

**Improving palliative and end of life care in Dorset
Dorset End of Life Care Partnership
Programme Charter June 2017**

KEY MESSAGES:

- **What really matters? Find out “What matters most?” to each individual**
 - **Help people to plan ahead – avoid a crisis**
 - **Care for each other, learn from each other**
 - **End of life care is everyone’s business**
 - **We have one chance to get it right**
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Our overall STRATEGY is to:

- Improve the **recognition** and **understanding** of people’s needs and preferences;
- Enhance the **capability, capacity** and **compassion** of the workforce and community;
- Improve **access** to other resources essential for good end of life care.

AIM STATEMENT: What are we trying to accomplish?

We want to achieve the national ambitions for palliative and end of life care in Dorset by October 2018. This means that:

- each person is seen as an individual;
- each person has fair access to care;
- comfort and wellbeing are maximised;
- care is coordinated;
- all staff are prepared to care and
- each community is prepared to help.

In other words, every individual approaching the end of their life has access to good palliative and end of life care to support them and their family.

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Problem to be addressed

Palliative and end of life care are variable, with some examples of excellent care but others of poorly coordinated care. More people die in hospital than would wish to do so and not everyone has fair access to timely care.

Reason for the effort

Failure to find out what matters most to individuals are their families, and to tailor their care and support accordingly, is a lost opportunity and results in unnecessary distress and disappointment, wasted resources, unwanted hospital admission, investigation and treatment. Unmet needs in symptom control, psychological support, practical support have a highly significant impact on individuals in their last months or weeks of life, and their families.

Unplanned admissions in the last months of life account for a high proportion of expenditure in the NHS. The cost of care in the last three months of life averages over £4500 per person, with the bulk of this cost arising from emergency hospital admissions and rising steeply as death approaches (Georghiou and Bardsley 2014). Unplanned admissions in the last year of life account for approximately 15% of the total, and up to 30% of adult inpatients are in their last year of life. In 2015, a total of 9032 Dorset residents died - 25 per day, on average - an increase from 8331 in 2014; this trend is predicted to continue and there is an increase in complexity of need (for instance, people having several coexisting health conditions).

Limited resources in health and social care mean that we have a significant challenge to meet the needs of everyone approaching the end of life and a duty to make the best use of the resources available.

A collaborative approach will enable us to achieve the best outcomes and experience for all, with an approach which is consistent locally and nationally.

End of life care is everyone's business. We have one chance to get it right.

Expected outcomes/benefits

- Improved experience for people in their last months of life, and their families;
- Improved outcomes for people in their last months of life, and their families;
- Reduction in unplanned admissions to hospital for people in their last months of life, and reduction in length of stay in hospital;
- Reduction in unwanted investigations and treatment in the last months of life;
- Overall savings for the healthcare economy in Dorset through treatment which is tailored to the individual's needs and preferences and through integrated working;
- Sustainability;
- Enhanced knowledge and skills for the wider workforce in health and social care.

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How do we know that a change is an improvement?

Measures are listed separately. Development of a Dorset-wide palliative and end of life care dashboard will enable us to monitor our progress and the impact of quality improvement initiatives. This is *measurement for improvement*, rather than for judgement.

Who are the key stakeholders?

Key stakeholders include the local population, particularly people with life-limiting illness and their families; local community and acute trusts; ambulance and transport services; integrated community services; GPs; out of hours providers; local authorities; residential and nursing homes; voluntary and charitable providers; hospices and palliative care services; Dorset CCG; Wessex End of Life Care Group (see terms of reference for the Dorset End of Life Care Partnership for full list).

What changes can we make that will lead to improvement?

Improvement requires change but not all change leads to improvement. An initial action plan has been developed by the partnership. It is anticipated that each working group will prioritise key areas to lead on and develop these using the Model for Improvement - identifying a clear Aim statement, Measures (Outcome, Process, Balancing measures) and changes to be tested through Plan Do Study Act cycles.

What are the constraints and barriers to success?

We will not directly address recruitment / retention of the palliative and end of life care workforce (though we anticipate these will be improved through the programme). Barriers to success include:

- Appetite for change and the will to make this work.
- Other pressures on time for members of the partnership and colleagues involved in the quality improvement work.
- No additional funding is allocated currently to achieve the changes required, although some project management is available through Vanguard and the Wessex End of Life Group.

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Our overall strategy is to:

- Improve the recognition and understanding of people's needs and preferences;
- Enhance the capability, capacity and compassion of the workforce and community;
- Improve access to other resources essential for good end of life care.

1. Recognition and understanding of the needs, priorities and preferences of people in their last year of life:

- Holistic understanding of people's needs, preferences and priorities at individual, locality and system-wide level - "what matters most?"; wide range of techniques to develop our understanding, including the use of shadowing. Use these insights to improve services across a range of settings
- Recognition of approaching end of life
- Supporting individuals and their families to plan ahead
- Shared decision making

2. Capability, capacity and compassion of the workforce and local community:

- Systems leadership, governance; engagement at board level
- Enabling the current workforce to use their skills and time effectively e.g. by:
- System and process redesign:
 - Integrated care models, coordination of services
 - Clear, streamlined processes for access to palliative and end of life care including risk stratification (e.g. for management of less complex symptoms or concerns and for referral for input from specialists for those with more complex needs)
 - Optimise tools and processes to support individualised care and seamless transfer between care settings - e.g. DNACPR/allow a natural death; Treatment Escalation Plans; Future care planning; Personalised Care Plan for the Last Days of Life; Rapid Discharge Home. Use a standardised approach where possible (this will enhance improve continuity of care, improve cross-boundary working, make education and training more efficient)
 - Shared electronic records; future care planning using the Dorset Care Record
 - Anticipatory prescribing - consider adopting a standardised approach with individualisation where needed
 - Availability of care - timely access; improving the Fast track CHC process; consider developing Hospice@home model
- Clear programme of education and training for all levels of staff working in each setting in health and social care, including care homes, ambulance staff, acute and community hospitals etc.; paid and unpaid carers; includes recognition of approaching the end of life, symptom management, communication, discussing end of life care issues, moving and handling, mental capacity act etc. Ensure staff can take time to attend / engage in education; ensure palliative and end of life care are incorporated into all relevant education and training strategies
- Building resilience and joy in work; meaningful work; psychological / peer support / clinical supervision
- Developing Dorset's compassionate community, including improving the way that families, neighbours and volunteers can contribute.

3. Improving access to other resources:

- Shared information - e.g. directory of palliative care services, website accessible to public and to referrers relating to palliative and end of life care; clear links from individual providers' websites; clear signposting re palliative and hospice services.
- Shared access to key outcome measures via Dorset-wide dashboard.
- Medications used in end of life care, including access out of hours.
- Palliative care transport - improving timely access by improving reliability and reducing variation.