

# **Dudley End of Life and Palliative Care Strategy**

## **Implementation Plan 2017**



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## End of Life and Palliative Care Strategy Implementation Plan 2016

This document is to be used in conjunction with Dudley's cross health economy document 'End of Life and Palliative Care Strategy on a Page' (attached as appendix 2).

### What is a strategy implementation plan?

Having a collaborative End of Life and Palliative Care Strategy is a good step for our collective organisations to take, and the goals and outcomes in that strategy are important for our health economy to own. However, many strategies fail due to a lack of a robust approach to implementation.

This document has been written by the three organisations taking part (Dudley Group of Hospitals NHS Foundation Trust, Dudley Clinical Commissioning Group and Mary Stevens Hospice) to help support all organisations delivering care to patients with end of life and palliative care needs and guide them with their own strategy implementation. The document will support this process by providing an approach to self-assessment of implementation.

Following the self-assessment process each organisation will be expected to complete the implementation process (appendix 1).

Strategy implementation often fails so by explaining this at the start of the process we hope to avoid it. The common mistakes are:

- The organisation ignores the plan and managers make decisions at odds with it, which is confusing for stakeholders
- There is poor communication of the strategy to stakeholders, or confusing terminology and language is used
- Operations day to day cause the organisation to lose sight of the strategy
- The strategy is an add-on rather than seen as core business of the organisation
- Once the strategy is written, the organisation goes back to business as usual and ignores the strategy
- The organisation avoids the sometimes tough decisions that implementation of the strategy calls for
- Measuring the wrong things - choosing what's easy rather than what's important
- No benchmarking against other organisations
- Stakeholders see the strategy as an end in itself

Each of the organisations in Dudley should look at ways of ensuring that these common mistakes do not happen as part of their implementation.

### Terminology

To provide clarity, for the purposes of this document, the more common term of 'Specialist Palliative Care' is referred to as 'Specialist Level Palliative Care'. Similarly 'Generalist Palliative Care' is referred to as 'Core Level Palliative Care' to highlight the universal need for a basic or core level of palliative and end of life care for all those facing progressive life-limiting illnesses.

### Demographics

In England, approximately half a million people die each year. The number is expected to rise by 17% from 2012 to 2030<sup>[1]</sup>. The percentage of deaths occurring in the group of people aged 85 years or more is expected to rise from 32% in 2003 to 44% in 2030.

Approximately three quarters of deaths are expected, so there is potential to improve the experience of care in the last year and months of life for at least 355,000 new people and those close to them each year<sup>[2]</sup>. High quality end of life care is required for all these people, and can largely be delivered by non-specialist health and care staff as part of their core work, provided they have adequate time, education, training and support to do so.

A proportion of these people will have complex needs requiring access to advice and/or direct care from professionals trained in specialist palliative care. Currently up to 170,000 people receive specialist palliative care each year<sup>[2]</sup> but this is likely to be an underestimate as there is growing recognition of unmet need, especially for those with conditions other than cancer and harder to reach population groups.

Currently there are 15 million people in England with a long term condition (LTC)<sup>[3]</sup>. By 2025, the number of people with at least one LTC will rise to 18 million. The number with two or more LTCs is projected to increase from 5 million to about 6.5 million. Most of these people will need end of life care as they approach their last years, months and days of life. An estimated 10-11% of people over 65 years, and 25-50% of those over 85 years, are frail. Frailty is strongly linked to adverse outcomes including increased mortality.

Around half a million carers provide support to people dying at home of a terminal illness. The cost to informal carers may include lost earnings, caring around the clock and physical or mental health consequences, some of which may be permanent<sup>[4]</sup>. Between 2001 and 2011, the number of unpaid carers has grown by 600,000<sup>[5]</sup>, with almost 4 million of the population care for 1-19 hours each week with the biggest increase in those providing 50 or more hours per week<sup>[6]</sup>.

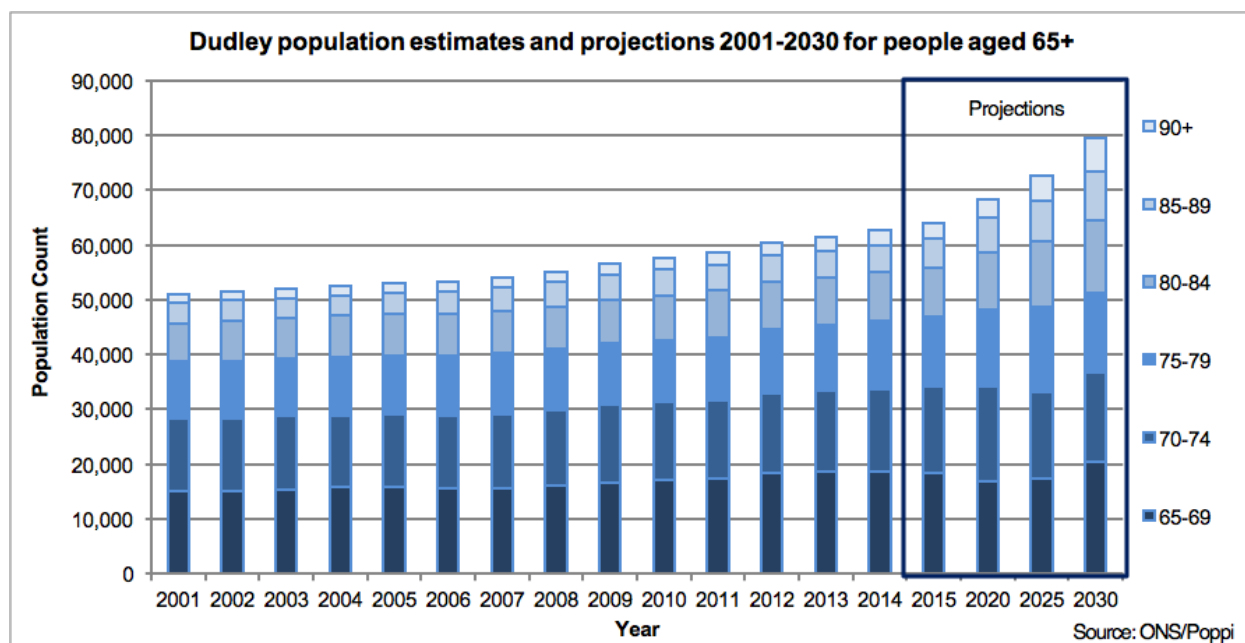


Figure 1

Figure 1 demonstrates the increase in the 65 and over population from 2001 to 2014 and the projected increase to 2030. Between 2001 and 2014 there has been a 23% increase in the number of people aged 65 and over in Dudley. This increase is weighted more heavily towards the older age groups; a 58% increase has been observed in the 90+ age band. This is expected to continue to increase with the over 64 year old population expanding by an additional 27% between 2014 and 2030, with a 134% increase projected for the 90+ age band. Overall an additional 16,825 people are expected to be aged 65 and over in 2030 compared to the 2014 population estimates. As a proportion of the total Dudley population the number of people aged 65 and over is expected to rise from 20% in 2014 to 24.2% in 2030. The increase is even higher in people aged 85 and over, currently this age group accounts for 2.5% of the population, it is expected that they will account for 4.5% of the population by 2030.

The implications from these population projections will be a rise in the numbers of people requiring additional palliative care support for a range of conditions including cancer, respiratory, cardiac, neurological and renal causes, dementia and general frailty. This will also correspond with an increasing need for support in the community particularly where patients identify their preferred place of care as their own home.

## **Definitions**

Many terms are used regularly and interchangeably so it was felt appropriate to define each concept and term used to clarify what is meant when used in this document.

### **Palliative care**

The World Health Organisation has defined palliative care as follows: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions<sup>[7]</sup>.

### **End of life care**

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death<sup>[7]</sup>.

### **Specialist level palliative care**

Specialist level palliative care is required by people with progressive life-limiting illness, with or without co-morbidities, where the focus of care is on quality of life and who have unresolved complex needs that cannot be met by the capability of their current care team. These needs may be physical, psychological, social and/or spiritual. Examples include complex symptom, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions<sup>[8]</sup>.

### **Core level palliative care**

Palliative care that can be provided by a person's usual care team, either in a primary or secondary care setting.

### **Ambitions for Palliative and End of Life Care**

The National Palliative and End of Life Care Partnership in the UK has produced a national framework for local action for the years 2015-2020. This contains the six ambitions for all palliative care services to aim for.

Ambition One: Each person is seen as an individual

Ambition Two: Each person gets fair access to care

Ambition Three: Maximising comfort and wellbeing

Ambition Four: Care is coordinated

Ambition Five: All staff are prepared to care

Ambition Six: Each community is prepared to help<sup>[7]</sup>

## **Strategy Aims and Desired Outcomes**

The long term aim of this strategy is to achieve a number of outcomes which are in line with the National Palliative and End of Life Care Partnership Ambitions as outlined above. These outcomes are listed below and need implementation across the whole of the Dudley to achieve the level of quality palliative and end of life care that is needed by all patients and their families.

### **Identification**

To ensure all patients and families with palliative care needs regardless of diagnosis or setting are identified in a timely manner.

### **Care planning**

To ensure patients and families with palliative care needs are offered the chance to create a personalised care plan.

### **Coordinated care**

To ensure the individual plans and care needs of patients & families are fully understood and coordinated effectively by and amongst all supporting agencies. This will involve provision of an effective system to enable shared records.

### **Equitable access 24/7**

To ensure all patients and families with palliative care needs regardless of diagnosis or setting can access the right help at the right time.

### **Positive rated experience**

To ensure effective data collection including person centred outcome measurement, patient and families experiences.

### **Education and training**

To develop and implement a framework for education, training, competency and Continuing Professional Development to ensure all staff have the necessary skills, knowledge and attitude to care for palliative patients.

## Appendix 1

### **End of Life and Palliative Care Strategy Implementation Self Assessment**

In order to achieve the outcomes listed above, the starting point must be to take stock and consider what is already being done in line with the outcomes. To do this, each organisation should use the six self-assessment tables below to identify where they already are in the process of implementing the strategy. The results of this will help guide the next steps of the work that each organisation needs to do in order to achieve the outcomes.

**Outcome 1 (Ambition 1 & 2)**

**Identification: To ensure all patients and families with Palliative Care needs regardless of diagnosis or setting are identified in a timely manner**

	No plan in place – no implementation	Plan in place – no implementation	Plan in place – partially implemented	Plan in place – fully implemented	Evidence to support rating
Systems / processes in place to identify the palliative care needs of patients and families					
Proactive communication about patient identification including use of Information Technology (IT)					
Education and training of staff in identification of palliative care needs					



**Outcome 2 (Ambition 1 & 4)**

**Care Planning: To ensure patients and families with palliative care needs are offered the chance to create a personalised care plan**

	No plan in place – no implementation	Plan in place – no implementation	Plan in place – partially implemented	Plan in place – fully implemented	Evidence to support rating
Agreed personalised care plan document in place					
Clear process agreement with who holds the document, how it is updated and communicated amongst professionals					
Education ensures professionals have the competencies to support patient and family to develop the care plan					

**Outcome 3 (Ambition 3 & 4)**

**Co-ordinated care: To ensure the individual plans and care needs of patients & families are fully understood and coordinated effectively by and amongst all supporting agencies. This will involve provision of an effective system to enable shared records**

	No plan in place – no implementation	Plan in place – no implementation	Plan in place – partially implemented	Plan in place – fully implemented	Evidence to support rating
Clear defined roles and responsibilities exist within organisation regarding the provision of specialist and core level palliative care for patients and families					
Shared electronic clinical record with robust consent procedure and data sharing agreements					

**Outcome 4 (Ambition 2,3,4,5 & 6)**

**Equitable access 24/7: to ensure all patients and families with palliative care needs regardless of diagnosis or setting can access the right help at the right time**

	No plan in place – no implementation	Plan in place – no implementation	Plan in place – partially implemented	Plan in place – fully implemented	Evidence to support rating
24/7 access to core palliative care					
24/7 access to specialist level palliative care					
Equitable access for all; including children, people transitioning from children’s to adult services, people from all cultural backgrounds					

**Outcome 5 (Ambition 3, 5 & 6)**

**Positive rated experience: To ensure effective data collection including person centred outcome measurement, patient and families experiences**

	No plan in place – no implementation	Plan in place – no implementation	Plan in place – partially implemented	Plan in place – fully implemented	Evidence to support rating
Collection of person centred outcomes					
Reporting process of person centred outcomes					

**Outcome 6 (Ambition 5 & 6)**

**Education and Training: To develop and implement a framework for education, training, competency and CPD to ensure all staff have necessary skills, knowledge and attitude to care for palliative patients**

	No plan in place – no implementation	Plan in place – no implementation	Plan in place – partially implemented	Plan in place – fully implemented	Evidence to support rating
Training needs analysis exists in your organisation					
Current training and education programme and process of implementation					
Assessment and reporting of competences					

## REFERENCES

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# Our vision for Dudley

All people with palliative and end of life care (EOLC) needs, irrespective of their diagnosis, together with those closest to them, are able to express their needs and wishes; and that as far as clinically appropriate and practically possible, these needs and wishes are met.



<b>Ambition 1</b> Each person is seen as individual	<b>Ambition 2</b> Each person gets fair access to care	<b>Ambition 3</b> Maximising comfort and wellbeing	<b>Ambition 4</b> Care is coordinated	<b>Ambition 5</b> All staff are prepared to care	<b>Ambition 6</b> Each community is prepared to help
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## Outcomes

### Identification:

To ensure all patients and families with palliative care needs regardless of diagnosis or setting are identified in a timely manner.

### Care planning:

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### Coordinated care:

To ensure the individual plans and care needs of patients & families are fully understood and coordinated effectively by and amongst all supporting agencies. This will involve provision of an effective system to enable shared records.

### Equitable access 24/7:

To ensure all patients and families with palliative care needs regardless of diagnosis or setting can access the right help at the right time.

### Positive rated experience:

To ensure effective data collection including person centred outcome measurement, patient and families experiences

### Education and training:

To develop and implement a framework for education, training, competency and Continuing Professional Development to ensure all staff have the necessary skills, knowledge and attitude to care for palliative patients.