

## End of Life Care Strategy Oxfordshire 2015/16

### Executive Summary

This document is designed to provide information regarding Oxfordshire Clinical Commissioning Group's (OCCG) strategy for end of life care and the model of care commissioned

The purpose of this document is to set out our aims and objectives in the commissioning and development of services for patients with end of life care needs, and detail how we are implementing and monitoring the National Strategy for End of Life Care<sup>1</sup>, One Chance to Get it Right<sup>2</sup> and taking into account of NHS England publication Actions for End of Life Care 2014-16<sup>3</sup> and Ambitions for Palliative and End of Life Care: A National Framework for Local Action: 2015-2020' .

This document also builds upon the excellent work developed over a number of years in conjunction with End of Life providers with strong clinical leadership and engagement.

The NICE Quality Standards (published in 2011) are specific, concise statements and specific markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. In light of these, an interim review of the strategy was requested not only assess progress made to date but also to refocus commissioning priorities and ensure that the quality standards are fully integrated.

*A Working Definition of End of Life Care (as developed by National Council for Palliative Care 2006 & The End of Life Care Strategy 2008):*

End of life care is care that helps all those with advanced, progressive, incurable illness with death expected within 12 months to live as well as possible until they die. It covers the supportive and palliative care needs of patient, family and carer to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Oxfordshire stakeholders have identified the following as guiding principles:

- Right care, right time, right place
- Full range of care options available
- Avoidance of unnecessary hospital admissions.

The vision for End of life Care in Oxfordshire is that it should be co-ordinated and personalised. Simple enough for anyone (patient and professional) to navigate, co-ordinated so that all services work together to deliver seamless care and personalised so as to meet the needs of the individual patient.

### Aims

The aims are:

1. To ensure best possible quality of end of life care for patients and families regardless of diagnosis or of where they are cared for. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.

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<sup>1</sup> End of Life Care Strategy: promoting high quality care for adults at the end of their life, Department of Health, 16<sup>th</sup> July 2008, <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

<sup>2</sup> One chance to get it right, Leadership Alliance for the Care of Dying People, June 2014, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/323188/One\\_chance\\_to\\_get\\_it\\_right.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf)

<sup>3</sup> NHS England Actions for End of Life 2014 -16 <http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

2. To ensure OCCG policy and commissioning arrangements support the quality standards in the NHS England Actions for End of Life 2014, NICE Quality Standards for End of Life Care 2011, the National Strategy for End of Life Care 2008 and “One Chance to Get it Right” from the Leadership Alliance of Dying People 2014, Ambitions for Palliative and End of Life Care: A National Framework for Local Action: 2015-2020’.

## Objectives

1. **To list current Oxfordshire services providing EoL care with enough details to provide clarity about what is commissioned and scope of services including voluntary sector services available in the county.**
2. **To develop a performance monitoring tool that collects information on key outcome measures and which can help compare local with national outcomes (e.g. preferred place of care and compare to actual place of death, numbers identified on palliative care register, % with Advance Care Plans)**
3. **To develop an electronic palliative care register that can be shared among appropriate health professionals**
4. **To develop an Oxfordshire web-based resource for health care professionals and patients/families/carers**
5. **To promote a culture of learning and professional development that enables both individuals and with wider system to provide cost-effective improvements in end of life care.**

## Scope

The scope of this strategy encompasses:

- Care provided to all across Oxfordshire with any advanced, progressive or incurable illness when death is expected within the next 12 months.
- Care provided in all settings i.e. home, residential/care/nursing home, hospice, acute hospital.
- Patients, carers, public, family members and staff.

## Context<sup>3</sup>

In England, approximately half a million people die each year. The number is expected to rise by 17% from 2012 to 2030. 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. High quality generalist end of life care is required for all these people, and can be delivered by non-specialist health and care staff as part of their core work, provided they have adequate time, education and 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>6</sup> but this is likely to be an underestimate as there is growing recognition of unmet need, especially for those with non-cancer conditions and harder-to-reach population groups.

- Nationally, the number of people dying in their ‘usual place of residence’, i.e. at home or in care homes has risen from under 38% in 2008 to 44.5% now. In Oxfordshire, the figure in Q4 2013/14 was around 47% (End of Life Care Intelligence ONS data). We acknowledge however that this does not reflect quality of experience and data from National Voices Survey notes that only 465 respondents considered care to be outstanding or excellent.

Population-based studies of preferences for place of death indicate that over 60% of people (including those who were not facing life-threatening illness at the time) would prefer to die at home. Key findings from the 2013 National Survey of Bereaved People (VOICES-SF)<sup>4</sup> which collected feedback from bereaved people between 8-11 months after the person's death including:

- Overall quality of care across all services in the last three months of life was rated as outstanding or excellent by 43% of respondents.
- Pain relief was reported to be inadequate for 53% of those who died at home, as compared to 32% in hospitals, 25% in care homes and 13% in hospices.
- Almost 16% of respondents reported that services were not well coordinated in the last three months of life.
- Over 16% of carers and families did not receive adequate support despite asking for more help.
- 82% of respondents felt that the person had died in the right place.

The local end of life care strategy reflects the aims and objectives of Oxfordshire CCG's five year strategic plan and two year implementation plan to:

- I. Be financially sustainable.
- II. Be delivering fully integrated care, close to home, for the frail elderly and people with multiple physical and/or mental health needs.
- III. Have a primary care service that is driving development and delivery of this integrated care, and is itself offering a broader range of services at a different scale.
- IV. Routinely enable people to live well at home and to avoid admission to hospital when this is in their best interests.
- V. Be continuing to provide preventative care and to tackle health inequalities for patients and carers in both its urban and rural communities.
- VI. Be providing health and social care that is rated amongst the best in the country for all its citizens in terms of quality, outcomes and local satisfaction with services.

This document also supports the delivery of a number of NHS England's ambitions, as set out in Everyone Counts: Planning for Patients 2014/15 to 2018/19, particularly:

- Improving the health related quality of life of the 15+ million people with one or more long-term condition, including mental health conditions.
- Reducing the amount of time people spend avoidably in hospital through better and more integrated care in the community, outside of hospital.
- Increasing the number of people with mental and physical health conditions having a positive experience of hospital care.
- Increasing the number of people with mental and physical health conditions having a positive experience of care outside hospital, in general practice and in the community.
- Reducing health inequalities.

## **OCCG Commissioning Intentions**

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<sup>4</sup> [http://www.ons.gov.uk/ons/dcp171778\\_317495.pdf](http://www.ons.gov.uk/ons/dcp171778_317495.pdf)

Contractual relationships exist with GPs, Oxford Health Community Trust, Oxford University Hospitals, the hospices of Michael Sobell House (Oxford City and Oxfordshire), Sue Ryder (Nettlebed in South Oxfordshire) and Katherine House (in North Oxfordshire), nursing and bereavement services from various providers. Helen and Douglas House provide age appropriate palliative and specialist palliative care for children and young adults (up to 35 years with life threatening and life shortening conditions. Douglas House are a significant Thames Valley provider of specialist palliative care but this is mainly purchased through personal health budgets.

There is currently a national NHS England project underway aiming to create a fair and transparent funding system for palliative care which will deliver better outcomes for patients & better value for the NHS

These aims should be achieved by developing:

- An NHS palliative care formula which is based on need
- A funding system which incentivises good outcomes for patients, irrespective of both time and setting
- The commissioning of integrated care packages which provision community services.

The developmental (draft) currencies are being tested during 2015/16 and the outcome will inform future funding arrangements.

The CCG has the following commissioning intentions for 2015/16 with regards to end of life care:

- Provide rapid and multi-disciplinary assessment and support, and where necessary same day home-based services for people at the end of life.
- Reduce avoidable admissions by improving end of life care.
- Self/carer referral/access to Single Point of Access for end of life care, providing advice and support with access to night sitting.
- 95% of Rapid Response referrals to be processed for end of life care within two hours.

**Current Provision:** See Appendix A current contracts

OCCG intention is to review all current contracts during 2015/16 to ensure most appropriate use of current resources to meet the needs of our local population

### Challenges Already Identified

- The need to establish patient and family wishes /preferences and to ensure these are documented in a way that all those involved in providing care are aware of them but also to show flexibility and adapt to changing wishes/needs.
- Ensuring coordination of care access to services at whatever time of day (or night)
- Training and support for staff and families/carers
- Complex care -It must be recognised that patients at the end of life may have additional complex physical, learning or mental disabilities which may not be identified. It is also recognised that a number of patients will have complex palliative care needs requiring specialist palliative care input.
- Ensuring we are commissioning appropriate services to meet the needs of our population
- Ensuring equity and accessibility of services by age and condition particularly for those who are homeless, have serious mental illness or where cultural/language barriers exist.
- Data to inform review of current services

### Key priorities

4 End Of Life Care Strategy v8 July 2015

Dr Julie Anderson (OCCG EoL Clinical Lead) & Sara Wilds (OCCG Lead EoL)

As identified in a 2012 joint health and social care interim review of the Oxfordshire End of Life Care strategy, our priorities remain:

**1. Early identification of people at the end of life**

- Increase the number of patients identified as nearing the end of life (within the last 12 months) in order that their final months are proactively managed. There would be an expectation that these patients would be recorded in a palliative care register.
- Accurate and timely identification of those who need specialist palliative care (in addition to the generic end of life care identification).

**2. Assessment and Advanced Care Planning**

- To enable the sharing of relevant clinical and social information about EoL patients. This information should be available when required to all key personal involved in the patients care.
- Encourage the use of regular documented discussions (in keeping with the Gold Standards Framework for Palliative Care meetings) throughout primary care.
- To develop an electronic palliative care register based on the Oxfordshire digital Proactive Care Plan shared between relevant agencies.
- Timely management of EoL patients to address symptom control and holistic care needs as well as to discuss and document Advance Care Planning wherever possible
- To improve and develop standards of end of life awareness and data across the county.

**3. Holistic Support**

- People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met, including access to medicines and equipment.
- Strong integration with health and social care to ensure coordinated working between the health and social aspects of end of life care.
- Patients are fully aware of the range of services available to them and are actively involved in how the services will respond to their changing needs and as far as possible have their wishes met.
- Health care professionals communicate with people approaching the end of life and their families/ carers to provide information, in an accessible and sensitive way in response to their needs and preferences.

**4. Access to enhanced end of life care services**

- All EoL services to be accessible via the single point of access if required
- Easily accessible and comprehensive EOLC information for patients, families, their carers and clinicians. Services to support people to stay within their own homes where it is most appropriate and provide a co-ordinated package of community based services aimed at providing best possible symptom control and supportive care needs. This will ensure a reduction in the number of unnecessary emergency admissions to hospital by providing co-ordinated anticipatory care at the end of life.
- Ensure that at least one of the key health professionals providing care is in a position to coordinate the appropriate services and identified as key coordinator.
- Supportive educational resources, to minimise the number of hospital attendances (ie where no longer in patient's best interests) and emergency admissions to hospital in the last year of life.
- Flexible, responsive services to support EoL patients in crisis to remain at home where appropriate.

- To provide a rapid response service to those patients discharged home to die.
- End of life services should address 24 hour care needs as much as possible

#### **5. Care in the last days of life**

- Wider and more timely recognition that the terminal stage has been reached.
- Implementation of the appropriate care to support the patient's and carers' needs at this time.
- To provide rapid response services to meet changing conditions.
- Primary and secondary care to work together to facilitate discharges into the community where possible.

#### **6. Care after death**

- Ensure there is prompt verification, certification and registration of death as well as attending to the removal of any devices or appliances from the body. Ensuring that there are suitably trained health care professionals to support this.
- Ensure there is sensitive but clear information provided to the bereaved and carers about the processes
- Ensure other key health professionals are informed about death and suitable arrangements made to remove drugs/equipment from home.
- Care provided after death, including the support provided to bereaved families and carers. Ensure there is dignity and respect with sensitivity to cultural / spiritual needs following death.
- Co-ordinated bereavement advice and support on practical and emotional needs
- Promote the use of after death review in primary care to include preferred place of death and actual place of death to determine future service planning and improvement.

#### **7. Workforce**

- Ensuring that the work force has the appropriate skill mix and education to enable all services to be responsive, informed and have adequate capacity to provide a high quality service.
- To provide an easily accessible, electronic resource on all EoL services across the county

This will form the bulk of the End of Life work plan over the next 5 years and will deliver the vision of simple, co-ordinated and personalised End of Life care for all.

The following outcomes have been determined through discussion with stakeholders and align to the NICE quality standards for end of life care.

There will be:

- an increase in the identification of patients in the last 12 months of life
- a reduction in the number of deaths in hospital
- a reduction in the number of unplanned hospital admissions for end of life patients
- a reduction in the total length of hospital stay for patients in the last year of life
- an increase in the number of deaths in a person's preferred place of death
- an increase in use of DNACPR and Advanced Care Plans (Proactive care plans)
- an improvement in patient satisfaction rates for end of life care services (VOICES National Survey)

- an on-going rolling programme of education for all services and settings.

**These feed into the 5 objectives listed at the beginning of this strategy document:**

- 1. To list current Oxfordshire services providing EoL care with enough details to provide clarity about what is commissioned and scope of services**
- 2. To develop a performance monitoring tool that collects information on key outcome measures and which can help compare local with national outcomes (e.g. preferred place of care, place of death, numbers identified on palliative care register, % with Advanced Care Plans)**
- 3. To develop an electronic palliative care register that can be shared among appropriate health professionals**
- 4. To develop an Oxfordshire web-based resource for health care professionals and patients/families/carers**
- 5. To promote a culture of learning and professional development that enables both individuals and with wider system to provide cost-effective improvements in end of life care.**

This strategy, associated aims, objectives and outcomes will be continuously audited, monitored, evaluated and adjusted accordingly.

**Next Steps (for discussion through EoL Reference Group):**

**A system wide work programme to be developed through the EoL Reference Group  
Governance – to report into OCCG Urgent Care Programme Board**

1. Make inventory of all current services available:
  - Hospices and number of beds, number of community specialist nurses in each
  - Number and role of community matrons (and provider)
  - Status of EoL care training in District Nursing services, community specialist nurses (eg community respiratory, heart failure and neurology specialist nurses), and secondary care oncology cancer site specialist nurses and haematology specialist nurses
  - Provision of syringe drivers and expertise in their use
  - GP practices approach to palliative care meetings (with documentation), an EoL care register of patients with key GP +/- DN, and % with ACPs.
  - Identified EoL Care lead in each GP practice
  - State benefits available to patients and carers such as DS1500
  - Educational services:
    - for patients/carers
    - for health professionals
    - monitoring data for commissioners and providers including strategy and implementation groups and feedback data
  - Other support services: Marie Curie nurses for night care, Hospital at Home or similar
  - Information services Oxfordshire-based
    - for patients/carers
    - for health professionals
    - monitoring data for commissioners and providers including strategy and implementation groups and feedback data
2. Collect currently available information on quality of care in EoL in Oxon, preferably benchmarked against national data
  - Place of death

- Death within 48 hours of admission
- Information from National Bereavement Survey (VOICES)
- Data under development through digital Proactive Care Plan development

3. Identify the gaps:

- Some clinicians not confident in EoL care
- Uncertainties/lack of confidence in managing symptoms in primary care at times
- Lack of clarity about when and how to access support services
- Imperfect systems for identifying palliative care patients and lack of pro-active advanced care planning
- Lack of clarity in mechanisms for sharing data between services caring for EOL patients.
- Absolute lack of provisions in some cases in sufficient support services to manage patient in their preferred place of care
- Inconsistent quality of EoL care in nursing and care homes
- Lack of information for commissioners and providers to know quite how we are doing including feedback from patients/carers
- Electronic proactive care plan not complete
- Review of all current services and contracts to include those not currently commissioned and those provided by voluntary sector.
- Delays in discharge process due to access to social care for assessment or domiciliary care, CHC or care home placement.

4. Identify priorities:

- Plug the knowledge gaps
  - website resources for patients/carers and health professionals
  - monitoring data for commissioners and providers (both on sections of OCCG intranet) including strategy and implementation groups and feedback data
- Plug the training and skills gaps
- Clarify the gaps in provision
- Raise the profile of EoL care so that it is high on the radar for all those involved in providing EoL care and understand the aims and aspirations of best quality EoL care

5. Set out action plan:

- Develop and advertise widely all the relevant website resources:
  - i.e. Oxfordshire-based Information services
    - website (section of OCCG website) for patients/carers (and printable leaflets for those without computers)
    - website resources for health professionals
    - include strategy, key contacts for service provision issues, implementation groups and feedback data for interested parties
- Develop database of services and consider development of a monitoring “dashboard” for selected aspects (“how are we doing”) e.g. similar to that used to monitor prescribing in practices and make comparisons for commissioners and providers



- Include financial as well as activity data where relevant (for commissioners)
- Explore potential of electronic palliative care register
- Set up regular educational and training resources (could be on-line ones)
- Define how existing groups and roles in EoL Care can be best used to achieve these aims

## Appendix A

<b>End of life Contracts 2015/16</b>	<b>Services provided</b>
Sue Ryder Hospice	Palliative care
Sobell House	Palliative care and Bereavement services
Kates Home Nursing	Night sitting
Lawrence Home Nursing	Night sitting
OXBEL	Befriending service
Katharine House Hospice	Palliative care
Cruse	Bereavement services
Marie Curie	Night sitting