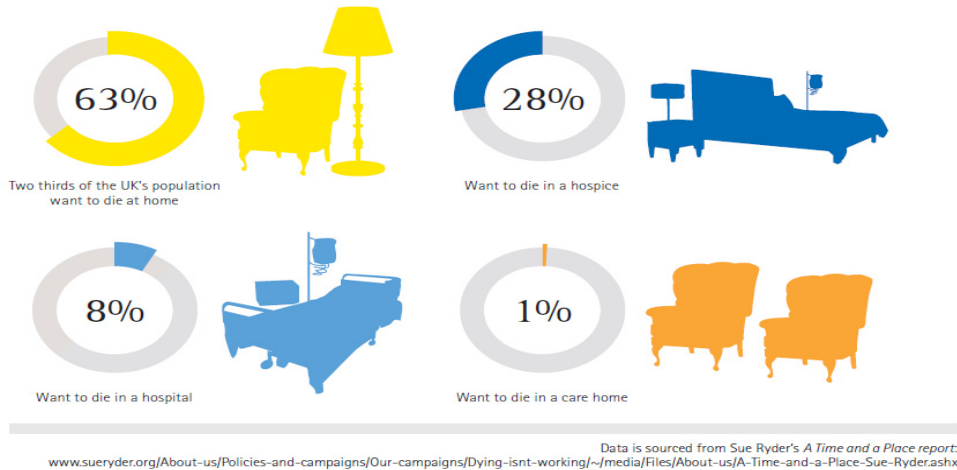
¹¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

¹² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

¹³ http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2013

- 5) In the last year of life, a patient will be admitted an average of 3.5 times to hospital and spend an average of 30 days in a hospital bed

The following shows visually where, during the study, people stated they would want to die;



Voices

The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services) collects information on bereaved people's views on the quality of care provided to a friend or relative in the last three months of life, for England

The key findings as published were:

Key findings

- Overall quality of care has not changed significantly between 2011, 2012 and 2013.
- Quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home.
- For those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012.
- The dignity and respect for patients shown by hospital nurses and hospice nurses has increased between 2011 and 2013.
- Pain is relieved most effectively in the hospice setting (62%) and least effectively at home (18%)
- Only half of people (50%) who express a preference to die at home, actually die at home.

3. The Local Picture

In West Sussex, we do not see huge variations from the national trends above. However, it is worthwhile acknowledging the headline issues across the County that will give a more informed picture of 'what we know now'.

Overall, West Sussex has a higher proportion of older people than the national average. The highest proportion of deaths in the UK occurs in the 65-84 years old category – shortly followed by those in the

85+ category. West Sussex has a 20.78% percentage population over the age of 65¹⁴, which is higher than the national average of 16.3%¹⁵.

The aging population, in addition to the already older demographics of the County will naturally mean more of a strain on resource and the amount of end of life care required. This will have an impact on the number of people living and ultimately dying with a cancer diagnosis and also age related diseases such as Dementia. The number of cancer related deaths is highest in the over 85 age group, closely followed by the age 80-85 group¹⁶. Dementia will be looked at in more depth later on within the report-however it's estimated that one in six people over the age of 80 has Dementia and also that 44% of people with dementia go undiagnosed¹⁷. Dementia (and other non-cancer diseases) presents more complications than cancer in respect of predictability and downward trajectory. Also, they are much more likely to carry co morbidities and complexities and often do not have the 'steady' trajectory that cancer does-meaning crisis support is even more vital.

In 2013, there were 8587 deaths registered within the West Sussex area. It is important to bear in mind that of those deaths registered in a hospital, some may be non-West Sussex residents who were visiting the area or attending the acute hospital closest to where they live, even if outside the CCG area.

Primary Listed Cause of Death in 2013 Across West Sussex (National Average figures taken from End Of Life Central Intelligence Network-EOLCIN Instant Atlas Report)

Cancer	2449 (28.5%)	national average in 2012 (28.51%)
Cardio Vascular	2377 (27.68%)	national average in 2012 (27.03%)
Respiratory	1177 (13.7%)	national average in 2012 (13.91%)
Mental and Behavioural Disorders	685 (7.98%)	
Other	1899 (22.11%)	

Mental and Behavioural Disorders will, for the most, reflect a diagnosis of Alzheimer's or Dementia. However, 'Dying Matters' have estimated that 30% of people with cancer over the age of 85 will also have dementia. Cancer will be recorded as the main cause of death, however this can also be seen as one of the 'co morbidities' as part of the complex pattern.

Location of Death in West Sussex 2013

Hospital	3517 (40.96%)	national average in 2012 (50.71%)
Hospice	696 (8.11%)	national average in 2012 (5.59%)
Usual Place of Residence Care Home	2479 (28.87%)	national average in 2012 (19.59%)
Usual Place of Residence Own Home	1733 (20.18%)	national average in 2012 (21.54%)

These figures give a rough demonstration that we are doing well in terms of hospital deaths-nearly 10% under the national average. From the other information we can maybe assume that this is because of the relatively high number of deaths within a care home and hospice setting. Looking at the JSNA for West Sussex¹⁸, the County does have one of the highest % of population in a care home setting therefore this is the caveat to the higher percentage of deaths in the same setting. The lower than average hospital death rate could also evidence the work happening with hospital avoidance, care home pro activity and the higher involvement of hospices in EOL care within West Sussex.

Of the 8587 deaths, 501, or nearly 6% of all deaths happened in hospital within 48 hours of an emergency admittance. There is little research about how this contrasts to other areas. In a very small study conducted by Brickner Holy in 2012¹⁹, 38 people (out of 109) died within 48 hours of admission to an A & E service NOT in West Sussex. This makes a percentage of 34.87% dying within 48 hours. This data is narrow but would indicate a good percentage ratio experienced by West Sussex. This could be an interesting area to explore further.

¹⁴ Taken from BCF submission for West Sussex September 2014

¹⁵ http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2013

¹⁶ <http://www.cancerresearchuk.org/cancer-info/cancerstats/mortality/age/uk-cancer-mortality-statistics-by-age#cancer>

¹⁷ http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341

¹⁸ <http://jsna.westsussex.gov.uk/jsna-Core-dataset>

¹⁹ http://spcare.bmj.com/content/4/Suppl_1/A109.3.abstract

Overall, West Sussex is served well by 3 acute settings based within the County (St Richards in Chichester, Worthing Hospital and Princess Royal (Hayward's Heath). Furthermore, parts of West Sussex are also served by the Surrey and Sussex Hospital (SASH) based in Redhill and Royal Sussex in Brighton. There are a further 8 community hospitals and various community based healthcare providers- Sussex Community Trust (SCT), Sussex Partnership Foundation Trust (SPFT), Macmillan Midhurst and Marie Curie. There are also 4 major hospices who, between them, cover the whole County on an inpatient, day service and community footing. The following is a 'What We Know Now' overview about these major services, before looking at moving forward, examples of good practice, gaps and recommendations for better and more effective integration.

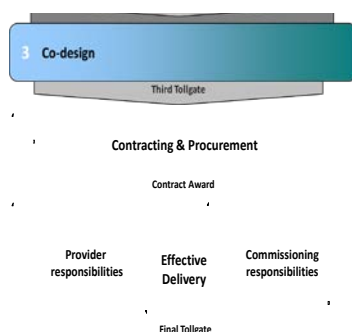
For full research into 'What We Know Now' about the following services, please see appendix 4

4. What We Know Now About Coastal CCG

Overall, 67.7% of deaths in West Sussex in 2013 took place in the Coastal West Sussex CCG area. According to the JSNA core data set²⁰, approximately 61% of the population of West Sussex live within the Coastal West Sussex CCG area.

In the later stages of 2013, the Coastal West Sussex CCG undertook an End of Life scoping project with the aim of identifying specialist EOL pathways within the Coastal region, develop a strategy and plan for improvement and identify key pilot areas.

A steering group has been established with representation from hospitals, community teams, pharmacy, hospices, care homes, GP's and WSCC. Current phases being completed are:



As part of this steering group, there are two sub groups around Education and Pharmacy.

There are currently 4 acute admission avoidance pilots being undertaken in the Coastal CCG area.

Coastal CCG have introduced a 2 page guidance document for EOL care in the health setting and are delivering awareness and training on this.

In Coastal West Sussex SCT currently employ 2 'Care Home Admission Avoidance Matrons'. There is a plan to ensure that 25% of their work will concentrate on EOL care.

5. What We Know Now about Crawley & Horsham/Mid Sussex CCG's

The main programme director for EOL care within the Crawley CCG also oversees work around unscheduled care, community services, dementia, care homes and urgent care. EOL fits well as it touches on all of these areas. This work spreads across both Crawley, Horsham and Mid Sussex and therefore the pilots and work happening will have an impact across both CCG's.

In terms of death trends we know:

²⁰ <http://jsna.westsussex.gov.uk/jsna-Core-dataset>

Crawley

8.4% of all West Sussex Deaths occur in Crawley. Of this number, 37.6% are over the age of 85 and 45.9% are between the ages of 65 and 84. We know through working with the WSCC Contracts team and through provider feedback that the 'care market' in Crawley is quite inconsistent. In the last 2 years two of the major care home facilities have closed with the loss of nearly 200 bed spaces, which has led to those requiring such care to move outside of the Crawley CCG area.

Horsham and Mid Sussex

23.9% of all deaths in West Sussex occur in Horsham and Mid Sussex CCG area. Of these, 48% are over the age of 85 and 39.3% are between the ages of 65 and 84.

Crawley CCG have undertaken a 'Deep Dive' into EOL care and the needs within the area.

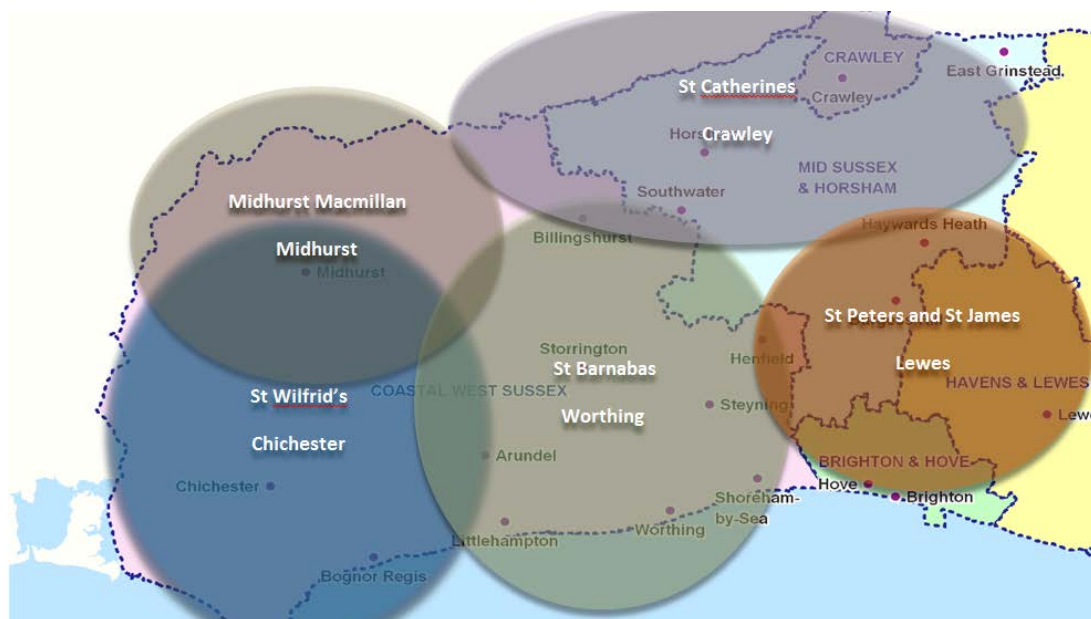
Crawley is also piloting a new EpACC system (Electronic Palliative Care Co-ordination System)-utilising the 'Share My Care' package – currently being used by the emergency out of hour's medical provider IC24 and updated by GP's for community teams.

Crawley CCG have incorporated EOL care into a 'quality premium' - which sets a target of at least 56% of people dying in their preferred place of death, and currently put themselves at achieving 54%.

In terms of pilots, Marie Curie are about to trial a 'supported discharge' service within the Crawley and Mid Sussex CCG area, based at the SASH hospital (Redhill). Available 7 days a week, the trained team can assess patients and be part of a rapid discharge plan, providing some bridging care and support for the patient at home whilst slightly longer term plans are put in place.

6. What We Know Now About Hospices (Adult Hospices)

The County is served by four adult hospices, which between them (with support from Midhurst Macmillan, discussed later) cover the County. The following is a visual for **guidance only** to illustrate locations and catchment areas.



The hospice movement is well documented and historically the hospices have grown organically with a focus on inpatient and cancer palliative care. What we know now is that this is changing and will likely continue to do so. Although there are some slight variations, the number of patients being supported with palliative care and at end of life without a cancer diagnosis is increasing year on year (ranging from 15% to nearly 30% non-cancer). These figures do not include Chestnut Tree House, a hospice for younger patients, which is discussed within marginalised groups.

Inpatient Services

In total, the four hospices in the year 13/14 admitted over 1700 people as inpatients to receive some form of treatment and care. The average stay in a hospice is typically 2 weeks or less, however there has been an increase in patients being discharged from the hospice.

Day Services

The 'day hospice' services that each hospice provides have also evolved to focus on patients much earlier in their diagnosis and again facilitate a better quality of life for a longer period. These offer information and support around a range of issues including:

- Advance Care Planning
- Dietary Advice
- Dementia Friendly Environments
- Specific Workshops for Carers
- Reablement and Counselling Services
- Treatment available including subcutaneous drug administration - lessening the need to attend hospital

Community Services

All of the hospices run some form of community nursing services. They do differ slightly in their scope, but fundamentally they are headed by Clinical Nurse Specialists, and offer a dedicated phone line for other professionals, such as district nurses and GP's to call and seek advice/reassurance about a patient. St Catherine's in Crawley offer this facility 24 hours a day and 7 days a week-as a 'support hub'. This can also be used by carers and patients themselves if required.

Carers and Bereavement

The support of carers is a focus of each hospice, with all offering dedicated support sessions through a day hospice for carers. Counselling is also available.

Education

Each hospice within the County also champion the role of education within the EOL field and integrate this into many settings including care homes, primary and secondary care, and the community itself.

Funding

Again differing between each hospice, the health funding that each hospice receives is no more than 20% of total running costs, leaving the other 80% to be funded through fundraising, trusts and legacy donations.

7. What we Know Now About Hospitals

In the document 'Exploring the Cost of End of Life Care' by Nuffield²¹ in 2014, some comparison work was undertaken to look at the cost implications for Marie Curie Nursing in relation to reduced acute admissions and involvement of other services. As part of this study, the costs of acute admissions were explored and (for those patients with a cancer diagnosis in their last 90 days prior to death) found to be approximately £5890 per individual, and non-cancer diagnosis, £3785.

²¹ <http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/Exploring%20the%20cost%20of%20at%20care%20at%20the%20end%20of%20life.pdf>

Leadbetter et al in the document 'To allow people the deaths they want, end of life care must be radically transformed...dying for change'²² summed up the culture of acute hospitals as a place 'to diagnose, cure and heal people....to prolong their life' – in some ways the opposite focus of EOLC.

The SASH trust are hosting a pilot led by Marie Curie to enable rapid discharge of those clients identified as at End of Life to go home with high levels of support, including pain management regimes and to bring all relevant agencies together in a more integrated way.

The SASH 2014-2017 EOLC strategy is just about to be ratified. The SASH hospitals cover the north part of the County and work closely with St Catherine's Hospice. The strategy looks to improve the EOL pathways within the acute setting, including the integration of health and social care, education and training, availability of specialist palliative staff and psychological interventions.

In Western Sussex Hospitals Trust, there is a similar palliative care nursing team that sits across both St Richards and Worthing hospital. This team will also benefit from the Coastal Pilot, employing another nurse to be more 'proactive' in the A&E and AMU settings, seeking out potential palliative care patients rather than waiting for referral into the team.

In Princess Royal (BSUH Trust) in Hayward's heath, there is an end of life care facilitator who coordinates the information and training and encourages a holistic approach to EOL, including the implementation of the new pathways to replace the LCP. In this year's CQC inspection, EOL services here were rated as 'Good' with EOL noted as being high on the agenda in team meetings and identifying a monthly EOL newsletter and annual conferences by the trust in the area.

8. What we Know Now about Primary Care (GP's)

Introduced as a quality and outcome framework, most GP surgeries will have a 'palliative care register' or 'end of life' register. Here will be recorded the patients of the surgery who, the GP's believe to be in the last 12 months of life. They were introduced to improve coordination and identification of those on the register and to look at any advance care planning, wishes for place of death and so on. These registers have been controversially called 'death lists'²³ in the press however serve as one of the only current tools to track those patients at the end of life stages in their disease.

Currently, GP's are being asked across West Sussex to perform a coordination role, as it's commonly believed they know their patients the best and have access to all the different services.

The GP's also take on the main role of prescribing within West Sussex and information on discharge from acute settings is now sent electronically to GP Surgeries and so this is getting better-however what we know now is that this discharge information is probably (and quite naturally) medically-centred and therefore the GP will not know what conversations have been had with that patient, be unaware if the patient understands they are near end of life, what treatment stage is current and what the next steps are- the more 'socio medical' aspect of the care.

The main feedback from GP's within the area is an anxiety, especially following the Shipman case and negativity around the LCP, in anticipatory prescribing and treatment with EOL, especially when the patient is not known to them. This demonstrates the need for explicitly and medically backed guidance on treatment at end of life and GP involvement.

In 'Exploring the Cost of End of Life Care' by Nuffield, some work was also undertaken looking at the pressure experienced by GP's from End of Life patients in the final 90 days of life. In a study looking at over 70,000 patients, it was averaged that each end of life patient had 4.6 consultations with their GP- although a third had none at all.

9. What We Know Now about Care Homes

The demographics show a much greater proportion of West Sussex residents die in a care home setting than the national average-and that reflects the older demographics of the County. This would then

²² http://www.demos.co.uk/files/Dying_for_change_-_web_-_final_1_.pdf

²³ <http://www.dailymail.co.uk/health/article-2219351/Three-THOUSAND-doctors-putting-patients-death-lists-single-allowed-die.html>

suggest a great pressure on care homes to offer good end of life care. Currently, about 30% of all deaths in both Coastal CCG and Horsham/Mid Sussex CCG occur in a care home if it's the usual place of residence. Crawley is about 15% (there are a much smaller ratio of care homes in Crawley).

There are approximately 383 care homes in West Sussex and many of these are privately owned/independent. In their Article 'Three Approaches to Delivering End of Life Education to care Homes in a region of South East England'²⁴, Booth et al looked at the three main types of training being delivered in Care homes to support them with EOL care:

- Action Learning End of Life Care Training
- 6 Steps Model
- Gold Standards Framework²⁵

This indicates there is no 'one way' to approach end of life care for care homes and this was resonated at the October 2014 Care Home Managers Forum, which covers services across West Sussex. The engagement in the education and training being offered has been piecemeal, with pockets of great engagement.

Anecdotally, some homes have expressed a concern for 'hosting' end of life care for their residents-as the CQC do pick up on death rates as a performance measure, and they are sceptical about the effect it will have to raise their death rates-even though it most probably is a 'positive death'.

10.What we Know Now About Adults Services

Currently, we do not know very much about EOL care and adults services role, as they have not been asked to capture this information. The reason being is that they will often work with people before any EOL or palliative issues are identified.

Based on a Framework1 snapshot in September 2014, adults services alone domiciliary care for those eligible for over 1800 customers in their own homes. The teams also assess and work as part of a multi-agency approach with many other people who have vulnerabilities and ensuing support needs. They can provide a highly skilled assessment and are well placed, already being based within customers' homes, to feed into any pathways or have conversations.

Anecdotally, we know that the adults services team have not had much involvement with EOL and would refer across to the CHC for specialist input. This could be a real opportunity for Adults Services support plans to be developed and work alongside the CCG's vision for EOL and promote integration.

11.What we Know Now about Community Services

Midhurst Macmillan

The Macmillan Cancer charity is one of the largest and best recognised within the cancer and end of life field. It often seed funds a project for a certain time period to demonstrate its validity, and will then either withdraw or part fund its continuation, leaving the CCG to match fund or secure other sources of income. In West Sussex there is the Midhurst Macmillan service, which began as a pilot in 2006 and since then has served as a model for other similar services across the country. It grew from the closure of Edward VII hospital in Midhurst and became a consultant led, community based service with the aims of avoiding hospital admissions, coordinating care and facilitating, when appropriate, people to end their lives in their home. The service itself services a 25 mile radius of Midhurst, which includes parts of Hampshire and Surrey and is lead staffed by SCT Staff.

The Midhurst Macmillan Annual Report gives an indicative figure of 160 new referrals for the service in 2013, in addition to 101 still continuing to be supported for the parts of West Sussex it covers. This support could range from emotional and phone contact to accessing the service within the community

²⁴ *International Journal of Palliative Nursing* 2014, Vol 20, No 1

²⁵ <http://www.goldstandardsframework.org.uk/>

hospital or full on support at home. 25% of referrals in total were non cancer, Of the total number of all cancer/non cancer patients who died, only 15% died in hospital.

Marie Curie

Outside of the pilot Marie Curie are running in conjunction with Crawley & Horsham/Mid Sussex CCG, it also offers a night care and sit service and can provide staff for 'hospice at home' function within the community.

To obtain a Marie Curie nurse support, a request will usually come through the community nursing team or GP practice. An assessment made as to whether a healthcare assistant or nurse is required and for how long. This service is rarely used within West Sussex. Marie Curie is however commissioned, usually via the CHC (below) to provide overnight support on their fast track system.

The projected number of clients support in West Sussex through this service, this year is 170. There is an average cost of £780 per client. Monitoring the actual place of death compared to stated preferred place of death, nearly 100% achieved their preferred place of death. Currently, about 21% of their clients have a non-cancer diagnosis.

Continuing Health Care (CHC)

In addition to facilitating longer term care for patients with a medical need the CHC team across West Sussex will also commission appropriate support to those at the end of life. Delivered through their 'fast track' system a referral will come into the service from a nurse or other clinician and an assessment made within 24 hours. The criteria for fast track is:

Has a primary health need' arising from 'a rapidly deteriorating condition, which may be entering a terminal phase, and with an increasing level of dependency'.

So although being at the end of life is not 'essential', it is a big feature of the Fast Track service. Based on figures so far, it's estimated that the number of fast track patients being supported with palliative care by CHC will be about 652 in 2014/2015. Often care is provided on a capacity basis rather than anything else, as these packages, although often short term, are intense and overnight services. As above, CHC do commission Marie Curie to provide some 'night sit' services, with either a healthcare assistant or registered nurse, depending on which is appropriate. In addition, the CHC will purchase packages from local hospice at home services, where appropriate.

The Ambulance Service

The role of the ambulance service made headlines last year when End of Life Registers were introduced and guidelines were mooted to give paramedics the flexibility, if someone was at end of life and wanted to remain at home and were registered, not to take someone into hospital²⁶. It has been recognised, within the Coastal CCG EOL strategy that the ambulance service is vital to ensuring good quality EOL care, with paramedics trained to recognise when there may be alternative solutions to a hospital admission for those at EOL. These may include access to specialist hospice at home teams, community nursing and advance care planning.

The Health and Wellbeing Hubs

Another suggestion from one of the CCG's is how the Health and Wellbeing Hubs can be used better. They could provide a wealth of information to keep both patients and carers as healthy as possible-including signposting to local community services for small house maintenance tasks, benefits advice and so on. What happens if the person near the end of life was the main cook in the house-the carer could access support and help to learn how to cook. Adult services can link closely into any of this work- although at a low levels, these could provide the foundations for a better quality of life, and death.

²⁶ <http://www.dailymail.co.uk/news/article-2380205/Ambulance-drivers-told-NOT-death-list-patients-hospital-Patients-tell-GPs-want-die-home-denied-vital-emergency-treatment.html>

12.What We Know Now About Dementia at End of Life

According to Alzheimer’s UK, approximately 850,000 will be living with dementia in the UK next year²⁷. By 2025, this figure is expected to rise to over 1 million. West Sussex currently has 13,000 people diagnosed with dementia which means that of all diseases that can lead to end of life, this is one of the most prevalent in the county- with the aforementioned 26% predicted increase in West Sussex by 2020, proceeding the predicted 14% increase by 2017.

Dementia is also relatively unique in that it can, in its latter stages, mean that the patient will lose capacity to make decisions about treatment and about care making it vital to look at advanced care planning and also how someone living with dementia is treated with dignity.

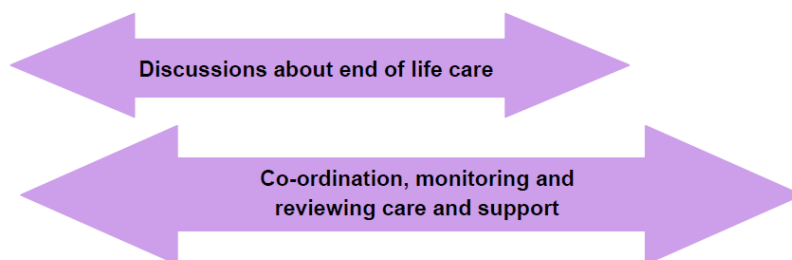
In 2013, Eleanor Langridge was commissioned by Sussex NHS to lead a project on EOLC and Dementia. The project aim was:

- To improve end of life care for people with Dementia across Sussex, so that more people with dementia die in their preferred place of death, with dignity, without undue pain and with their advance wishes respected.

The introduction of a clear pathway for dementia and end of life has been written and embedded into the procedures for the acute settings and also primary care. This pathway identified 6 ‘stages’ to good dementia care and support at end of life. These stages look like:

The Pan Sussex Integrated End of Life and Dementia Care Pathway

Phase 1	Phase 2	Phase 3	Phase 4	Phase 5	Phase 6
Recognising there is a problem	Discovering that the condition is Dementia	Living Well with Dementia	Getting the right help at the right time	Nearing the end of life including care in the last days of life	Care after death



13.What we Know Now About Some ‘Marginalised’ Groups:

Although it could be argued that every person at the end of life is facing some form of marginalisation, this document suggests there are some specific patient groups whom further research could benefit a greater understanding of their specific issues and the impact these have on accessing appropriate care.

HIV:

Now considered a chronic disease, the Medical Foundation for HIV and Sexual Health (Medfash) undertook a report and published standard recommendations for working with patients with an HIV/AIDS diagnosis and with a focus on palliative care²⁸. They recommend that palliative care can be

²⁷ http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341

²⁸ <http://www.medfash.org.uk/uploads/files/p17abl6hvc4p71ovpkr81ugsh60v.pdf>

delivered by general palliative care providers in the same ways as with any other condition. However focus needs to be paid to:

- A higher than normal percentage of people living with HIV/AIDS may be from marginalized parts of the community, such as gay men, drug users and sex workers – increasing the need for sensitivity.
- That it affects a younger demographic population than other chronic/terminal diseases
- That certain co morbidities exist with an HIV diagnosis-which may range from HIV related dementias to HIV related cancers, plus a higher rate of hepatitis B and C.
- That an AIDS diagnosis may not be recorded as primary cause of death, as this may be listed as the infection or 'top' condition that actually caused the death instead of Pneumonia

The Sussex Beacon, based in Brighton, is the only dedicated HIV inpatient and day service environment in the South East (outside of London). It provides palliative/EOL care in addition to pro active services to keep people healthy and avoid acute admission. Patients with HIV related palliative care and EOL needs can access general services, such as hospices, however rarely seem to.

Learning Disability

The term learning disability covers wide range of issues and needs, far more than can be detailed here. However, what we do know is that although life expectancy for those with a learning disability is much lower than for those without²⁹ (about 58 years old for adults with a severe LD), life expectancy is increasing and with this comes greater co morbidities and complications. In their article 'health inequalities and learning disability in the UK 2010', Emerson et al found that respiratory disease was the leading cause of death in those with a learning disability (52%), that 22% of all people with an LD will have a dementia diagnoses, compared to 6% of the total population and that people with Downs Syndrome are much more likely to develop dementia 30-40 years before the national average age of development.

Children

'Together for Short Lives' is a national charity with a focus on children with life limiting and terminal conditions. They support children's hospices, medical professionals and write tools and guidance for those working in and around end of life and palliative care for children.

In their strategy 2012-2015³⁰, their four main aims with children and families are:

- The right information from the moment of diagnosis so they can make choices about the care they receive.
- Easy access to services so that they can spend more time together.
- The best quality of care.
- Reliable support now and throughout their journey.

As part of this, they estimate that around 49,000 children are living with life limiting conditions and issue guidance, such as 'A Guide to End of Life Care'³¹ for other professionals to use. Their policy priorities reflect and mirror those above for adults at end of life care, which includes integration, choice and holistic support for carers too.

Based on public health figures, 32 deaths a year are those aged 15 and under and an overwhelming majority of these are in hospital (25 in total).

²⁹ McGuigan SM, Hollins S, Attard M. Age specific standardised mortality rates in people with learning disability. *Journal of Intellectual Disability Research* 1995;39:527-31.

³⁰ http://www.togetherforshortlives.org.uk/assets/0000/1396/TfSL_Strategic_Plan_2012-2015__FINAL_.pdf

³¹ http://www.togetherforshortlives.org.uk/assets/0000/1855/TfSL_A_Guide_to_End_of_Life_Care_5_FINAL_VERSION.pdf

The main facility in Sussex and for part of Hampshire is the Chestnut Tree House hospice, which specialises in hospice care for those aged 17 and under at first referral. They support over 300 young people a year with referrals from East and West Sussex, Portsmouth and Brighton & Hove³².

Mental Health

In their review 'Mental Health and palliative Care-Literature Review'³³, the Mental Health Foundation found very little research in this area, although acknowledged that mental health issues are increasing and people are living longer, leading to the assumption that people with mental health issues prior to being diagnosed with a physical disease are 'underrepresented' in any discussions on palliative care. Their paper finds that those with enduring mental health issues will have a higher mortality rate based on:

- Lifestyle - more destructive behaviours and less interest in health promotion
- Worse diet
- Lack of engagement with medical services and failure to attend routine medical appointments
- Physical symptoms of actual disease being attributed by medical profession as a symptom of mental health diagnoses

Homelessness

Homelessness is a growing issue across the UK-and particularly in the South East³⁴, which had the highest number of rough sleepers in the 2013 Rough Sleeper Count.

The National End of Life Care Programme Board published the document 'end of life care – achieving quality in hostels and for homeless people'³⁵ to recognise the issues that are faced by this patient group. The average age of death of those monitored to be rough sleeping was between 40-44 years of age, and the instances of those rough sleepers with chronic conditions, learning disabilities, mental ill health, substance misuse issues, muscular skeletal issues were many times that of the average population.

14. A Case Study (full version in Appendix 4)

L is a West Sussex Resident. 4-5 years ago both of her parents fell ill with multiple and complex diagnosis. Her mother with COPD, congestive heart failure, circulatory issues and her father with COPD, diabetes, Parkinson, dementia and depression. In September 2014 her mother died in a hospice and her father, who is still alive, resides in a residential care home.

L's Mother:

L's mother was told by her consultant that her diseases were incurable when they were diagnosed in 2009, however due to the nature of the diagnosis she was told her life expectancy could not be predicted. No advance care planning was ever discussed. In what would be the last 12 months of her life, she was admitted to an acute setting 7 times. During this time, a new community matron took over her care and coordinated all services, including GP, Pharmacy and community nursing. 3 months before her death following another admission, the ward sister had an end of life conversation with L and her mother, and a referral was made to the Palliative Care Team within the hospital. This team supported L's mother to be discharged home and have some adjustments made to her property to facilitate this. 2 weeks prior to her death, she was admitted again to the acute hospital, and told she would probably die over the coming 2/3 days. She stabilised and the palliative care team arranged for her to go into the local hospice. She had to wait for 4 days and was then transferred to the hospice. She remained and stabilised in the hospice and was due to be discharged, following an application for CHC fast track funding to allow her to die at home. However she died before being discharged.

L's Father:

Following his diagnosis in 2009, L's father underwent a single leg amputation and as he needed to be discharged from the acute service, went into a care home. No end of life conversations have been had any point with L's father.

L's mother could not support him whilst he recovered due to her own conditions. He was a self-funder and L can remember no involvement from Adults Services at this point. The home was chosen due to proximity to the family home. Over time, L's father's condition became more complex and the placement in the care home broke down. Both the home and L tried to get support from various sources but couldn't. L's father tried to commit suicide and was admitted to the local inpatient psychiatric unit. L was given very short notice when he was ready for discharge but found another local care home for him to self-fund and be discharged to. During his time in this care home, adult services became part funders and therefore he had to change rooms to one approved. This aggravated his mental state and the placement once again broke down. The home also were having difficulties managing his diabetes and had great issues accessing nurse support to help with this. Adults Services were involved and offered other care home places which were at least a 15 mile drive from the family home which were deemed unsuitable and unmanageable by the family. L's father was once again admitted to the acute unit and discharged to another home in the area (which was not suitable but the only home that would take L's father -who is friends with the owner). A CHC bid was made to secure nursing in the home, which was refused and the placement broke down, with him being once again admitted to the acute. Once again discharged to a new home, L's father is currently awaiting the outcome for another CHC bid for nursing care within the care home, which was submitted 4 months ago. The home is currently threatening him with eviction for this reason, and as the Adults Services part of the funding has not yet been paid. He has been physically and mentally deteriorating for the last few months and would appear to be towards the end of life.

Asking L to reflect **her own thoughts** on the EOL and Palliative Journeys for both parents, L stated:

- Her mother's journey was positive, with her choice to always try and go home respected and facilitated where possible. Her mother benefitted from some very dedicated services and staff across all fields.
- L felt the key to her mother's care was the community matron who coordinated all agencies and ensured information was shared. The matron remained with her mother even after she moved patches-which L feels could have been because she knew her mother well-but it definitely felt like a good service because of the individual professional not because there was a consistent system.
- Both her parents have different GP surgeries and there is a marked difference in their approach.
- Other than when the hospice became involved, no one has supported or even asked how L was doing, as the main carer for both parents.
- L believes some respite stay within the hospice earlier would have prevented some acute admissions for her mother and also helped her pain management.
- L believes the worry around her father's situations shortened her mother's life
- L has taken time off work with stress related to the situation around her father's care and support
- No one had any form of EOL conversation until the ward sister following 4 acute admissions

15. What We Know Now Moving Forward:

Where Do We Want and Need to Be?

This report of 'What We Know Now' just touches on the main areas of health and social care that are involved in delivering what is nationally agreed as good palliative and End of Life care. Each agency and each patient group could yield many months work of detailed research and recommendations. What is apparent is the sheer volume of national reports and strategies that have been delivered in recent years on EOL care. Its importance goes across each client group and each disease and medical model as end of life is just as certain as start of life. There is only 'one chance to get it right' for an individual and ensuring a 'good death', whatever that may be for someone.

What is being said both nationally and locally supports the needs for services to be joined up and integrated in their approach. The 10 questions from 'Dying Matters' have at the heart of them the themes of how thought and strategy translate into tangible care and support for those receiving EOL and palliative care and those who care for them and love them. This sets out the role for an integrated approach and our role in enabling this.

EOL care requires medical and social intervention at many levels – ranging from GP's, community nursing services, specialist services to acute settings and urgent interventions to prevent admissions or expedite discharge. In terms of social support – counselling, wellbeing and Adult service intervention to wrap around services and individuals to deliver a cohesive approach. This echoes the wider work happening across services with the introduction of the Care Act and the Better Care fund and the need to commission services in a joint way.

From this superficial research it can be demonstrated that longer term cost savings can be achieved whilst improving care through integration and coordination. Many patients want to die at home if possible and providing robust services to enable this to happen costs less than utilising the often inappropriate acute settings where patients end up when community services break down – either because of a lack of coordination or lack of service in the first place. In a recent article the BBC looked at this issue³⁶. Entitled 'Dying at home patients lack 24 hour expert support' it confirmed 'What We Know Now' in that of 180 CCG's which responded to them, only 8% have some form of palliative care coordination centre or 24 hour help for those who are dying. It also cites a case study in which, in the last 3 days of a patient's life, over 40 different professionals came into the home however none really knew that the others were there or had any information about the patient's background and diagnosis.

West Sussex

We can see that West Sussex has some unique characteristics, not least an older population that will bring challenges for the health and social care system around EOL over the coming years. Not as many of our population are dying in hospitals as the national average, but we have more dying in care homes and hospices.

Overall, West Sussex could be seen to be ahead in some areas of EOL care and there are some good outcomes visible. The four main acute locations covering West Sussex each have some form of strategy around EOL and the four hospices that are present each support thousands of patients and families every year.

There are pilots taking place within the CCG's to prevent admission and readmission and community services with both Marie Curie and Macmillan supporting people in their own accommodation wherever possible. Care Homes are working on training and awareness and there are clear identified pathways in each service.

³⁶ <http://www.bbc.co.uk/news/health-29612283>

16. How Do We Get There?

There are gaps and inconsistencies across services that need to be addressed to 'get there'. These include

- Not one central coordination hub to detail and give equality of access to services.
- Not one shared vision or strategy for EOL care across the County.
- It's unclear what the follow up and longer term benefits have been from the Dementia work undertaken by Eleanor Langridge.
- Each acute service has different methods of working with EOL.
- Community Services concentrate pockets of work across the County.
- Some GP's are anxious about their role in relation to EOLC.
- Community Nursing services around EOLC are piecemeal.
- The market to attract staff to a hospice at home team or a care provider offering overnight EOL support is fragile.
- There could be unidentified marginalised groups who face an inequality of access to EOL provision.
- There is no one agency currently leading on identification and coordination of EOL care across all services, which includes identifying who has the EOL conversations with patients.
- Adults Services have traditionally sat outside of EOL care but could play an instrumental part in the services people receive at end of life.
- Lack of clarity in outcomes and definitions. A death at home is not automatically a good death or a positive statistic, even if that patient wanted to die at home. The person needs to have died at home, as pain free and dignified as possible with 24 help and support available to be classed as a 'good death'.

Recommendations:

EOL care is a real example of how integrated health and social care can come together to provide solid pathways to provide better outcomes for customers and also utilise resources in a more effective way. To achieve this we would propose the following

- Sharing the best practice of the hospices in providing in patient, home and community care to patients and carers.
- Further research into deaths within 48 hours of admissions into acute services.
- Continued work across health and social care to develop 24 hour services to provide care and support at home for those at EOL.
- Follow up E Langridge work around Dementia and EOL Care Pathway.
- Collate and draw out similarities in EOL strategies for each CCG, including definition of 'what a good death looks like'.
- Deliver EOL training and awareness to Adults Services.
- Further Research into marginalised groups.
- Further study of pilot 'coordination hubs' (Bexley and Greenwich).
- Adoption of any new national metrics/guidelines for measurement of quality and effectiveness of services.
- A shift towards identifying at least 50% of patients/customers who are estimated to be in the last year of life.

Integration:

If integration was to be looked at, a consistent approach and agreement would be needed around:

- **Identification** – when and how are people approaching EOL identified and who has that conversation with them?
- **Coordination** – How will patients know who, when and where their choices are and at 3 am in the morning, who can they contact for advice and support? Which agency will have their details, where can specialist drugs be found at that time and who will support the carer?
- **Innovation** - how can cost savings be made whilst improving care and support?

Agenda Item No. 6

- **Evaluation** - from 'What We Know Now' to where the services need to be, how will this be measured? What is a 'good death?'

Appendices:

Appendix 1 – WSCC 10 Questions Response – January 2014

Appendix 2 – NICE Guidelines

Appendix 3 – What We Know Now Summary 2013

Appendix 4 – Full Case Study

[Appendix 5 - Presentation](#)

Appendix 1: WSCC 10 Questions Response – January 2014

End of Life – 10 Questions Audit

Q1) Where are local people dying and where are they being cared for before they die?

The National End of Life Care Intelligence Network ³⁷ shows the comparison of place of death between West Sussex and the national average in 2012 as below:

	% deaths by setting	Number	West Sussex %	National average %
Place of death	hospital	4133	47.6	54.5
	own home	1580	18.2	20.3
	hospice	644	7.4	5.2
	care home	2150	24.8	17.8

Horsham and Mid Sussex are commissioning the Electronic Palliative Care Co-Coordination System (EPaCCS) which will enable the record of a patient's preferred place of care and ultimately their preferred place of death. This will enable cross referencing with where people actually dies in order to monitor how wishes are being achieved and to consider remedial action to ensure that where possible, preferences are adhered to.

Q2) What are people saying about the quality of care they and their loved ones have received locally?

A national questionnaire called 'Voices' has been developed to enable feedback from bereaved relatives. The first information from VOICES was published in 2012 and although not broken down to a County or CCG level, this information shows that the PCTs operating at the time within Sussex were recorded as delivering quality of care in the middle 60% or top 20% of PCTs across the country.

There are examples in West Sussex of local services asking customers and relatives about their experiences in order to inform service provision and feedback on the quality of care. For example, the Midhurst Macmillan services with the assistance of the University of Sheffield and Hull have undertaken research including seeking the views of relatives and carers, and Western Sussex Hospitals Trust undertake a survey, adapted from VOICES, to ask bereaved relatives the experience of their services.

The outcomes of these individual pieces of work have yet to be collated in order to explore the wider experiences and when originally considering progress against this question in March 2013, it was identified that further feedback work to gain feedback on customer and relative experiences would be beneficial. This has been an area of discussion for stakeholders

³⁷ http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_2012_pdfs

through a small group focusing on quality of provision, and potential to consider further research around experiences is being explored.

Q3) What local systems are in place to ensure that people who might be approaching the end of their lives have been identified and plans about their care can be coordinated?

Crawley and Horsham and Mid Sussex CCGs are progressing with the implementation of an Electronic Palliative Care Co-ordination System under the name 'My Wishes My Care,' working in collaboration with a local hospice and in conjunction with East Surrey CCG.

In addition, the development of ProActive Care across West Sussex will use risk stratification to identify people at risk of health deterioration who can be supported through a multi-disciplinary approach.

The Sussex End of Life Care in Dementia Project started in April 2012 supported by Regional Innovation Funding with the aim of improving End of Life care for people with dementia in Sussex. This project is now drawing to a close, although the achievements that have been put in place should support the development of End of Life Care going forward. This project included the development of the Sussex Integrated Dementia Care and End of Life Pathway for Practitioners, which outlines the key phases, and actions for practitioners at each phase. This pathway has now been adopted as best practice guidance. In addition guidance has been developed for the public to provide information and guidance for people with dementia, and their relatives/carers.

This project has also achieved the distribution of 10,000 'This Is Me' bags across Sussex. These bags have been designed to support and improve communication and the access to important information when people with dementia are transferred from one care setting to another, and enables an opportunity to understand an individual's needs and wishes for future care.

Work is being undertaken across West Sussex to encourage and support Advance Care Planning for individuals to plan their future care, to enable consideration of people wishes and preferences in relation to their care. The CCGs in West Sussex, along with, Sussex Community NHS Trust, Sussex Partnership NHS Foundation Trust, Western Sussex Hospitals Trust and local hospices and services have endorsed an Advance Care Plan 'Planning Future Care' to identify wishes and preferences for future care.

This is being implemented across West Sussex, in the community, care homes, and virtual wards.

Alongside the Advance Care Plans, In the North of West Sussex 'This is About Me' document and in Coastal West Sussex 'Knowing Me' document, enable more information about individuals to be taken with them to hospital or to be available for people providing care.

This document is in addition to the existing DNACPR (Do not attempt Cardio-Pulmonary Resuscitation) documentation which primary care discuss and complete with patients at end of life.

Q4) What services are available locally “at any time of day and night” to enable people to be cared for in the place they want to be?

In Crawley, Horsham and Mid Sussex, the CCGs have focussed considerable resource in to ensuring that where appropriate, care is delivered wither within the home or as close to the home as possible, to ensure that the individuals independence can be maintained and sustained for as long as possible. For example, the introduction of One Team – the 72 hour rapid response nursing team was established to facilitate early discharge from hospital.

Sussex Community NHS Trust provide an overnight service across West Sussex. Although not exclusively for End of Life care, this can provide support for symptom control overnight, and has access to specialist nurses and services for extra support. This is delivered in addition to a sitting service. In addition, domiciliary care services in the community support people as a part of meeting their care needs, which will extend into care and support at end of life.

A Hospice at Home service is available in Midhurst, and also provided by St Barnabas and St Wilfred Hospices, and in addition hospice services and care and nursing home services provide support and care 24hours a day for people residing or using these services.

One Call is a single point of access for urgent medical problems which is available 24 hours a days, 7 days a week.

Historically, services have been commissioned on a Monday-Friday 9-5 approach and it is recognised that this traditional model sometimes needs to be extended to ensure that alternative care is available, preventing unnecessary admissions into hospital.

Q5) What support is available locally for carers of people approaching the end of life, including into bereavement?

Carers input into Advance Care Planning is welcomed, and as mentioned previously a range of initiatives are in place to encourage awareness and enable difficult conversations to be commenced around end of life.

Carers support services are available for all carers, and Cruse Bereavement Care, is available across West Sussex, and aims to promote the wellbeing of bereaved adults and children and to provide support, advice and information when someone dies.

The Midhurst Macmillan home service provides a support group for bereaved carers, a respite sitting service, and volunteers provide support with hospital visits and other support as required.

Recently a project has been developed in the west of the County as part of a national programme looking at spiritual care which uses volunteers to provide support to patients and their relatives at end of life. This was developed as part of a two-year programme after identifying an unmet need in this area. In addition there is a chaplaincy support team for relatives.

Q6) What is being done to ensure that local services are genuinely available and accessible to everybody in the local community?

Referrals to hospices and district nurses for end of life care come largely from GPs but also from consultants, which is supported by links with community matrons.

As mentioned previously, the development and dissemination of 'This is Me' documentation and training around Advance Care Planning is seeking to raise awareness to improve communication and understanding about End of Life. This will encourage conversations, which can then support the dissemination of further information about services.

In Crawley CCG and Horsham and Mid Sussex CCG, local support services are advertised within GP practices and across community sites and centres such as libraries etc. The CCGs are however aware that there are a significant number of services provided through the voluntary sector and both CCGs are actively engaging with these providers to better understand how to promote and work with them more effectively.

Q7) What training in end of life care are local organisations giving their staff?

Sussex Community NHS Trust is an accredited Gold Standards Framework Regional Centre and the End of Life Care Coordinators across the County have been proactively working with care homes and primary care to deliver the Gold Standards Framework.

In Crawley, Horsham and Mid Sussex, national monies received in 2011/12 were also used to provide a range of training to a variety of organisations (hospices, community provider, acute trusts) and aimed to address the following priorities:

- Advance Care Planning
- DNACPR (Do not attempt Cardio Pulmonary Resuscitation)
- EOL Register
- Communication skills
- Prognostication skills

The End of Life Care Co-ordinator Team work across health and social care in West Sussex to support those caring for individuals at the end of life. They are able to sign post to other experts as necessary in order to give advice, support or care. They hold 6 weekly Care Home Link meetings to help care homes share best practice, encourage discussion of issues around end of life care and increase awareness of local and national policy.

Joint training is also delivered between Sussex Community Trust and St Catherine Hospice, and '6 steps' training has also been provided in hospices in the Coastal area. In addition 'Sage and Thyme' training programme for generalist staff has been facilitated by local hospices, and the Midhurst Macmillan service has weekly training sessions open to staff in the local area.

Q8) Has End of Life care been identified as a local priority and who is providing local leadership and accountability?

End of Life has been prioritised by all three CCGs in West Sussex, which are identified in the respective CCGs commissioning plans.

Within the Clinical Commissioning Groups of Crawley and Horsham and Mid Sussex an End of Life Programme Board is in place and there is a nominated clinical lead for end of life that

liaises with the nominated management lead and also acts as a clinical champion to cascade information to member practices. The programme board includes stakeholders in those two CCGs as well as working with the East Surrey CCG area. This is in recognition of the need to work across boundaries: around Surrey and Sussex Hospital Trust supporting Crawley, East Surrey and Princess Royal Hospitals (the patient flow from Mid Sussex). The Programme Board is mapping its pathway in order to establish whether there are gaps in service to inform the commissioning priorities.

In Coastal West Sussex CCG a stocktake has been completed to benchmark against local and national End of Life care priorities. The emerging recommendations from this piece of work will be taken forward as part of a service co-design project. This collaborative project will develop and agree a long term strategy with stakeholders, public and patient engagement, with the aim of addressing the identified inequalities, raising the profile of EOLC and ensuring the most efficient and appropriate use of available resources in order to improve the patient and carer experience at the end of life.

Following discussions at the Health and Wellbeing Board in its shadow year, a meeting of interested stakeholders including representatives from hospices, community providers, care homes, Adults Services, Public Health and Health and Social Care Commissioning took place in May 2013, with the aim of establishing the baseline position, considering collective objectives and formulating a work plan. The key outcomes from this meeting included:

- a) Develop and maintain a virtual email network of key individuals to share knowledge and information, keep up to date on developments, feedback gaps in services and training, and formulate small groups of members to work on key areas.
- b) Small group to focus on quality of provision. This to include exploring how to access and use feedback from customers and relatives, clarity on national directives, regulations and guidance, where the areas for improvement in quality are, and how these improvements can be made.
- c) Health and Social Care Commissioning to incorporate End of Life into the specification development and future commissioning of Domiciliary Care Services.

End of Life has been included as part of the "Think Local Act Personal" Action Plan for West Sussex for 2013/14 with the cited objective of reviewing customer choice and control over palliative care service options and their experience of current services. The action plan identified above and the plans of the Clinical Commissioning Groups are expected to support the achievement of this objective.

Q9) What local activities are being undertaken to raise public awareness about death, dying, bereavement and build people's confidence in having discussions and making plans?

The national initiative 'Dying Matters' week in May 2013 in West Sussex included a red bus transporting around West Sussex with support provided from a solicitor, an undertaker, a service user, carer support, nurses, Age UK, health and wellbeing, and the Lions Club to raise awareness about death, dying and bereavement in the general public.

The End of Life in Dementia Work stream has identified a number of tools that are being promoted to healthcare professionals which will encourage them to open the discussion which in turn, encourages individuals to broker such conversations. The products include 'sage and thyme training' and 'conversations for life'

In addition the work identified in Question 3 and Question 6 are aimed at raising awareness and building confidence in initiating conversations and making plans for future care.

Q10) what steps are being taken to involve local people and those with personal experience in the way services are shaped and evaluated?

Specifically the organisation HOPE supports local education events when dementia sufferers can speak about their experiences and raise awareness to professionals.

More generally, critical to all service development and redesign is the inclusion of patients and carers. This is undertaken in a variety of ways including representation on stakeholder groups, focus groups to seek views from a wider target audience, utilising established sector groups through voluntary organisations i.e. Forward Thinking Groups.

In addition, please see Question 2 in relation to feedback from relatives and carers . It is anticipated that further work on learning from patient and relatives experiences would be beneficial in undertaking the work identified as priority under Question 8.

Appendix 2: Nice Guidelines

NICE released their guidelines in 2011 which have since been reviewed in light of the LCP decision. They authored 16 Quality Statements with the intention:

This quality standard describes high-quality care that, when delivered collectively, should contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and carers. This will be done in the following ways, regardless of condition or setting:

- *Enhancing quality of life for people with long-term conditions.*
- *Ensuring that people have a positive experience of (health) care.*
- *Treating and caring for people in a safe environment and protecting them from avoidable (healthcare-related) harm.*

These quality statements run from identifying that someone may approach the end of life, to treatment of the body, care of the bereaved and standards in what EOL care workforce organisations. There is once again an emphasis on joined up and integrated working.

16 Quality Statements:

[Statement 1](#). People approaching the end of life are identified in a timely way.

[Statement 2](#). People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

[Statement 3](#). People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

[Statement 4](#). People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

[Statement 5](#). People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

[Statement 6](#). People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

[Statement 7](#). Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

[Statement 8](#). People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

[Statement 9](#). People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

[Statement 10](#). People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

[Statement 11](#). People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.

[Statement 12](#). The body of a person who has died is cared for in a culturally sensitive and dignified manner.

[Statement 13](#). Families and carers of people who have died receive timely verification and certification of the death.

[Statement 14](#). People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

[Statement 15](#). Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

[Statement 16](#). Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

In addition, quality standards that should also be considered when commissioning and providing an end of life care service are listed in [related NICE quality standards](#).

Appendix 3: What We Know Now Summary 2013

Published by Public Health England, this document gave an analytical overview of the services across the UK and what we know now in terms of where, when, and how people were dying, where people wanted to die and how people felt about current EOL care. Among other things the report found that:

Demographics

More and more people over the age of 85 were dying and less and less people between 64 and 85 were dying. The South East has the highest relative population of over 85's and also has the highest over 65 population.

In a recent study cited in 'What We Know Now 2013', in high income countries – 69% to 82% of all people will need some form of palliative care³⁸. This includes the UK and we have no reason to believe that West Sussex would be any different

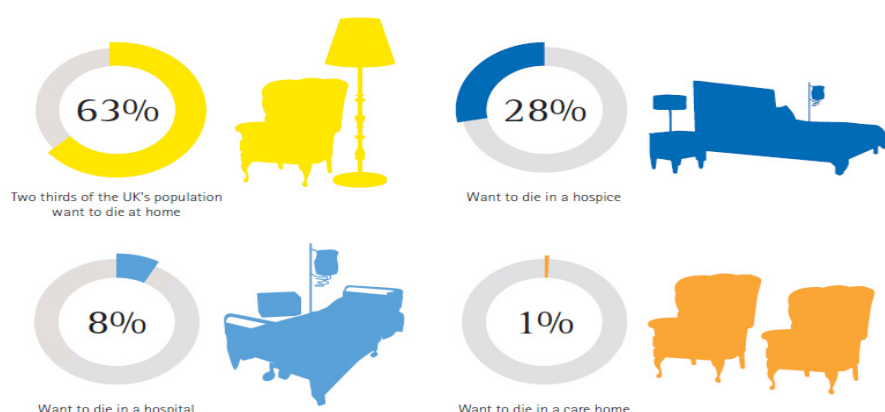
Using the data toolkit provided through the End of Life Intelligence Network³⁹, we can see national data from 2012. Important to note is that on average, Cancer in 2012 accounted for an average of 28.51% of deaths across the UK. Cardiovascular issues were 27.31% (average) of all UK deaths

Attitudes

- 70% of people felt comfortable to talk about dying however most had not expressed these wishes to loved ones.
- Only 5% had some form of advanced care plan if they could not make the decisions themselves.

Preferences

The following shows visually where, during the study, people stated they would want to die



Data is sourced from Sue Ryder's *A Time and a Place* report: www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isnt-working/~/_media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx

³⁸ Source: Murtagh FEM, Bausewein C, Verne J, Groeneveld EI. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med* <http://pmj.sagepub.com/content/early/2013/05/20/0269216313489367.abstract>

³⁹ http://www.endoflifecare-intelligence.org.uk/profiles/CCGs/Cause_of_Death/atlas.html

- Included in this document, we know that people are least likely to die at home in Surrey, Sussex and Kent (18.7%), compared to the national picture.
- Nationally, 50.71% (average) of people die in a hospital setting. This is from the 2012 End of Life Care Intelligence network mapping tool. The above Sue Ryder report now places this figure at about 58%.
- In the last year of life, a patient will be admitted an average of 3.5 times to hospital and spend an average of 30 days in a hospital bed.

Voices

The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services) collects information on bereaved peoples' views on the quality of care provided to a friend or relative in the last three months of life, for England. The survey has now been in place for three years and was commissioned by NHS England in 2013. It is administered by the Office for National Statistics (ONS). It provides a detailed insight nationally into the thoughts and opinions of end of life care to those directly affected.

The VOICES survey for 2013 was published in July 2014⁴⁰ and had 22,220 responding-this is just for the period covering 1st Jan 2013 to 30th April 2013. Over 99% of respondents were relatives of the deceased person.

The key findings as published were:

Key findings

- *Overall quality of care has not changed significantly between 2011, 2012 and 2013.*
- *Quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home.*
- *For those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012.*
- *The dignity and respect for patients shown by hospital nurses and hospice nurses has increased between 2011 and 2013.*
- *Pain is relieved most effectively in the hospice setting (62%) and least effectively at home (18%).*
- *Only half of people (50%) who express a preference to die at home, actually die at home*

⁴⁰ <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html#tab-Background>

Appendix 4: Full Case Study

L is a West Sussex resident. Both of her parents have been ill for the last 4-5 years and in September 2014 her mother passed away in a hospice. Her father is currently in a nursing home.

4 years ago, by coincidence, both parents were diagnosed with various complex medical issues following several months of acute admissions and visits to primary care. Her mother with COPD, congestive heart failure and circulatory issues. Her father with COPD, Diabetes, Parkinson's, early stages of Dementia and depression. Both, at the time, were in their late 60's. They remained living together in the family home until both required leg amputations within 2 months of one another, 3 years ago. At point of discharge L's father entered a care home and L's mother returned to the family home, where she then lived alone.

At point of diagnosis, L's mother was told her conditions were incurable; however she could live for many years but may go downhill very quickly. No mention was made of advance care planning. In the last 12 months of her life, L's mother deteriorated and was admitted to an acute setting 7 times. This triggered the involvement of the proactive care team for the area and L's mother was then seen by a community matron on a regular basis. The community matron coordinated L's mothers care and liaised closely with the acute unit, GP, Pharmacist and voluntary agencies. At each point of admission, L's mother decided she wanted to be at home. 3 months before her death the matron on her acute ward had an End of Life conversation with L's mother and L and stated that she felt that L's mother may be approaching EOL within the next few months. This was backed by the specialist on the acute ward. A referral was then made to the Palliative Care Team in the hospital, who helped advise the ward staff. L's mother made the decision if at all possible she would choose to die at home. The RAIT team were put into place, coordinated by the Community Matron, and L's mothers living environment altered, including creating a high oxygen sealed room environment in her bedroom.

During her last acute admission, 2 weeks before death, L and her family were told her mother would probably die that same weekend, by the ward staff in the acute setting. When this did not happen, a referral was made immediately to the hospice within the catchment area, who came in and assessed, placing L's mother on a waiting list. Waiting 4 days, L's mother was transferred as an inpatient to the hospice. She remained there for 4 days and, as she had stabilised, was about to be discharged back home with support from the hospice at home team, and an application for Fast track CHC funding was successful and almost in place. However, before going home she deteriorated and then died 2 days after this, in the hospice.

L has been offered bereavement counselling and has been supported by the Hospice. When asked for a reflection on her mother's palliative care and EOL journey, including agencies involved L stated:

- Her mother's decisions were respected at every junction and choices always given/explained, along with consequences of those choices.
- The lynch pin in the last three months of care was the community matron, who was patient, understanding, 'worth her weight in gold' and provided a single point of contact for L's mother and the family to access all services.
- The GP service was excellent, visited when appropriate and delivered medications when required.
- The professionals involved had good communication, such as the pharmacist, community nursing, team, GP, Acute setting and hospice. L believes this could be more to do with the community matron, plus the fact her mother was from a small community and was well known and liked-she felt that the communication did not happen because it was 'standard' or 'procedure' and may not have been as good with different staff in roles.
- L felt that **until** the hospice became involved in the final week, that she as main carer was not considered-although all professionals were nice to her, nothing was offered to her in terms of emotional or physical help/support.
- L believes having seen it that respite stay within the hospice setting would have prevented some acute admissions and allowed her mother to remain at home for longer, if the hospice was referred to earlier.
- L believes her mother's life was shortened because of complications with her father.

L's father, as above, went into a care home follow discharge after his amputation. His medical conditions were complex, including dementia, Parkinson's, diabetes and COPD. He was a self-funder and L can remember no involvement with adult services at this point. He and L's mother chose the residential care home based on close proximity to the family home, as L's mother and L were his main carers-despite L's mother starting be very unwell. The placement broke down and L attempted to get involvement for her father from various sources, but could not. Her father tried to commit suicide, and was admitted to the psychiatric unit/rehabilitation unit. Once on the road to recovery, there was pressure placed upon L and the family to support his discharge.

As he was still a self-funder, there was little involvement from adult services-although he was allocated a worker whilst in the psychiatric unit. L identified another home near L's mother and L, and he was discharged to there. Whilst there, his savings reduced and adult services started to part fund-which meant he had to change rooms as the current room he lived in was outside of the cost remit. This led to changes in his mental health and the home were no longer able to manage his behaviours or medical conditions. Adult services suggested some other homes, approximately 15 miles away, but none were deemed suitable by L's father and the family. L's father was admitted to an acute unit again as the home could not manage his diabetes and no nursing support from community teams were available.

L's father was told he could not return to this home, and the acute unit were requiring him to be discharged. L found a care home which would take him at short notice- only due to the fact L's father had been friends with the owner's parents and he was supported to be discharged into there by L. Nursing care was bought in as they could not get community support, and a Continuing healthcare bid was turned down. This placement broke down because his health needs could not be met and he was once again admitted to the local acute.

Depending on whom L spoke to and on what day would lead to conflicting information about best possible routes for discharge, placement and timescales and dates. While there, a DnR order for L's father was overruled as it contained a signature in the wrong place. Her father was therefore resuscitated twice against his will.

Upon discharge, L's father, with issues affecting capacity, had managed to secure a new place in a nursing home – which adult services would also part fund. He has now been there for 4 months and is getting on well. The healthcare team, along with L, have made an application for the CHC funding – as with his co morbidities and complexities seems appropriate as his needs are very health driven- however the application which went in in August 2014 is still awaiting a decision. Until this is made, it will affect L's funding and also all financial matters to be organised following L's mothers death.

In the last 3 months several invoices from the various homes have been received and funding from adult services has taken 3 months to transfer from one provider to another-leading to L's father being threatened with eviction from the home. L has legal guardianship and is sole beneficiary of her mother's half of the property and solicitors are working on this- however invoices and paperwork is still confusing, duplicated and erroneous. Asked for her thoughts about her father's journey L commented **that she felt:**

- No end of life or palliative care conversations have been initiated from any agency- although she believes with the diagnosis and the visible deterioration ion her father, who mainly sits in a chair all day unresponsive, that the point may be approaching.
- That the stress of the uncertainty and lack of health or social care support for her father has impacted on shortening her mother's life. L has also been admitted to the acute unit with symptoms of stress during the last 12 months.
- That nursing care within the care home setting/community would have prevented at least 2/3 acute admissions for her father in the 12 months.
- The current situation with no one person taking control and liaising with the family on finances, care plans and health issues is leading to further stress an L believes she will be signed off work shortly, with stress.