

Wolverhampton Integrated End of Life Care Strategy 2016 – 2020



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1. Executive Summary

The aim of this strategy is to detail Wolverhampton's integrated approach to the design and delivery of a person centred, integrated, end to end End of Life care service.

We believe this strategy will deliver a flexible, responsive, quality service to those approaching the end of their lives.

It will provide reassurance that services will be wrapped around the patient at this difficult time and will facilitate person centred care encompassing the following elements:

- Early identification of the dying person to ensure patients are receiving appropriate care
- Advance care planning to facilitate the persons needs and wishes
- Coordinated care to ensure people don't fall through gaps
- Optimum symptom control based on clinical need
- Choice to support preferred place of care and death
- Workforce fit for purpose

Supporting this strategy will be a detailed outcomes framework that will include the requirement for providers to place equal importance on the improvement of patient/carer experience alongside key clinical indicators.

As Commissioners and providers we want to work collectively to make the care that surrounds dying, death and bereavement as good as possible, for all.

In line with the national vision for End of Life care, we aspire to ensure residents of Wolverhampton can say:

*"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."*¹

The strategy recognises the need to ensure that everyone should have the right to high-quality palliative and end of life care when they have a terminal illness, regardless of their condition, where they live, or their personal circumstances and so is inclusive of all faiths, cultures and groups.

We recognise that the delivery of a truly integrated End of Life care service requires a significant cultural shift that sees a move from the commissioning and delivery of episodic care to a more responsive, person centred model that places the patient (and their loved ones) at the centre.

The strategy recognises that 'one size doesn't fit all' and that services need to flex and adapt as patients progress through each phase of their illness.

We intend to ensure our workforce is fit for purpose and that they work with patients and carers to 'make every moment count'.

¹ 'Every Moment Counts' National Voices, National Council for Palliative Care and NHS England

2. Forward

“Care of the dying can be seen as an indicator of the quality of care provided for all sick and vulnerable people.”²

It is an inevitable fact that everyone will die. The vast majority of us will also care for someone who is dying.

Death and dying are inevitable. Palliative and end of life care must be a priority. The quality and accessibility of this care will affect all of us and it must be made consistently better for all of us.

The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities must be addressed, taking into account their priorities, preferences and wishes.

The provision of good quality End of Life care is essential if we are to fulfil our aspirations to enable everyone to have a good death.

It is difficult to achieve perfection for everybody every time. There can be a mismatch between what services can offer, what professionals hope to achieve and what the person, and their families, carers and those close to them seek or expect.

Palliative and end of life care requires collaboration and cooperation to create the improvements we all want.

Health and social care are equal partners in this endeavour. Cross-organisational collaboration is vital to design new ways of working that will enable each community to achieve these ends. These systems must reach out beyond the usual networks of organisations and communities to call upon contributions, ideas and actions from a wider spectrum of people. We need integrated health and social care systems that work with people, as well as for people.³

The Commissioners and Providers of Health and Care services in Wolverhampton are dedicated to achieving integrated care predicated upon what really matters to their patients and local communities. They see an absolute requirement for all providers to work together in a co-ordinated and coherent manner to provide the best end of life care for every person, irrespective of where, or how, they access the system and supporting them in achieving their preferred place of care.

We only have one chance to get it right.

The Government have recently issued their commitment to ensuring people receive good quality end of life care.⁴

They will ensure the delivery of their vision for personalised end of life care through the NHS Mandate and the CCG Improvement and assessment framework.⁵

² Department of Health (2008) End of Life Care Strategy: Promoting high quality care for all adults at the end of life. London: The Stationery Office

³ Ambitions for Palliative and End of Life Care, National Palliative and End of Life Care Partnership

⁴ Our commitment to you for end of life care – DH July 2016

⁵ NHS England 2016 CCG Improvement & Assessment Framework 2016/17

The Health & Social Care system is currently facing an unprecedented rise in demand whilst at the same time, it has little access to additional funding. Coupled with this, advances in medicine are resulting in a growing population of patients living longer with increasingly complex, chronic, life-limiting conditions.

Significant changes to how care is delivered to these patients is necessary, including the empowerment of patients to make informed choices about their care; working in partnership with them to deliver these choices.

The ambitions of Commissioners and Providers of Health and Social Care across Wolverhampton is to transform end of life care and ensure they are aligned with the “NHS Five Year Forward View”, which sets out the strategic vision for NHS England, as the following extracts highlight:

“It is a future that empowers patients to take much more control over their own care and treatment... that dissolves the classic divide... between family doctors and hospitals, between physical and mental health, between health and social care, between prevention and treatment.... that no longer sees expertise locked into often out-dated buildings, with services fragmented, patients having to visit multiple professionals for multiple appointments, endlessly repeating their details.

Over the next five years and beyond, the NHS will increasingly need to dissolve these traditional boundaries....it requires a partnership with patients over the long term rather than providing single, unconnected ‘episodes’ of care.”⁶

The vision also states clearly that patients’ own life goals are what count, that services need to support families, carers and communities, that promoting wellbeing and independence need to be the key outcomes of care, that patients, their families and carers are often ‘experts by experience’ and that Commissioners should learn much faster from the best examples, not just from within the UK but internationally.

National Voices have developed a narrative for person centred care for people near the end of their life – Every Moment Counts.⁷

The narrative details what person centred care means from the point of view of someone nearing the end of their life.

What is most important to them is:

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

For this reason, Commissioners and Providers across Wolverhampton have worked in partnership to develop this integrated strategy for End of Life care.

The successful implementation of the strategy will provide benefit most importantly for our patients and their carers, but also for the health and Social care professionals providing services, and for the local health economy.

⁶ NHSE Five Year Forward View October 2014

⁷ Every Moment Counts – National Voice & National Council for Palliative Care

⁴ NHS England 2016 CCG Improvement & Assessment Framework 2016/17

⁵ NHSE Five Year Forward View October 2014

⁶ Every Moment Counts – National Voice & National Council for Palliative Care

This strategy is outcomes focussed with the dying persons needs based at the centre of those outcomes.

3. Acknowledgements

The development of this strategy has been supported and influenced by the following people and groups, who we would like to acknowledge for their encouragement, commitment, input and contribution:

- The Patients and Carers who attended the user engagement events and completed the online survey
- Local provider representatives who attended the stakeholder engagement events
- The project Strategic Group
- The project Operational Group
- Healthwatch
- Attendees of focus groups (Patients & Professionals)
- Respondents to the online survey
- Macmillan Cancer Support
- Local providers of End of Life care

3. Background

National Picture

The Palliative Care Funding Review commissioned research by King's College London and partners, estimates that between 92,000 and 142,500 people each year have an unmet need for palliative care.

People living with a life limiting illness and nearing the end of their lives have specific support needs which, if left unmet, can damage their quality of life. It is important that their needs for information, advice and support are addressed. These needs can include information about treatment, care options, psychological support, advice on financial assistance, support in self-managing their condition and planning for eventual death. Carers or those important to the patient also play a vital role in supporting people at the end of life.

- 1,539 people die in the UK every day
- 561,000 people die in the UK every year - Of these deaths 75% are not sudden, but expected
- 457,000 people a year need palliative care

The need for honest conversation and the importance of joined up care are as important for carers and families as individuals. The need for support from, and for, empathetic and competent health and care staff is as important for carers, families and those who are bereaved, as it is for the dying. As is the help that can be given by the communities of which we are part.

The Ambitions for Palliative and End of Life care published in September 2015 provides a framework for national and local health and care system leaders to take action to improve end of life care.⁸

We need to have a nation where each death matters. This means extending our concern beyond the care required by those living with predictable life shortening illness, to ensure a better response from the health and care system and from society, to sudden, unpredictable or very gradual dying.

⁸ The Ambitions for Palliative and End of Life care September 2015

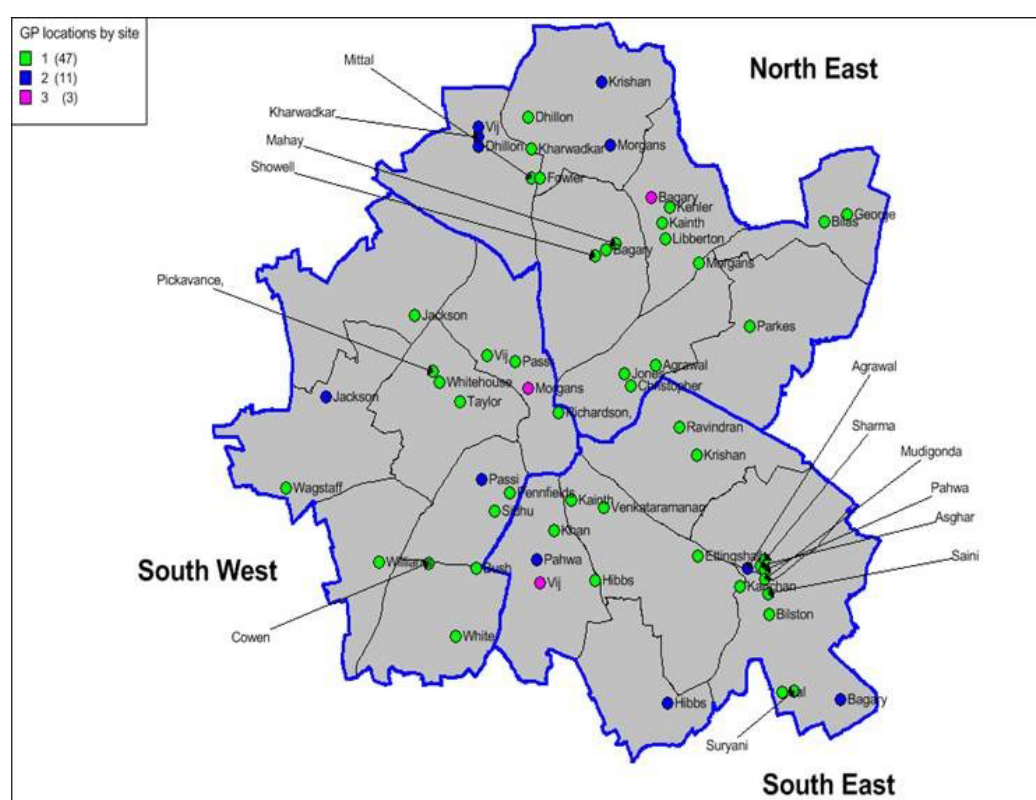
Current Situation

The City of Wolverhampton has approximately 2500 deaths per year.

Number of deaths in Wolverhampton 2004-2014 by age group -⁹

Age Band	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
<65	424	451	476	430	479	403	411	401	404	391	412
65-74	469	478	472	389	376	397	422	375	388	383	406
75-84	919	881	859	843	822	765	818	694	709	766	704
85+	709	759	767	825	803	805	804	852	873	920	909
TOTAL	2521	2569	2574	2487	2480	2370	2455	2322	2374	2460	2431

The City is diverse with an ever increasing population



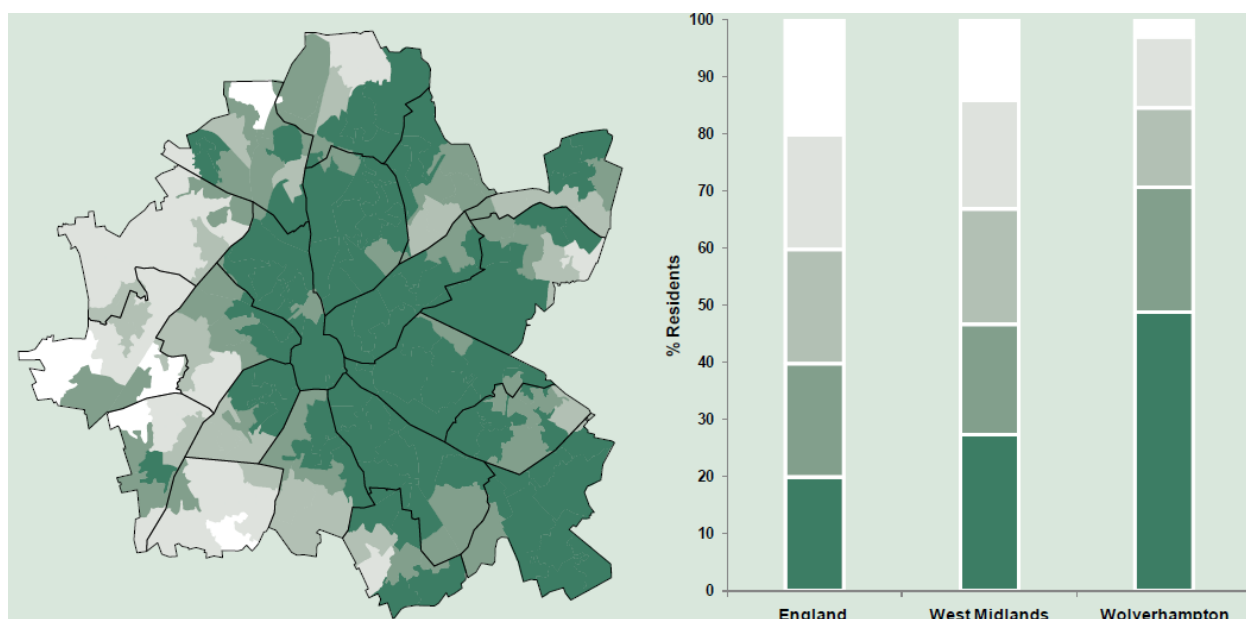
Based on Census 2011 data, the majority of residents in the city belong to the White ethnic group (64.5%), whilst the percentage of Black, Asian and Minority Ethnic (BAME) residents has risen since 2001 by 11% to 35.5%.

This Strategy recognises the requirement to commission and provide services that meet both the cultural and religious needs of our multi cultural population.

In 2007, 2 of Wolverhampton's 158 lower super output areas (LSOAs) fell into the top 1% most deprived in England

⁹ Public Health England 2016

The figure below shows the deprivation level comparator between Wolverhampton, the West Midlands region and England, the darker the green, the more deprived, which shows Wolverhampton as a city area experiencing more than 2 x the level of most significant deprivation than the national average, and proportionately much lower areas of prosperity.



In recent years, new arrivals from European Accession countries have had an impact on the city's population.

People in Wolverhampton are living longer than ever before and the gap between life expectancy in the city and the national figure is closing. We know that socio-economic factors affect life expectancy.

In Wolverhampton and similarly disadvantaged communities, the determinants of health such as skills, jobs and housing, are well below the national average. There are six conditions which account for over half of the difference in life expectancy that exists between Wolverhampton and England.

These are heart disease, stroke, infant mortality, lung cancer, suicide and alcohol. This is seen disproportionately in the most disadvantaged communities.

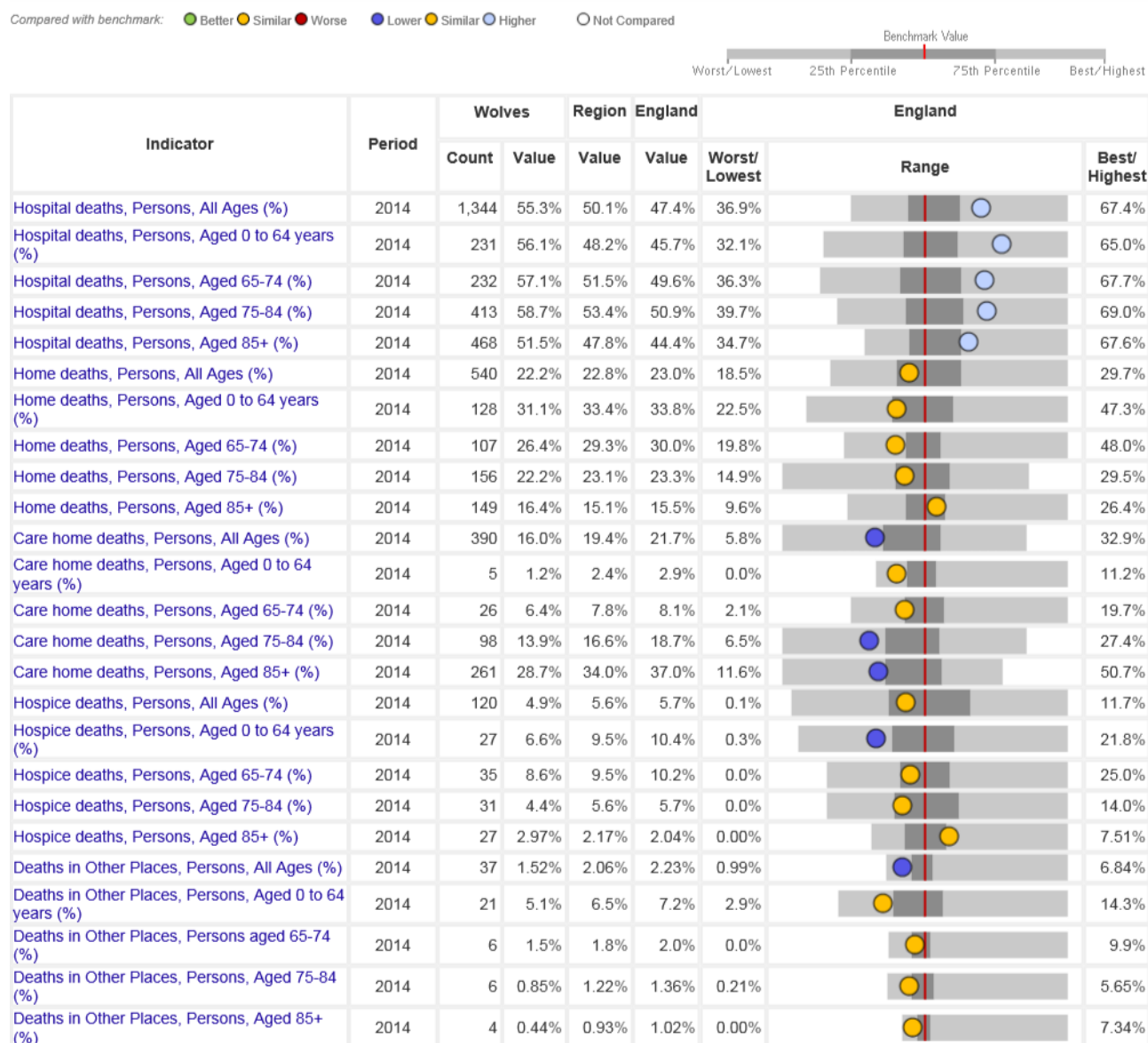
Deaths due to alcohol and those occurring in infancy are the major reasons why life expectancy has not improved.¹⁰

Over the 10 year period between 2004 and 2014 there have been some changes in where people in Wolverhampton end their lives. There has been a consistent decrease in the percentage of people dying in hospital and an increase in those dying at home or in a care home, but there are some years where those overall trends are much less pronounced.

- 6.6% fewer people died in hospital
- 3.7% more people died at home
- 2.6% more people died in a care home
- 0.7 % more people died in a hospice

¹⁰ Wolverhampton In Profile Wolverhampton City Council

Place of Death¹¹



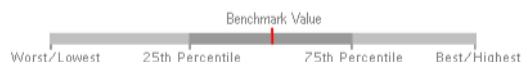
Nationally, 86% of all hospital admissions in the last year of life are emergency hospital admissions with an average length of stay of 27 days accounting for 2.8million bed days.¹²

¹¹ Public Health End of Life care profiles 2014

¹² National end of life care intelligence network. What do we know now that we didn't know a year ago - 2013

Cause of Death¹³

Compared with benchmark: ● Better ● Similar ● Worse ● Lower ● Similar ● Higher ○ Not Compared



Indicator	Period	Wolves		Region		England		
		Count	Value	Value	Value	Worst/Lowest	Range	Best/Highest
Percentage of Deaths from Cancer, Persons, All Ages	2014	681	28.0%	29.0%	28.8%	24.6%		34.6%
Percentage of Deaths from Circulatory Disease, Persons, All Ages	2014	728	29.9%	26.8%	27.1%	21.1%		36.9%
Percentage of Deaths from Respiratory Disease, Persons, All Ages	2014	283	11.6%	12.9%	13.3%	9.7%		17.4%
Percentage of Deaths from Cancer, Persons, Aged Under 65 years	2014	139	33.7%	37.3%	38.0%	27.4%		53.1%
Percentage of Deaths from Circulatory Disease, Persons, Aged Under 65 years	2014	94	22.8%	20.7%	20.1%	14.6%		28.7%
Percentage of Deaths from Respiratory Disease, Persons, Aged Under 65 years	2014	29	7.0%	6.3%	6.5%	2.5%		11.7%
Percentage of Deaths from Cancer, Persons, Aged 65-74	2014	184	45.3%	44.6%	45.1%	34.7%		54.9%
Percentage of Deaths from Circulatory Disease, Persons, Aged 65-74	2014	105	25.9%	23.3%	24.0%	17.8%		36.7%
Percentage of Deaths from Respiratory Disease, Persons, Aged 65-74	2014	38	9.4%	12.3%	12.2%	5.2%		21.0%
Percentage of Deaths from Cancer, Persons, Aged 75-84	2014	191	27.1%	31.3%	31.5%	22.7%		38.8%
Percentage of Deaths from Circulatory Disease, Persons, Aged 75-84	2014	240	34.1%	28.5%	28.3%	20.6%		34.7%
Percentage of Deaths from Respiratory Disease, Persons, Aged 75-84	2014	95	13.5%	14.2%	14.4%	8.6%		22.1%
Percentage of Deaths from Cancer, Persons, Aged 85+	2014	167	18.4%	16.7%	16.2%	13.1%		21.2%
Percentage of Deaths from Circulatory Disease, Persons, Aged 85+	2014	289	31.8%	29.7%	30.3%	22.3%		48.2%
Percentage of Deaths from Respiratory Disease, Persons, Aged 85+	2014	121	13.3%	15.0%	15.6%	9.4%		22.1%

Evidence shows that people who die from Cancer experience a better death.

Evidence also shows that older people dying sometimes experience wide variances in quality of care and being able to express choice.

41% of cancer deaths in older people took place in hospital and only 29% of cancer deaths in older people take place in the home.¹⁴

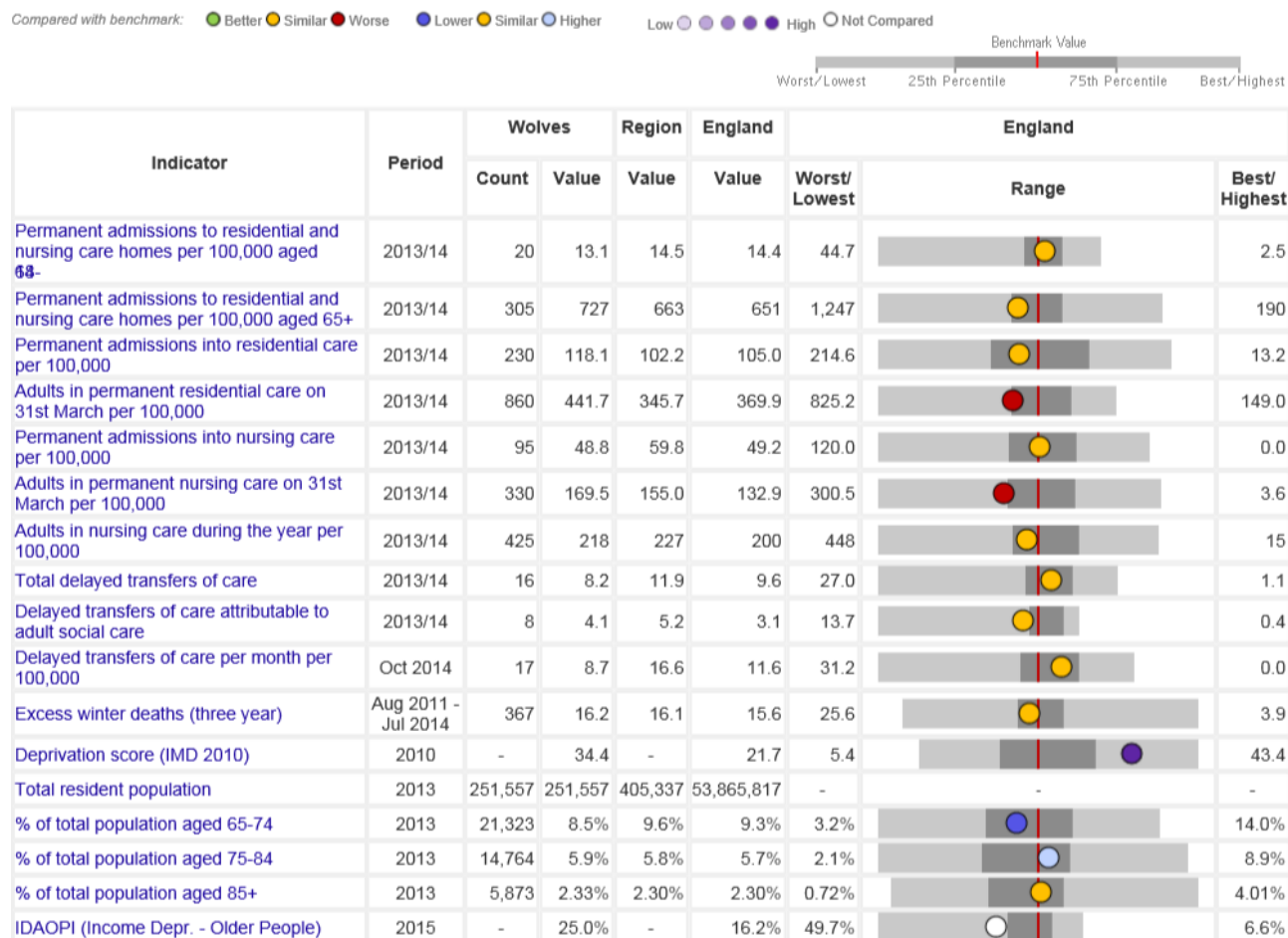
A recent report by the Health Service ombudsman¹⁵ highlighted that older people and their families may not be getting the dignified, pain free end of life care that everyone deserves.

¹³ Public Health End of Life care profiles 2014

¹⁴ Place of death from cancer by local authority for over 65 – 2011 ONS

¹⁵ Report from HSO on ten investigations into NHS care of older people 2011

Residential Care



The number of unplanned emergency admissions from a nursing or residential home in 2015 was 1,785 at a cost of circa £900K

A recent report into the future of an ageing population¹⁶ states that improvements in healthy life expectancy at ages 65 and 85 are not keeping pace with increasing life expectancy. Unless this trend is reversed, an ageing population will mean increased overall demand for health and care services.

The Personal Social Services Research Unit (PSSRU) projects that users of publicly funded home care services will grow by 86% to 393.300 in 2035.

As the population of Wolverhampton ages and the demand for services increases, there is a need to ensure that staff delivering care within the care home sector are educated and supported to appropriately manage patients within their usual place of residence (home).

¹⁶ Future of an ageing population. Government office for Science. July 2016

Throughout Wolverhampton a range of organisations are responsible for delivering different elements of end of life care via a series of contracts.

What is working well	What isn't working well
Cross sector working of the Palliative Care Consultants	Care Coordination
Swan Care (RWT)	Further development and roll out of advanced care planning across sectors
Roll out of the GSF in an acute setting (development phase only –pilot to commence)	Further development and roll out of EPACC system across all sectors
District Nursing crisis line	GSF In Primary Care
Rapid intervention services into Nursing Homes	GSF IN Care Homes
Welfare Rights Service	Syringe Driver training & support in care homes
Housing Services	Early identification of patients approaching end life in primary care
Carer Support	
CNS Team at Compton Hospice	
Third sector agencies supporting patients with low level interventions	

In common with the rest of England, Wolverhampton's health and social care economy is experiencing unprecedented demand growth for services with limited resources to meet those demands. Despite progress in recent years, the resultant pressures are being reflected across the hospitals, GP surgeries, community healthcare teams and social services on a daily basis. As the population grows and people live longer, the challenge to balance available resources and local needs will continue to grow.

This Strategy aligns with the priorities of the City of Wolverhampton Joint Health & Wellbeing Strategy:

- Wider Determinants of Health
- Alcohol and Drugs
- Dementia (early diagnosis)
- Mental Health (Diagnosis and Early Intervention)
- Urgent Care (Improving and Simplifying)

It also aligns with the four priorities of Wolverhampton CCG:

- Improve the outcomes and cost effectiveness of planned care
- Build a sustainable and effective urgent care system
- Create a sustainable and effective system for the whole care journey of patients with long term conditions (including mental health)
- Reduce the gaps in mortality across Wolverhampton

Some progress has been made toward delivering integrated care under the Better Care Fund with the development of integrated community nursing teams into Community Neighbourhood teams that include a range of services including Social Care.

This development is a positive step towards the further development of person centred integrated care for all patients including those approaching end of life.

We now need to implement this at pace across the whole end of life care pathway to ensure those nearing the end of their lives can be certain of truly integrated, person centred care when and where they choose to be treated.

A recently published report by the National Council for Palliative Care and National Voices 'Every Moment Counts', (March 2015) has adopted the following message as its guiding principle:

*"You matter because you are you, and you matter to the end of your life."*¹⁷

(Dame Cicely Saunders founder of the modern hospice movement)

Commissioners and Providers across Wolverhampton aim to ensure that this message is at the centre of the transformation of End of Life care services by ensuring that patients and their carers are at the centre of every decision made regarding their care so that the care received is personal to them.

¹⁷ Every Moment Counts March 2015

4. Our Vision for End of Life Care

The population of Wolverhampton approaching end of life, can be confident that they will receive person centred, integrated care from all professionals involved in their care.

Whilst a recent report has ranked end of life care in the UK as the best in the world¹⁸, there are areas where care can be improved and made more consistent.

The General Medical Council definition of end of life care is¹⁹:

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

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

This would include people with dementia and all long term conditions, young people with life-limiting illness who are **transitioning** to adult palliative/end of life services, and seldom heard groups; e.g. travellers, prisoners, people with learning disabilities, minority ethnic groups.

There is increasing recognition of the particular challenges faced by young people with life limiting illness and their families in the process of transition. For young people with palliative care needs transition is particularly complex. Their independence and need to aim for personal goals are very important, but deteriorating physical health and cognitive faculties may make this a challenging prospect.

The Department of Health have identified the following definition of transition:

'...a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems'. (Blum RW et al, 1993)

The vision for End of Life care in Wolverhampton includes all of the above definitions.

There is a need to see a shift in the delivery of health and social care to empowering patients and carers through choice.

A recent review into Choice at the End of life highlights a number of key themes following wide engagement with the general public: ²⁰

¹⁸ Economist Intelligence Unit –October 2015

¹⁹ Treatment and care towards the end of life: good practice in decision making. GMC

²⁰ What's important to me – A Review of Choice in End of Life Care, February 2015, The Choice in End of Life Board

- I want to be cared for and die in a place of my choice;
- I want involvement in, and control over, decisions about my care;
- I want access to high quality care given by well trained staff;
- I want access to the right services when I need them;
- I want support for my physical, emotional, social and spiritual needs;
- I want the right people to know my wishes at the right time; and
- I want the people who are important to me to be supported and involved in my care.

Commissioners and providers of end of life care in Wolverhampton should aspire to facilitating these statements for those approaching the end of their life.

All evidence shows that if patients are involved in the development of their care plan, they are more likely to be compliant with the requirements of that plan.

This strategy details the need for holistic, person centred care based on the needs and the wishes of the patient and will support services to provide care that enables patients (and carers) to be able to claim those statements.

Person Centred Care

In the delivery of person-centred care, health and social care professionals work collaboratively with people who use services. Person-centred care supports people to develop the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own health and care. It is coordinated and tailored to the needs of the individual. And, crucially, it ensures that people are always treated with dignity, compassion and respect.

Adopting person-centred care as 'business as usual' requires fundamental changes to how services are delivered and to roles – not only those of health and social care professionals, but of patients too – and the relationships between patients, health and social care professionals and teams.²¹

There are a number of recognised issues associated with illness and bereavement as detailed:²²

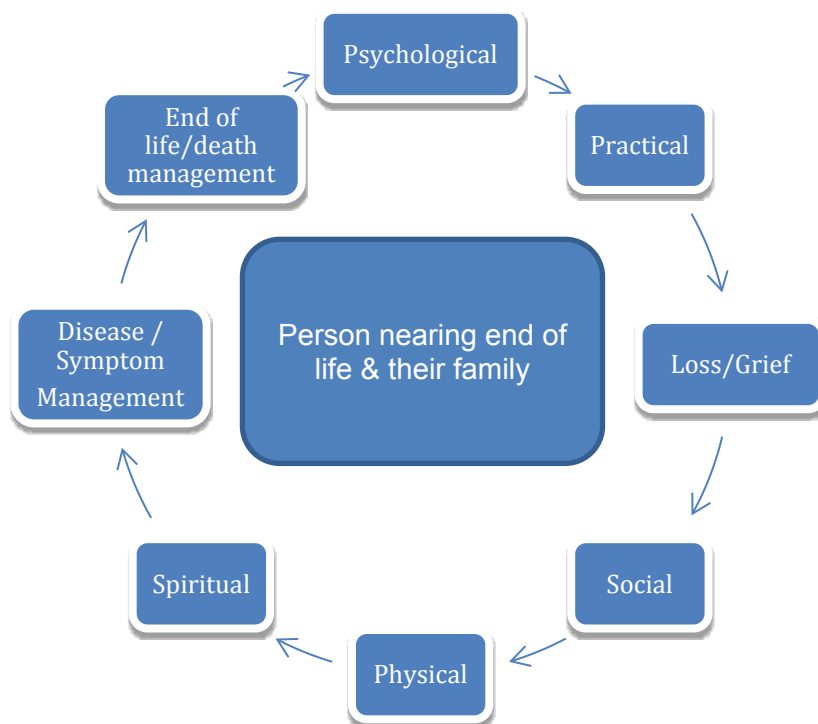


Figure 1- Issues associated with end of life care and dying

To ensure a complete approach to Person Centred care is adopted, all of the above issues need to be identified and addressed.

To do this effectively, care should be coordinated utilising a holistic advanced care plan developed in partnership with the person nearing the end of their life and the people important to them (based on the wishes of the dying person).

²¹ Person-centred care made simple- The Health Foundation 2014

²² A Model to Guide Hospice Palliative Care- Canadian Hospice Palliative Care Assc 2013

Care should be coordinated around the dying person by the most appropriate professional – irrespective of setting or organisation

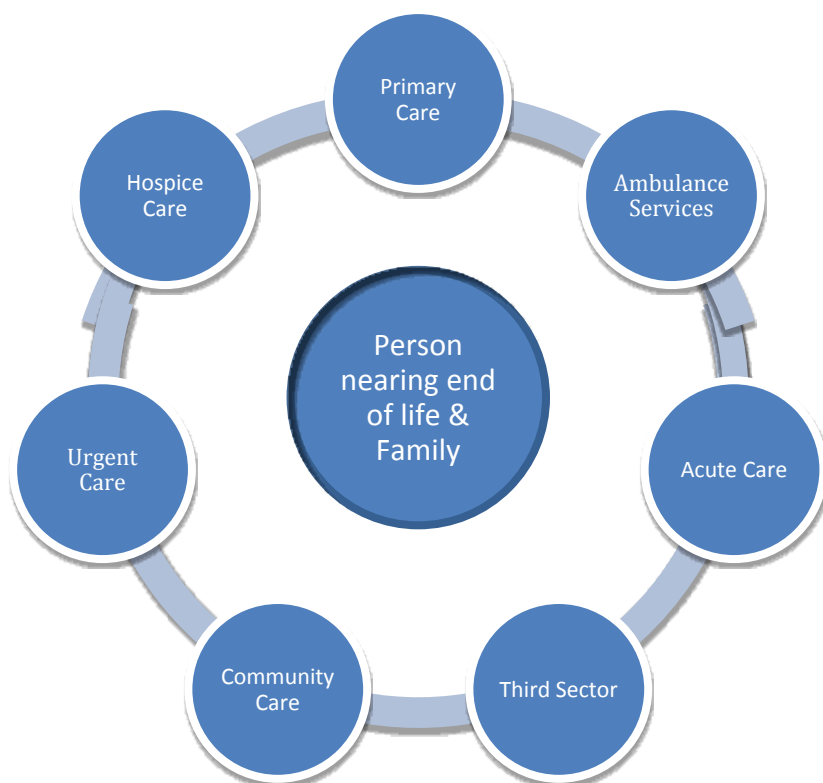


Figure 2- Providers of person centred care

Early Identification of the Dying Person

Everybody should have the opportunity for honest, sensitive and well-informed conversations about dying, death and bereavement, whether they are the person dying, their family, their carers or those important to them. We recognise that the 'when' and 'how' of such conversations need to take account of the preparedness and the perspective of the individual nearing the end of their life. However, professionals have to be sure that opportunities for honest and sensitive conversations about the future are clearly offered, irrespective of setting. Where possible these offers to talk should be early enough to enable people to reflect on their circumstances, to adapt and to plan.²³

Each GP will have approximately 20 patient deaths per year.

About 1% of the population will die each year - e.g. with a list size of 10,000 patients, an average practice will have about 100 patient deaths/ year

Most of our patients now die from

- cancer (about a quarter)
- organ failure - heart failure, COPD etc (about a third)
- or frailty/dementia/multiple co-morbidities (about a third)

With the predicted demographic changes over the coming years, more people are living longer with serious illness, and more will die from non-cancer illnesses, often related to their long term conditions.

Improving care for patients nearing the end of their lives is one of the most important and highly valued aspects of the work in general practice. Yet until now, professionals have often failed to target care towards this group of patients, mainly because of difficulty in identifying them and responding to their needs.

There are many tools to support Primary Care with this important work; yet, the number of patients on Palliative Care registers in Wolverhampton still falls below the national average. Primary care professionals should be supported to investigate and adopt the preferred method of supporting them to improve the number of people identified as approaching end of life.

Locally we have embedded a risk stratification tool (Aristotle) within Primary care and there is also developing work across sectors looking at the frail elderly and utilising the EFI (Elderly Frail Index) tool to identify patients with a range of long term conditions and then categorise into mild/moderate/severe frailty. These tools could be utilised to support the earlier identification of the dying person.

However, tools must never override clinicians concerns for a patient.

Research by 'Dying Matters' shows that people are four times more likely to want to talk to their GP about planning for their end of life than to a solicitor, and ten times more likely than to a nurse. GPs are the gate-keepers to health services in England. If they do not plan support for a dying patient, he or she will end up in crisis

Recognising that someone is entering their last year of life benefits everyone:

²³ Ambitions for Palliative and End of Life Care, National Palliative and End of Life Care Partnership

- The patient and their carers have time to deal with the news and realign their priorities
- The patient is less likely to be subject to treatments of limited clinical value
- GPs can plan appropriate end of life care rather than deal with a series of crises
- Well organised community support can halve the cost of hospital admission and result in 70% of people realising their choice to die at home

To establish the 1% in the practice area, GPs should start with basic numbers:

- If about 1% of the practice population will die in the next year, roughly how many should be on the register?
- Death usually occurs in old age: in 2008, 62.6% of all women who died were over 80 years and 43.2% of all men; older people are a priority to consider
- Cancer only accounts for about 25% of all deaths
- Almost a quarter of all deaths are now in a residential or nursing home. People are typically already frail by the time they move into registered 24-hour care and on average die within 18 months of admission
- Some deaths will be genuinely 'unexpected': around 16% each year are in under 65-year-olds, but in over 65-year-olds only 0.25% are from 'external causes'. Many of these deaths will occur in older people with established disease, with the main causes being cerebro-vascular, acute respiratory and acute myocardial infarction
- In more deprived populations, more deaths occur in the younger ages of the older population for both men and women

QOF registers in Wolverhampton are as detailed:

Total Number of Practices	Total number of patients registered	1% of total number registered	Actual numbers on registers
45	254,713	2547.13	748 = 0.3%

Table 1

Based on 12/13 data, the following National Data applies²⁴:

	Recorded prevalence (QOF 2012/13)	Expected prevalence (2012/13)	Estimated under recording (percentage)	Projected prevalence based on expected prevalence			
				2014	2015	2016	2021
England	130,233 (0.2%)	339,647 (0.6%)	69%	338,305 (0.6%)	338,156 (0.6%)	338,380 (0.6%)	344,936 (0.6%)

Table 2

There is a need to promote earlier identification of patients nearing the end of their life in primary Care to ensure appropriate care planning takes place.

²⁴ Quality and Outcomes Framework (QOF) for April 2012 to March 2013, Quality Management and Analysis System (QMAS) database – 2012/13 data as at end of June 2013

As part of the CCG Primary Care Strategy, it is recognised that there is a need to develop the workforce in Primary Care to ensure the City has the right clinicians with the right skills available in the right quantity in the right place.

NHSE General Practice Forward View²⁵ provides some detail on plans to expand and support GP's and wider Primary Care staffing.

The plans are to target a range of clinical staff across Primary care with investment from the sustainability & Transformation fund. This includes the development of the capability of the current workforce.

To enable Primary care to take its place at the forefront of the delivery of good end of life care, this strategy outlines plans to place education and development in end of life care front and centre of workforce planning.

Only well-trained, competent and confident staff can bring professionalism, compassion and skill to the most difficult and intensely delicate physical and psychological caring.²⁶

To ensure that Primary Care professionals are appropriately staffed and skilled to undertake this important role and the wider role of a Primary Care clinician, the CCG is currently undertaking a detailed workforce analysis programme. The outcomes of the analysis will form an integral part of the Primary Care workforce development.

To give care day in and day out requires organisational and professional environments that ensure psychological safety, support and resilience.

Specifically, in relation to End of Life care we aim to:

- Immediately deliver training to support having difficult conversations
- Ascertain the possibility of providing resource to support improved coding of palliative and end of life patients

²⁵ NHSE General Practice Forward View April 2106

²⁶ Ambitions for Palliative and End of Life Care, National Palliative and End of Life Care Partnership

Advance Care Planning

Caring for people at the end of their lives is an important role for many health and social caring professionals. One of the aspects of this role is to discuss with individuals their preferences regarding the type of care they would wish to receive and where they wish to be cared for in case they lose capacity or are unable to express a preference in the future.

These discussions clearly need to be handled with skill and sensitivity.

The outcomes of such discussions then need to be documented, regularly reviewed and communicated to other relevant people, subject to the individual's agreement.²⁷

ACP is a process of discussion between an individual and their care providers irrespective of discipline.

The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

Examples of what an ACP discussion might include are:

- the individual's concerns
- their important values or personal goals for care
- their understanding about their illness and prognosis, as well as particular preferences for types of care or treatment that may be beneficial in the future and the availability of these

In Wolverhampton an integrated ACP has been developed across all partners including patients and carers.

This document includes a wide range of personal information about the dying person in conjunction with the clinical, social information requirements of the professionals providing care.

Comment from a focus group member

It's a bit of a 'gloomy' document. It needs brightening up a bit with a few pictures to make you want to read it and fill it in

Comment from a focus group member

Really good document and the section for the patient/carer to complete is really good. However, how are we going to ensure that patients/carers bring it with them to appointments?

²⁷ Advance Care Planning: A Guide for Health and Social Care Staff. Nat End of Life Care Programme

Shared Care Record

As the end of life approaches, individuals and families must be able to rely on safe, appropriate care that is consistent with their wishes, at any time of day or night and no matter who is providing this care.

The 2008 National End of Life Care Strategy recommended locality registers as a way to enable effective communication among professionals.

From this experience grew the Electronic Palliative Care Co-ordination Systems (EPaCCS), which are now being implemented across the country.

EPaCCS provide a shared locality record for health and social care professionals. They allow rapid access across care boundaries, to key information about an individual approaching the end of life, including their expressed preferences for care.

EPaCCS provides a National information standard defining the core data set required.

A case study of a pilot in Bedfordshire saw a central electronic register was established containing relevant information on those in the last year of life to which all services would have access. The pilot proved successful in highlighting the fact that a central register supported coordinated care and increasing the amount of people able to die at home.

Some of the findings of the recent final evaluation report into EPaCCS are²⁸ ;

- An indication that patients, carers and professionals in EPaCCS locations suggest that co-ordination of care is both important and increasingly being realised;
- That EPaCCS may bring an additional degree of system integrity;
- That given the evaluation design and methodology there is as yet no conclusive evidence of system-wide impacts on indicators such as deaths in hospital that can be distinguished between EPaCCS and non-EPaCCS sites;
- That there is reason to believe that overall costs associated with EPaCCS and its impact are unlikely to increase and that therefore the case for further development is good;
- That to achieve full benefit from EPaCCS a number of contextual and cultural challenges need continuing emphasis including the building of capability amongst staff, taking full advantage of technological advances and overcoming the complex nature of end of life care service delivery through building strong teams that collaborate effectively across agencies, organisations and professions

To ensure the advanced care plan can guide a person centred approach, it has to be available to that person, so that they can review, change and update it themselves.

Subject to that person's consent, or, if they lack mental capacity, in their best interests, the plan should also be shared with all those who may be involved in their care. All electronic systems for sharing health related preferences must encompass the recording and sharing of preferences at the end of life.

To ensure a better response to dying, death and bereavement, the local organisations that give care need accurate and up to date information that can help them improve services.

²⁸ Independant evaluation of EPaCCS in England March 2016

Locally, very little has progressed with the further development and roll out of this and so there is an urgent need to accelerate this work and start the shift towards an integrated electronic patient record for those approaching the end of life.

More work is required to map all stakeholders requiring access to a shared care record and some consideration to how we enable care homes and the voluntary sector to provide holistic care based on the persons wishes.

Coordinated Care

A local carer's experience

My mom was discharged from hospital following a discussion with a Consultant advising that a prolonged stay in hospital would not be in her best interests and would we like to take her home?

We welcomed this conversation.

We agreed and she was discharged.

We then had to begin the battle of trying to get a special mattress from the Independent Living Service. Following delivery of the wrong size mattress, numerous calls to get it replaced finally realised delivery of the correct size. The only problem was, they delivered it to my parent's house and 'dumped' it in the spare room. They were not allowed to put it on the bed! My father was 80+ years and not capable of changing the mattress himself, so, a very kind neighbour came in to help.

The first visit by a District Nurse gave us hope as she said that in her opinion, there was now a need to increase the frequency of visits to mum.

The following week (a whole week on), a more senior District Nurse visited and told us that she was discharging mum because 'her legs were now better'

What about the rest of her care? She was in the last days of life.

We had to admit her to hospital on the Saturday because she had a fall. Social Services couldn't (or wouldn't) help with support and neither would the District Nurses.

My mom wanted to die at home, but she eventually died in the local Hospice on the day she was transferred there from the local hospital.

The care received there was exceptional.

It's just a shame it came so late.

Both my mom and my family were greatly let down by services at this traumatic time.

Things have to change

Time after time reports tell us that care for people nearing the end of their life remains fragmented and is delivered in silos and that people nearing the end of their lives and those close to them have to repeat information numerous times.

This continues to create anxiety and issues with continuity of care.

Effective systems for person centred care need to encompass: systematic ways of reaching people who are approaching the end of life, effective assessment as well as effective decision making support, care coordination, care planning, and care delivery.

It also requires effective ways of managing the timely and sometimes repeated input of Specialist Palliative Care services or dedicated children's palliative care services, when needed. Such systems should identify the goals of the person nearing death.

Part of the approach should include the appropriate use of person centred tools to measure the quality and impact of care on the dying person within the context of local audit and reflection.

There are a range of tools available to measure person centred care:²⁹

- Ambulatory Care Experiences Survey
- Baker and Taylor Measurement Scale
- Barriers to Providing Family-Centred Care
- Benchmarking Person-centred Care

There is no 'one size fits all' tool and a range of tools should be applied to obtain a whole view.

People nearing the end of their life and their family, want to be able to access services when they need them and not have to navigate their way through a myriad of professionals and contact numbers.

Services need to be flexible and responsive, with access to key services 24hrs per day.

People nearing the end of their life should know what they can expect from Health & Care services in Wolverhampton. Those who commission local systems of care should tell people what they might reasonably expect of their health and care services as they approach death.

The distress of uncontrolled pain and symptoms cannot wait for 'opening hours'. This is a necessary system-wide expectation and good end of life care cannot be achieved without it.

The shift to provide 24hr access to services has already started with the Community based services in Wolverhampton under the BCF programme. This needs to be built upon, at pace, to ensure all services are accessible and responsive.

To ensure we can deliver coordinated care to the people of Wolverhampton we have to ensure that each person nearing the end of their life, has a named care coordinator who will ensure that the health and care needs and wishes of the dying person are coordinated and delivered in accordance with the care assessment.

The details of this care coordinator must be available to the dying person and those closest to them to ensure a swift response in times of crisis or times of anxiety and stress to provide reassurance and support.

²⁹ The Health Foundation – Helping measure person centred care 2014

Symptom Management

Care Home Manager – Wolverhampton

We recently had two patients who died without pain relief.

Our staff are not trained to administer drugs via a syringe driver.

This is an issue locally as District Nurses are not commissioned to support nursing homes with pain relief.

Key to symptom management is the role of the Palliative Care team.

Palliative Care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatment.³⁰

The core role of the palliative medicine physician may be defined as the medical assessment of distress, symptom management and end of life care for patients with complex clinical needs due to advanced, progressive or life threatening disease. They provide medical leadership within palliative care services and hold clinical responsibility for the treatment of patients in their care. Areas of responsibility include ensuring good quality, efficiency and equitable access to services, advising on strategic planning including commissioning of services, and developing strategies for research, education and training in relation to specialist and generalist palliative care.³¹

In 2015, NICE updated their guidance on the symptom control of the dying person³².

This guideline includes recommendations on:

- recognising when people are entering the last few days of life
- communicating and shared decision-making
- clinically assisted hydration
- medicines for managing pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions
- anticipatory prescribing

This Strategy recommends the full implementation of this guideline in conjunction with the Five Priorities of Care as developed by the Leadership Alliance for the care of the dying in their report 'One Chance to Get it Right'. These make the dying person themselves the focus of care in the last few days and hours of life and exemplify the high-level outcomes that must be delivered for every dying person.

³⁰ National Council for Palliative Care

³¹ The role of the Palliative Medicine Consultant. Assc for Palliative Medicine 2012

³² Care of dying adults in the last days of life NICE guidelines [NG31] December 2015

The Priorities for Care are that, when it is thought that a person may die within the next few days or hours;

- this possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
- Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
- the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

There is also a need to ensure that optimal symptom control is delivered throughout the dying phase to ensure that the patient can live the best quality of life and is enabled to live well.

Anticipatory Prescribing is the mechanism by which health professionals ensure that those approaching the end of their lives have access to the medications they will need in a timely manner.

It is recognition that all people approaching the ends of their lives have the potential to develop symptoms and that the correct medication with correct dose is available to address these symptoms.

Anticipatory prescribing occurs on an individualised, case-by-case basis, generally when it is thought that someone is within the last days to limited weeks of life (but timing / appropriateness will be dependent on various factors, including geographical location etc).

In Wolverhampton clinical professionals have developed an approved list of medications to be used across the city.

Out of hours medication is held in the Urgent Care Centre with access for GP's and District nurses to pain management drugs.

In addition there are a number of Community Pharmacists commissioned to hold and dispense an agreed list of medications to enable symptom control in the community.

It is the vision of Commissioners and Providers of health & social care in Wolverhampton that all people at the end of their lives should have a good death and that we can confidently state that we supported those nearing death and their carers to 'make every moment count'.

Bereavement Care

Good palliative and end of life care includes giving care and support to families, friends, carers and all those who are important to the dying person.

This must encompass good bereavement and pre-bereavement care, including for children and young people. It must also respond to the needs of those who are affected by death caused by sudden illness or trauma, including suicide.

Although some bereavement care is delivered through Compton Hospice, this is not routinely available to all – only those whom have accessed care at the Hospice.

Commissioners of services may wish to consider commissioning bereavement services that are accessible to all.

District Nursing Teams across Wolverhampton report some delays in verification of death causing distress to relatives and loved ones.

It is crucial that all services respond to these calls as a priority to avoid unnecessary distress and anxiety.

It is recognised that if a competent registered nurse can verify expected patient death, increased quality of care can be offered both to the patient, relatives and carers.

The Nursing and Midwifery Council (NMC) advised that “nurses can confirm that death has occurred, provided there is an explicit local policy or protocol to allow such an action and only in cases where the death is expected.” (NMC 2008).

Commissioners of services may wish to consider commissioning this service to enhance the quality of services at this difficult time.

End of Life Care Workforce

Comments from a local focus group

‘Consultants won’t let patients go and offer them unnecessary treatment and hope’

‘Clinicians will not have the difficult conversation and leave it to the nurses’

When you ring Social Services, the first question is ‘do you have over £23k in the bank?. If so, we can’t help you’

They do not provide help and support to access privately funded provision.

Every professional needs to be competent and up to date in the knowledge and practice that enable them to play their part in the delivery of good end of life care.

End of Life Care (EoLc) cuts across specialisms, settings (hospital, care home, community and hospice), workforces (nurses, social care workers, ancillary staff, GPs, specialists) and geographies.

While many parts of the health service deliver excellent EoLc, the risk of an endemic culture of neglect and poor practice in certain environments has devastating consequences for patients: a minimum level of skills in EoLc across all workforces and settings was one of the themes of a recent report into the education of those delivering EoLc by The Democratic Society for Health Education England³³.

Commissioned annual training should focus on up skilling generalists, as appropriate, in the recognition of dying patients, difficult conversations, pain management and personalised care planning. In terms of efficacy, we recognise that a blended learning approach can improve the proficiency of students and qualified staff. Learning that is reinforced through different opportunities and approaches ensure that key ideas are embedded. The most important skill cited by participants was communication and this is a clear focus for any training strategy. Strengthening mandatory training for both EoLC and communication (as a universal skill) early in the clinical learning paradigm was seen as critical, as was focusing subsequent reinforcements of this throughout educational strategies.³⁴

This report highlighted eight key themes regarding education for those delivering EoLc:

- Extend the workforce for delivery of EoLC
- Define, develop and disseminate information about the role of HEE and the LETBs;
- Develop relationships and strategic partnerships to support network building in EoLC;
- Create a hub for EoLC education and training resources;
- Improve awareness of and access to funding;
- Focus on communication skills as a universal skill underpinning EoLC;

³³ The Democratic Society for HEE

³⁴ The Democratic Society for HEE

- Create a baseline of EoLC tools; and
- Support Blended Learning to deepen knowledge in EoLC.

Health Education England's Palliative and end of life care education and training strategy³⁵ highlights the recommendations of the Francis Report (Francis R 2013)

The report recommends that organisations should:

- Develop a set of fundamental standards, easily understood and accepted by patients, the public and healthcare staff, the breach of which should not be tolerated;
- Provide professionally endorsed and evidence-based means of compliance with these fundamental standards which can be understood and adopted by the staff who have to provide the service;
- Ensure openness, transparency and candour throughout the system about matters of concern;
- Ensure that the relentless focus of the healthcare regulator is on policing compliance with these standards;
- Make all those who provide care for patients – individuals and organisations – properly accountable for what they do;
- Ensure that the public are protected from those not fit to provide such a service;
- Provide for a proper degree of accountability for senior managers and leaders to place all with responsibility for protecting the interests of patients on a level playing field;
- Enhance the recruitment, education, training and support of all the key contributors to the provision of healthcare, but in particular those in nursing and leadership positions, to integrate the essential shared values of the common culture into everything they do;
- Develop and share ever improving means of measuring and understanding the performance of individual professionals, teams, units and provider organisations for the patients, the public, and all other stakeholders in the system;
- All health and social care support workers must undergoing fundamentals in care training before being allowed to care for patients;

For some, these recommendations require a major shift in attitudes to care delivery; education and training should give staff an opportunity to explore and embed these skills.

The Nursing and Midwifery Council has updated the Code of Conduct for nurses and midwives to highlight the importance of delivering fundamental care to dying people so that they can expect to receive the high standard of care afforded to any other person needing nursing care.

“Anyone training to be a nurse in the UK is required to demonstrate that they can deliver care safely, competently and with compassion. Following the publication of More Care, Less Pathway in 2013 we published our standards for competence to make the public aware of the fundamental standards of care that a nurse is expected to be able to deliver. In addition, as part of the review of our Code, we have incorporated these standards into the draft to make sure that all nurses registered in the UK, regardless of where they trained, understand what the public expect from them.” Jackie Smith, NMC Chief Executive and Registrar, 2014.

³⁵ Palliative and end of life care education and training strategy. March 2015

The recent Cavendish Report (Cavendish, 2013) provided an independent review into healthcare assistants and support workers in the NHS and social care settings and goes on to make a number of recommendations in relation to HCA's, Social Care Staff and Care Home staff. The report proposes minimum standards of competence before staff can work unsupervised, in the form of the "Certificate of Fundamental Care".

The recommendations of the Francis and Cavendish Reports and the Chief Nurse's 6 Cs, translate easily to all areas of care especially end of life care. The NHS core values (NHS, 2013) embed much of the recommendations of these reports cited above; end of life care education and training should aim to embed these values.



A recommendation of this strategy is to ensure that Commissioners and Providers of End of Life care develop strong working relationships with the local LETB's to ensure Wolverhampton is first in line to access any training and education to support front line staff

Access to Social Care

People approaching end of life must be supported with rapid access to needs-based social care. The reality of care at the end of life is that it encompasses what professionals see as a mix of 'health' needs and 'personal and social care' needs. Expertise in both is important for the best clinical assessment of need and the best delivery and management of hands on care.

The 2010 report into a study by the Nuffield Trust into the use of Health & Social Care services at end of life³⁶ found the following:

Level of uptake of social care:

- On average, 30 per cent of the people in the study group had some form of local authority funded social care service in the 12 months prior to death. For older people this proportion exceeded 40 per cent
- There were marked differences in the use of local authority-funded social care between the three study PCT/local authority areas with one area showing much lower overall use
- The numbers of people accessing local authority-funded social care in any one month gradually increases over the last 18 months of life
- The proportion of the group accessing any social care in any one given month increases from 15 to 30 per cent during this period
- A large proportion of the increase in social services used in the last twelve months can be attributed to increases in the use of care homes and medium-intensity home care services

Interactions between hospital and social care:

- For the cohort of 16,479 people – in the last year of life 7.2 per cent of the group accessed only social care, 49 per cent accessed hospital inpatient care and 23 per cent used both types of services
- Use of local authority-funded social care increased gradually in the last 12 months of life, whereas use of NHS funded inpatient hospital care sharply increased, particularly in the final two months
- The balance of hospital inpatient and social care costs shifted dramatically with increasing age
- Above age 60, hospital costs at the end of life declined with increasing age, while social care costs increased
- A crossover occurs in people aged 90 and above when estimated social care costs in the last year of life exceed the hospital inpatient costs
- There is some evidence across all age groups that higher social care costs at the end of life tend to be associated with lower inpatient costs
- There were marked differences between the three sites in terms of the balance of hospital and social care costs. The area with the highest social care costs had much lower hospital inpatient costs which may reflect substitution of services.

Differences in social care use with long-term conditions:

³⁶ Social care and hospital use at the end of life, The Nuffield Trust, 2010

- The use of social care differs according to the presence of certain long-term conditions;
- people with mental health problems, falls and injury, stroke, diabetes and asthma tended to use more.
- People with cancer appeared to use local authority-funded social care the least – an effect not simply due to the younger age profile of these cases.
- Though the number of long-term conditions a person has is related to higher hospital costs, it appears to be unrelated to social care costs

The concept of meeting the person's needs recognises that everyone's needs are individual and personal to them.

Asset based assessments are completed with recognition to the importance of the individual participating as fully as possible in decisions about them and to them being provided with the information and support necessary to enable the individual to participate.

Care and support should be personal, and local authorities should not make decisions from which the person is excluded. Beginning with the assumption that the individual is best placed to judge the individuals wellbeing Building on the principles of the Mental Capacity Act, the local authority should assume that the person themselves knows best their own outcomes, goals and wellbeing.

The principle of wellbeing must be embedded throughout the social care system (Care Act 2014).

For the above reasons, and more, it is imperative that Wolverhampton Local Authority are partners in the development and redesign of End of Life care services across Wolverhampton.

Great strides have been made in Wolverhampton to move towards integrated Commissioning across Health & Social Care through the BCF Programme.

This work has enabled a greater understanding of the issues each organisation faces with regard to providing care and support to the population of Wolverhampton.

To this end, both organisations have developed a set of shared goals and values and are:

Working together in better ways to put health and social care systems on a steady footing, translating improved outcomes for customers into long-term, sustainable support for our communities as a whole is fundamental to Wolverhampton's approach.³⁷

Domicillary Care

Patients nearing the end of their lives may need some support to carry out the basic daily living needs.

Domiciliary care is defined as care provided to someone in their own home.

The aim of domiciliary care is to enable people to remain living as independently as they can be in their own homes through the provision of personal care and support.

This may include care and support with daily personal tasks including with medication, however care and support will be predominantly non-medical.

³⁷ BCF Submission 2016

The support provided should be of a re-ablement nature when appropriate and will be tailored to suit the individual's needs.

Carers

Feedback from a local carer

“Trying to hold down a full time job and care for someone who is dying is a considerably stressful time and looking back I don't know how I did it, I eventually had 2 weeks off sick but trying to get a sick note off the doctor was stressful in itself even though it was the same doctor as mum although a different surgery - why can't the doctor treating issue a sick note”

A carer is anyone who provides a significant amount of support for a relative, friend or neighbour on a regular basis without payment. The person that you look after may have a mental health need, learning disability, physical and sensory disability or may be an older, vulnerable person³⁸.

Wolverhampton City Council offer a range of support to carers via the carer support team:

- Practical information and advice
- Carer's assessment
- Benefits advice
- Signposting
- Carer's emergency card



Adults

Information and support for adults and those that are caring for them.

Advice and Information
Health Matters
Keeping Safe



Children, Young People and Families

Information and support for families with children and young people aged 0-19.



SEND Local Offer

Information and support for children & young people with special educational needs and disabilities aged 0-25.

Advice and Support

³⁸ Wolverhampton City Joint Carers Strategy August 2016

Adult Carers

Across the UK today 6.5 million people are carers, supporting a loved one who is older, disabled or seriously ill. In Wolverhampton alone it is estimated that there are around 27,500 carers.

It is important that end of life care services enable carers to access support to carry on with their life whilst undertaking their caring role.

The Wolverhampton Joint All Age Carer Strategy 2016 – 2020, 'Who cares? We do' ³⁹ Recognises that carers play a critical role in supporting someone who would otherwise be unable to look after themselves; often putting the needs of the cared for before themselves.

It is also recognised through national research, and more locally from talking to carers, that caring impacts on their quality of life.

The Care Act brings significant advances in the rights of carers and for the first time places carers on the same legal footing as the person they care for.

The report 'Valuing Carers 2015 – The Rising Value of Carers' Support' published by Carers UK sought to quantify the value unpaid carers contributed to the national and local economy.

In Wolverhampton unpaid carers provided support to the value of £594 million per annum.

³⁹ Wolverhampton Joint All Age Carer Strategy 2016 – 2020 – September 2016

City of Wolverhampton Integrated End of Life care

Early identification of person Identification: Prognosis – years / months Identification of Palliative and Supportive Care needs during regular LTC reviews, use of SPICt or GSF Prognostic Indicator Guidance “Surprise Question”. Inclusion on Supportive Care Register (Green) / Initiation of ACP discussions Identification of life-limiting diagnosis and palliative care needs on letters (admission, hospital OPA or discharge) / new referral to Specialist Palliative Care communicated nearing the end of their life

Supportive Care Register entry- (green – stable)

Months to live

Inclusion on Supportive Care Register and reviewed at MDT minimum 8 weekly
Care coordinating professional identified
Clinician completes: Holistic assessment, discusses aims and priorities for care, and care plan (ACP) for palliative needs with patient.
Review dates appropriate to patient condition and setting.
Timely referral to specialist palliative care services
Electronic notes for palliative care, and communication with Out of Hours

Supportive Care Register updated - (amber - Unstable).

Months/Weeks to live

Care Plan review at MDT and as necessary.
Clinician reviews patient and family holistic needs and personalised ACP. Discuss Preferred Place of Care and Death, and Resuscitation Options including DNACPR form.
Review date agreed appropriate to patient condition.
Timely referral & liaison with specialist palliative care and support services
Additional support from Hospice at Home or 24 hour nursing / support services in community if necessary
Anticipatory medications prescribed and equipment provided as necessary

Supportive Care Register updated- (red – deteriorating/dying)

Days/Hours to live

Care plan for care in the dying phase initiated.
Minimum daily review (5 Priorities for Care). Focus on providing personalised care with dignity.
Resuscitation Options / DNACPR paperwork reviewed
Information shared with MDT
Additional support available from Hospice at Home or night sitting support services or District Nurse crisis service in community
Anticipatory medications and equipment in place as necessary

Post Death and bereavement

Verification of death completed promptly and appropriate services notified
Body cared for in a culturally sensitive and dignified manner
Timely issue of Death Certificate
Carer information on registering a death and bereavement support
Complete electronic record indicating place of death.
Reflection and learning reviewed at next service or practice MDT meeting
Audit patient outcomes

Holistic support, Carer Support, pre-bereavement and bereavement care: Cultural and spiritual needs identified through holistic assessment. Identification of Carers. Carer needs regularly assessed and referral for support if appropriate. Immediate and on going bereavement emotional and spiritual support

24 hour access to support and information with adequate workforce to deliver person centred care

It is recognised and acknowledged that patients will shift through these phase on an individual basis in line with each disease trajectory.

It is not the intention of this strategy to promote a 'one size fits all' model of care.

It is essential that patients approaching the end of their lives are assured that all End of Life care services are responsive and timely throughout their end of life journey.

If care is coordinated around the dying person, then appropriate support will be available at each transition point of the patients journey.

5. Delivering the Vision

To achieve equitable access to high quality, consistent palliative and End of Life Care for patients when they need it, a local standardised model for Palliative and End of Life Care has been developed (above) which, when delivered, will be a step towards equitable service provision and facilitate greater coordination of care.

This model encompasses an end to end approach to care, commencing with early identification of the dying phase in Primary Care through to post bereavement care.

Successful delivery of the strategy will achieve the following key outcomes for people nearing the end of their life and support the system outcome ambitions.

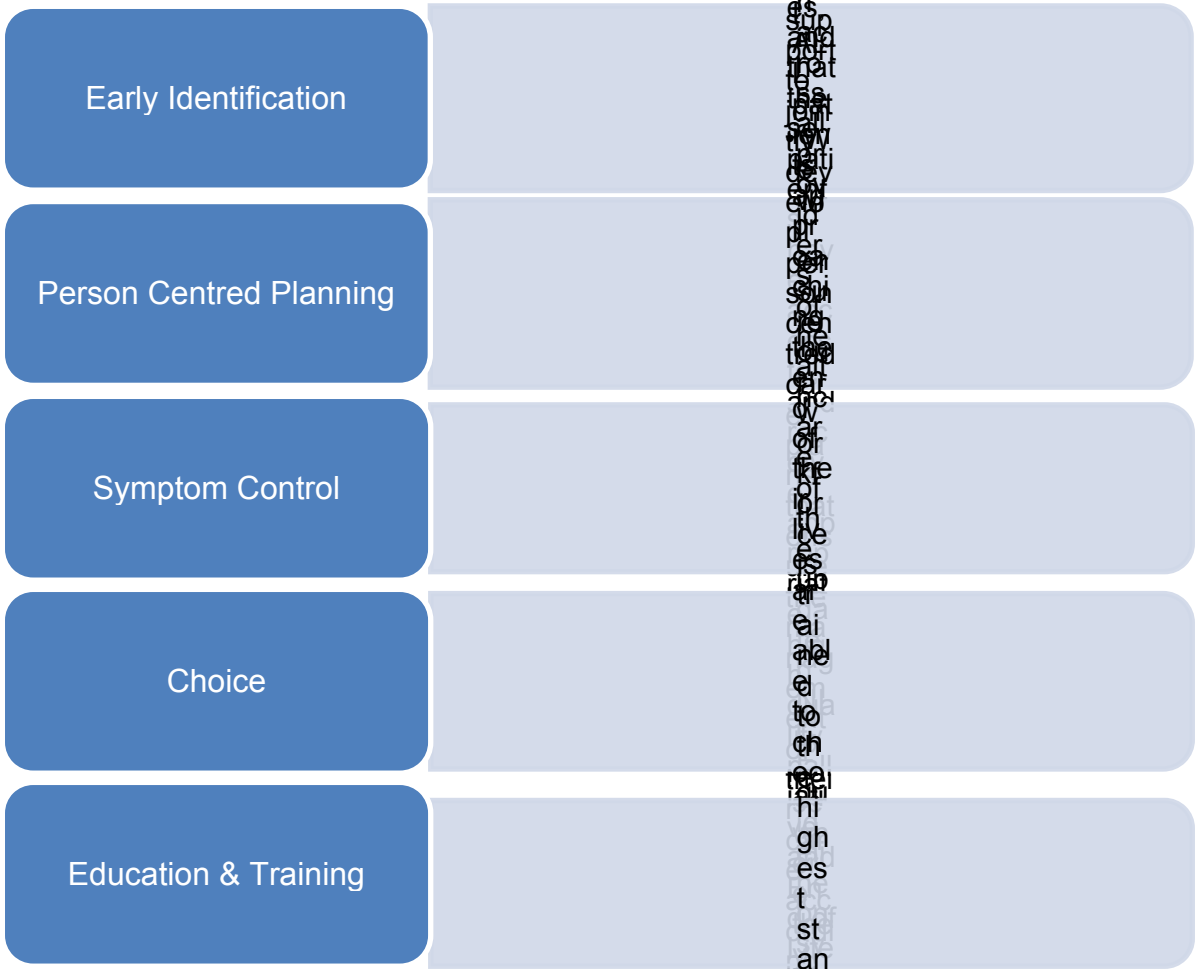


Figure 3: Key outcomes for Palliative and End of Life Care

More detailed outcomes will be included in the End of Life Care Outcomes Framework.

Carer experience

My father in law was a very educated, articulate man.
He had suffered for many years with his long term condition and knew that he was nearing the end of his life.
He had voiced his wishes and choices regarding his death and had completed a DNAR.

During a period of an exacerbation of his condition, he was admitted to the local Hospice where we were told 'this is it'.
The care he received in the hospice was outstanding.
The care we received as his family was outstanding.

Quite remarkably, the clinical staff managed to stabilise his condition and bring his symptoms under control.
We were then told that he was to be discharged.

This came as a great shock as we believed he was to be in the hospice until he died. This was probably an assumption on our part.

So, my father in law decided he would prefer to go into a nursing home rather than home as my mother in law was unable to cope due to her own health issues.

We then set about trying to find a suitable home.

We weren't pressurised by the hospice, but we felt under pressure to move him quickly to free up the bed.

We found a suitable home and arranged for him to be transferred.

It was at this transition point that things went horribly wrong. All of his wishes regarding his death were not transferred with him and indeed when the paramedics were called during an acute phase, they tried to resuscitate him.

This caused great distress to the family and I am sure that had my father had completed an ACP that he held, this would have transferred with him and all of the anxiety and upset could have been avoided.

The Coordination Hub

A key element to the coordination of care is the central function of a coordination point.

Building on the work already in development to co-locate the Community Neighbourhood Teams in each of the three localities across Wolverhampton, it is our intention to utilise this model as the coordination point for End of Life care services.

A number of key end of life care services will already be locality based providing local services to local people (e.g. District Nursing). Therefore, it is recognised that there is room for future development of these contact hubs to include the coordination of End of life care services.

This would enable the use of one contact number per locality for both professionals and patients.

- A single contact number per locality
- Access to registered patients
- Access for help/advice/support
- Specialist professional support
- Support for Primary Care

There is a range of evidence proving that coordinating care for those at end of life ensures improved outcomes in patient experience, symptom management, timely response from integrated services and timely communication to aid the delivery of good quality care.^{40,41}

There are a number of models nationally that could be adopted across Wolverhampton. Consideration should be given to the development of a local offer of end of life care utilising a place based approach.

This approach will enable the delivery of a range of services based on population need. Statutory services will be supported by a wide range of third sector services and social prescribing to enhance the level of service provision.

⁴⁰ PEPS service Bedfordshire

⁴¹ Greenwich Care Partnership

Phases of Illness/Currency for Palliative Care

An example of a clinical measure for patients nearing the end of their lives has been developed in Australia has recently been validated as a reliable and acceptable measure that can be used for palliative care planning, quality improvement and funding purposes.

Table 3 contains the definitions from this study.

A person at the end of their life may have more than one phase of care within a spell of care. One phase ends and another begins when a clinical decision is made that the person has moved between one of four phases of illness – Stable, Unstable, Deteriorating and Dying.

The Australian Model⁴²

The recommendations around developing a currency model based on phase of illness came from looking at the model utilised in Australia under the Australian National Sub-Acute and Non-Acute Patient classification 5 (AN-SNAP).

The Palliative Care Funding Review identified the similarities between British and Australian palliative care need. The ANSNAP model identified the key cost drivers for palliative care to be phase of illness, age, functional status and severity of problem.

NHS England have utilised this study as the basis for their 'discussion on developing a tariff for palliative care.

⁴² http://ahsri.uow.edu.au/Publications/pre2001_pubs/snapstudy1997.pdf

Phase of Illness Criteria

Phase	Start of phase	End of phase
Stable	<ul style="list-style-type: none"> • Patient problems and symptoms are adequately controlled by established plan of care and: • Further interventions planned to maintain symptom control and quality of life; and • Family/carer situation is relatively stable and no new issues are apparent 	The needs of the patient and/or family/carer increase, requiring changes to the existing care plan (i.e. the patient is now unstable, deteriorating or terminal)
Unstable	<p>An urgent change in the plan of care or emergency treatment is required because:</p> <ul style="list-style-type: none"> • Patient experiences a new problem that was not anticipated in the existing plan of care; and/or • Patient experiences a rapid increase in the severity of a current problem; and/or • Family/carers' experience changes which impact on patient care 	<p>The new care plan is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. the patient is now stable or deteriorating); and/or</p> <ul style="list-style-type: none"> • Death is likely within days (i.e. patient is now terminal)
Deteriorating	<p>The care plan is addressing anticipated needs but requires periodic review because:</p> <ul style="list-style-type: none"> • Patients overall function is declining and • Patient experiences an anticipated and gradual worsening of existing problem and/or • Patient experiences a new but anticipated problem and/or • Family/carers experience gradual worsening distress that is anticipated but impacts on the patient care 	<p>Patient condition plateaus (i.e.. patient is now stable) or</p> <ul style="list-style-type: none"> • An urgent change in the care plan or emergency treatment is required and/or • Family/carers experience a sudden change in their situation that impacts on patient care, and requires urgent intervention (i.e. patient is now unstable) or • Death is likely within days (i.e. the patient is terminal)
Dying	Death is likely within days	<p>Patient dies or</p> <ul style="list-style-type: none"> • Patients condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating.)

Table 3

**It is recognised that patients will pass between phases whilst approaching the end of their life. Each patient is unique and we will ensure that our services are responsive enough to meet each need*

Children Transitioning to Adult Services

The 'Transition Taskforce' (2012-2015) commissioned by Together for Short Lives⁴³ mission is to *overcome the barriers to good transition for young people with life-shortening conditions, by building and strengthening bridges between adult and children's services and that they will make the transition to adult services and live their lives as independently as possible according to their wishes, while receiving the care and support they and their families need.*

Commissioning children's palliative care - A guide for Clinical Commissioning Groups states that Children's Palliative Care services should be:

- flexible and focused on children, their parents and their siblings.
- accessible 24 hours a day, seven days a week, 365 days a year – from diagnosis or
- recognition to bereavement.
- supports and enables children and families to choose the type, location and the provider of the care they receive and allows them to change their mind.
- not age, time or diagnosis specific – 15% of children who need CPC have no definitive underlying diagnosis.
- multi-disciplinary and multi-agency.
- accessible to people of different faiths, culture, ethnicity and locations.
- Include pre and post-bereavement support for families
- able to manage symptoms.
- supports parents in caring for their children according to their needs and wishes
- supports and enables smooth transitions for young people with life-limiting and life threatening conditions who move from children's to adult's services

40,000 children in England live with a life-limiting or life-threatening condition

Children dying in Wolverhampton		
Age Range	2013	2014
Under 15yrs	4	23
Over 15yrs	24	1

Wolverhampton CCG commission children's end of life care services from Acorns Hospice. The service aims and objectives are:

- Works with families who have a life-limited or life threatened child who is expected to die before his or her 18th birthday.
- Aims to work with families in a direct response to their expressed needs in palliative care and bereavement support, being committed to a family led service where clients and families are viewed as partners in the care offered.

⁴³ The 'Transition Taskforce' (2012-2015) commissioned by Together for Short Lives

- Offer planned palliative short breaks, emergency short breaks, end of life care, day care, hospice outreach care, community psychosocial support, transitional support and access to hydrotherapy and physiotherapy and, where appropriate interpreters.
- Strive to work collaboratively with professionals from other care agencies who may already be involved with a family at the time their child is referred to Acorns.
- Support families to access treatment for pain and symptom control for specialist complex health conditions
- Provide emergency / crisis support both for medical and social emergencies
- Reduce hospital admissions via planned short-breaks and emergency admissions to the hospice
- Provide transitional support for young people from the age of 14 years and their families, supporting them to access adult palliative care services post 18 years
- Reduce family isolation and increase support network
- Strengthen family health and wellbeing
- Reduce family breakdowns by offering consistent and comprehensive support
- Provide bereavement counselling and support to families
- Support children & young people to enjoy life.

Commissioning for smooth transitions and age-appropriate care for young people with life-limiting conditions in England 'A guide for Clinical Commissioning Groups' ⁴⁴

Many young people with life-limiting conditions and their families find transition daunting. On leaving the comprehensive care offered by children's services, they will often have to deal with and establish important relationships with a range of unfamiliar agencies and professionals. The result can be gaps in services or fewer or less appropriate services⁴⁵.

For many young people with life-limiting conditions, transition into adult services often coincides with a rapid decline of their condition and eventual death.

As such, they have specific health needs which differ from both younger children and older adults who need palliative care.

These include advance care planning (ACP) and end of life planning. Young people should have plans in place where it is unclear whether their condition will stabilise, deteriorate or enter the end of life phase; this is known as 'parallel planning'.

⁴⁴ Commissioning for smooth transitions and age-appropriate care for young people with life-limiting conditions in England A guide for Clinical Commissioning Groups. Together for short lives

⁴⁵ Marie Curie Cancer Care and Together for Short Lives (2012). Don't let me down: ensuring a good transition for young people with palliative care needs

Although this strategy is for adults, services must take into account the needs of children transitioning into adult services to ensure they are prepared to manage the complex needs of these young people.

Local Commissioners and providers of Palliative and End of life for young adults care should work collaboratively and in an integrated manner to ensure processes enable a smooth transition taking into account the parallel planning process and ensuring alignment with the advanced care planning process adopted in adult care.

It is essential that the ‘care coordinator’ role is implemented at the very beginning of the transition phase to ensure relationship building commences prior to transfer.

The Transition Taskforce has conceptualised the way that the five key agencies should work together as a ‘pentagon of support’

This pentagon is underpinned by health and social care working closely together to provide a foundation for all the other provision, with work, leisure and education being the two ‘enabling agencies’ on either side and independent living as the ‘capstone’ at the top.

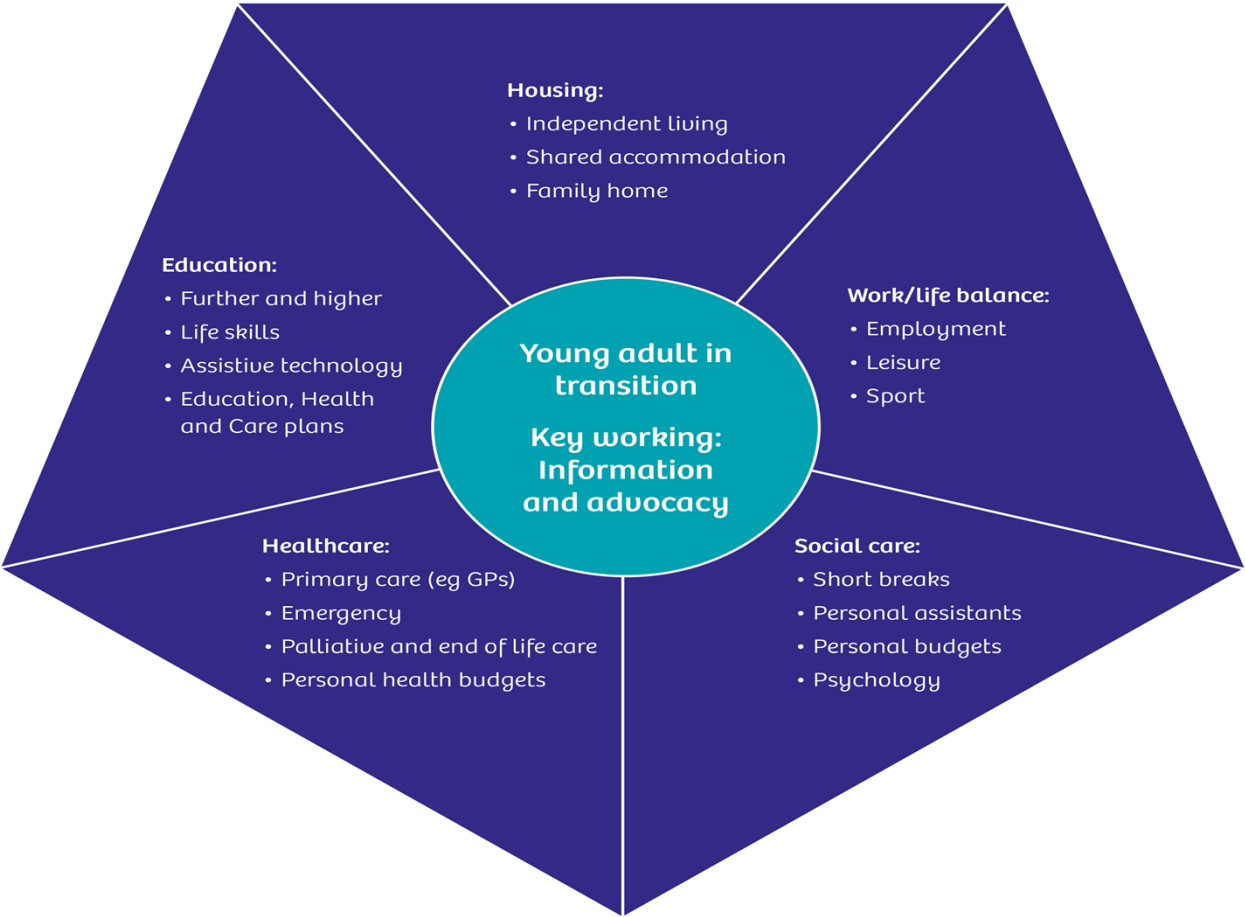


Figure 4 Pentagon of Support

All services must work together to ensure the successful transition to adult services.

6. Patient and Carer Experiences of Current Services

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”⁴⁶

For some, this is an apt description of how the system provides for them. For too many, it just doesn't match their experience. This should and does frustrate us. Our goal is to make this experience a consistent reality for all.

NHS England in its publication Actions for End of Life Care: 2014-16 states:

“The 2008 Strategy managed to reverse the upward trend of people dying in hospital. We now need to ensure that living and dying well is the focus of end of life care, wherever it occurs. This is the challenge: together we can and must achieve it.”⁴⁷

Most people (63%) would prefer to die in their own home, and just under a third would prefer to die in a hospice⁴⁸.

Locally, we have been gathering the experience and opinions of current End of Life care services in a range of different ways.

This evidence can be summarised by the following points:

The following are excerpts from engagement sessions across Wolverhampton.

Communication

68% of carers felt that teams didn't work or communicate with each other, 80% of them said they had to repeat information between 3-5 times, during the last few weeks of life to teams of professionals, here are some of their comments

“Lack of cohesive communication, repetition to several parties who should have known the information “

“There didn't appear to be the communication amongst the hospital teams. The district nurses, GP and Palliative Specialist nurse was very good”

“GP did not show any real concern or compassion”

“I don't feel there was enough communication.”

⁴⁶ 23National Voices and The National Council for Palliative Care (NCPC) and NHS England (2015). Every Moment Counts: A narrative for person centred coordinated care for people near the end of life

⁴⁷ NHSE Actions for End of Life Care 2014-2016

⁴⁸ Macmillan Rich Picture on End of Life care

Care Planning

With the exception of one, all patients were referred to the palliative care team in the last few weeks, but only 31 % patients had a written care plan (ACP) (44% didn't and 19% weren't sure) of those who had a written plan, in 60% of these cases the plans was discussed with both patient and family.

Carers

100% of carers felt they were supported in the last 3 days of life, with regard to Hygiene, toileting, personal care and support to stay where they wanted to be, however 80% felt they didn't have enough spiritual support and 67% expressed they didn't feel they had enough emotional support. All carers felt the family as a whole were supported at the time of death, however 83% of carers expressed that they wanted to have someone to talk to after their loved ones death

Co-Production

The underpinning ethos of this Strategy is 'co-design' which reflects the values of the Commissioners and Stakeholders involved in its development.

The 'patient voice' is at the heart of it, and patients are the additional partner in the Strategic vision for End of Life care provision.

Numerous national reports detail stories of patients and carers whom have experienced less than adequate care and support from End of Life care services and have expressed their desires and wishes for improvement in care at this distressing time.

Providers of care, both health and social care, express concerns regarding the current level of constraints, both financial and time to care.

To ensure that this Strategy goes some way to ensuring that all Partners are invited to have an equal voice in the development of this document, all partners have been invited to input into its development and will be actively involved in its implementation.

Partners also recognise that to deliver the outcomes, integrated services are key and to that end partnerships have been developed relationships with the following:

- primary care providers, to ensure a clinical focus and to understand the impact upon the current workforce to deliver improved end of life care; and
- Local Authority Public Health, to ensure the Strategy addresses the local variances, health and social care inequalities and to understand and develop realistic targets for the outcomes.

7. Glossary

ACP	Advanced Care Plan
CQC	Care Quality Commission
CCG	Clinical Commissioning Group
Co-design	Co-design Means designing, implementing and reviewing service redesign with patients and carers as equal partners.
DNAR	Do Not Attempt Resuscitation
DH	Department of Health
EoLc	End of Life care
EPaCCS	Electronic Palliative Care Coordination System
EoLc pathway	means the standardised step by step framework for all health and social care professionals working with patients who are nearing the end of their lives.
Healthwatch	means the consumer champion for health and social care.
Health & Wellbeing Strategy	A joint strategy between health & social care to improve the health & wellbeing of the population of Wolverhampton
HEE	Health Education England
Hub	A place where care is coordinated
JSNA	Joint Strategic Needs Assessment
LETb	Local Education Training Boards
MDT	Multi Disciplinary Team
NICE	National Institute for clinical Excellence
RWT	Royal Wolverhampton Hospitals

