Appendix 1

Desk Top Search to support:
The Banbury Area Bereaved People Needs' Study
April 2016

Content

A review of Oxfordshire Bereavement Services by Dr Marilyn Relf in 2012 was commissioned by OCCG and Sobell House. The detailed findings have been extensively used through this needs study.

Bereavement Needs Study for the Banbury Area

June 2016

1. The scope of this needs study

This study covers the Banbury Area as defined by Oxfordshire Clinical Commissioning Group (OCCG) North Oxfordshire Locality Group (NOLG). It includes Bloxham, Chipping Norton, Cropedy, Deddington and Hook Norton.

The North Oxfordshire Locality Group is one of the six Clinical Commissioning Groups in Oxfordshire which are part of the (OCCG).

Oxfordshire has been divided into six geographical localities which are made up of the GP practices in that patch. The GP practices of each locality meet on a regular basis to discuss progress on their priorities for healthcare in their area of the county.

The NOLG has 108,040 registered patients, served by twelve GP practices. They are all member practices of Oxfordshire Clinical Commissioning Group. The figure of 108,040 is around 15% of the total Oxfordshire registered patients.

http://www.oxfordshireccg.nhs.uk/your-local-area/localities/north/ (viewed 23/6/16)

NB: OCCG boundaries are based on the location of GP practices rather than where people live. This means that some people living outside Oxfordshire will be registered with GP practices in the OCCG area. Conversely, some Oxfordshire residents will be registered with GPs located outside the county – and some may not be registered with a GP at all.

The population of Oxfordshire was 653,800 at the 2001 census, and was estimated to be 673,000 in June 2013 with estimated growth to 684,000 by 2016. (Office National Statistics) The area under consideration for this study falls within the Cherwell District Council boundaries. The population of Cherwell was estimated at 144,494 in 2014.

2. The case for bereavement services

This review found that there is no evidence to support the universal use of intense bereavement interventions as a majority of people find that their inner resources combined with support from family and friends help them to adjust to their loss. However, a substantial minority of 15-20% of bereaved people experience enduring physical and mental health problems which may continue at high levels for more than a year and impact negatively on their capacity to cope with everyday life.

When a death is expected anticipatory grief may be experienced at the diagnosis of a life shortening or life threatening illness. This is particularly the case for those caring with someone with dementia (Schultz et al 2003).

The end of life bereavement care pathway shows what services the family may need at this stage and that there is a need for close links been pre-bereavement care prior to death and bereavement support after death.

3. National guidance

- NICE (National Institute for Health and Care Excellence) guidance, *Improving supportive palliative care for adults with cancer* (2004) recommends a 3 component model of bereavement care and the national End of Life Care Strategy applies this model to all expected deaths (2008)
- NICE Quality Standard {QS13} End of life care for adults (2011) update 2013
- With Quality statement 14 - care after death bereavement support
- Bereavement care service standards, Cruse and Bereavement services association, 2013
- The Oxfordshire Clinical Commissioning Group's 'End of Life Care Strategy, 2015/16'. See below.

4. Components of good bereavement care

NICE guidance for improving palliative care for adults with cancer 2004 recommends a three component model of bereavement care and the End of Life Care Strategy 2008 recommends applying this model to all expected deaths**.**

Table 1 component model of good bereavement care

Component	**Description of service**
1	All bereaved people should be provided with information about grief and bereavement and how to access local and national support services
2	Some people need more formal support to reflect on their loss this can be provided by faith and community groups, mutual help groups, volunteer bereavement support workers – it does not have to be professionals.
3	A minority of people will need more specialist interventions as their grief may be complex – this should be provided by specialist counsellors or mental health professionals.

4.2. Levels of support

Estimates of the proportion of people who may need more formal support vary. Aoun et al (2015) found that 35% of bereaved people had a need for component 2 services and Relf's survey of 10 years' experience at Sobell House(1992-2002) found that 33% of bereaved people made use of a component two service. There is a growing consensus that 5-10% of bereaved people will need more specialist intervention because their grief is

complex or complicated (Shear 2015, Bonanno 2002) with Aoun et al (2015) reporting 6% and Relf 9% using such intervention.[1]

For the purposes of this study:

- we assume that everyone needs component 1 support
- 60% of bereaved people will not need additional support other than from family and friends
- 30% of people may need component 2 services and
- between 5-10% of people may need component 3 services

5. Analysis of Banbury services by component

Services in Banbury are offered at 3 different stages in the bereavement pathway.

Pre bereavement services –offered to family members beyond that given by health and social care staff**.** This includes: Samaritans, Lawrence Home Nursing Service,

Services at time of death – which include district nurses, GPs, funeral directors, and ministers of religion/faith groups and the OUH NHS Foundation Trust Bereavement Services in Oxford and Banbury.

Post bereavement services – which offers family members and care givers on-going support and /or bereavement counselling and peer support. Includes Cruse, MIND, Late Spring Way Up, Primary Care Bereavement services

6. Risk factors associated with complicated or complex grief

Research shows that there are risk factors associated with complicated grief and that these factors are cumulative (Stroebe and Schut 2001). Dr Relf's report categories them as follows:

Table 2: Risk factors associated with complicated grief

Category	Risk factor	Reason
1	events and circumstances surrounding the death	unexpected or shocking, long periods of care giving
2	personal factors interpersonal factors	social support is lacking or perceived to be so the person feels isolated
3	intrinsic to the bereaved	difficult life experiences,

1

Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B, Hegney D. (2015).Who needs Bereavement support: A population based survey of bereavement risk and support need PLOS one 2015;26: 1-14.

	person	concurrent losses or health problems

7. Oxfordshire and Banbury demographics

7.1. Oxfordshire's estimated population mid-2014

Table 3: Oxfordshire's estimated population by District mid-2014

District	Total estimated population	Number of people aged 65+	People over 65 as % of area's population
Cherwell	144,494	24,500	17%
Oxford	157,997	17,800	11.3%
South Oxfordshire	137,015	27,300	19.9%
Vale of White Horse	124,852	24,400	19.5%
West Oxfordshire	108,158	21,600	19.9%
Oxfordshire Total	672,516	115,600	17.2%

There are three wards in Cherwell – Cropedy, Deddington and Adderbury where older people make up more than 25% ie a quarter of the population.
(Source: ONS mid-year population estimates, mid-2014)

7.2. Future Housing development affecting population growth

The Oxfordshire Local Plan, anticipates that most of the housing and infrastructure growth will be directed to locations within or immediately adjoin Banbury town. **(Source: needs analysis for older people in Oxfordshire, April 2016)**

7. 3. Ageing population

The older population in Oxfordshire aged 65+, is expected to grow twice as fast as the overall county population (and is already growing faster than at national and regional levels). Although in some respects older people may be considered better off than their younger counterparts, they are more likely to be living with limiting health conditions and may be especially vulnerable to problems such as isolation and loneliness.

Older people are now estimated to make up just over a sixth (17.2%) of the county's population. At the time of the 2011 Census that proportion stood at 15.9%; in 2001 it was 14.5%. It is expected to continue growing in the future
(Source: needs analysis for older people in Oxfordshire, April 2016)

7.4. Cherwell race and ethnicity

According to the 2011 Census, Black or Minority Ethnic (BME) communities makes up 9.2% of the county's population almost double the 2001 Census figure of 4.9%.
This proportion varies by District.
22.4% Oxford - almost a quarter of population
7.8% Cherwell
5.1% Vale of White Horse
3.9% South Oxfordshire
3.2% West Oxfordshire

(Source Oxfordshire Insight Nov 2014 http://insight.oxfordshire.gov.uk/cms/system/files/documents/RINews_Nov14_FINAL.pdf)

7.5. Cherwell health in summary

The health of people in Cherwell is varied compared with the England average. Deprivation is lower than average, however about 11.1% (3,100) children live in poverty. Life expectancy for men is higher than the England average.

Living longer Life expectancy is 9.6 years lower for men and 7.1 years lower for women in the most deprived areas of Cherwell than in the least deprived areas

7.6. Deaths in Oxfordshire

Table 4. Deaths in Oxfordshire by area of usual residence

Area of usual residence	Number of deaths	Number of deaths	Number of deaths
2012	Persons	Males	Females
Oxfordshire	**5,291**	**2,527**	**2,764**
Cherwell	1,122	518	604
Oxford	932	443	489
South Oxfordshire	1,207	576	631
Vale of White Horse	1,055	518	537
West Oxfordshire	975	472	503
2013			
Oxfordshire	**5,355**	**2,537**	**2,818**
Cherwell	1,151	538	613
Oxford	919	458	461
South Oxfordshire	1,155	514	641
Vale of White Horse	1,092	529	563
West Oxfordshire	1,038	498	540
2014			
Oxfordshire	**5,399**	**2,592**	**2,807**
Cherwell	1,268	630	638
Oxford	910	430	480

South Oxfordshire	1,178	574	604
Vale of White Horse	1,032	512	520
West Oxfordshire	1,011	446	565

Sources: https://www.ons.gov.uk/

In 2013 slightly under half of the deaths among older people in Oxfordshire occurred in the person's usual place of residence.

(Source: needs analysis for older people in Oxfordshire, April 2016.)

7.7. Deaths in Cherwell District Council by age

Statistics for 2015 will be available from December 2016 on the ONS website.

Table 5: This data on the ONS website is analysed further by gender male and female and has been amalgamated here .

(Table 5 and 6: Source ONS website)
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredbyareaofusualresidenceenglandandwales

Table 5 Deaths in Cherwell District by age

Age in years	Deaths in 2014	Deaths in 2013	Deaths in 2012
under 1	5	4	3
1-4	3	3	1
5-14	5	2	3
15-24	6	6	9
25-34	10	5	10
35-44	22	26	12
45-54	37	39	39
55-64	111	95	94
65-74	165	179	179
75-84	383	342	318
85 +	521	450	454

From 2014 data is broken down into 5 year age ranges and has been amalgamated in Table 1 for comparison.

Table 6: Deaths in Cherwell by 5 year age range

Age range	Deaths in 2014
Under 1	5
1-4	3

5-9	2
10-14	3
15-19	1
20-24	5
25-29	5
30-34	5
35-39	8
40-44	14
45-49	18
50-54	19
55-59	42
60-64	69
65-69	65
70-74	100
75-79	158
80-84	225
85-89	244
90+	277

Table 7: Deaths by suicide in Cherwell

2013	**Suicide rate**	**Not recorded**
2014		**13**
2015		**12**

(Table 7 Source: Cherwell Health Profiles, 2013, 2014, 2015)

8. Grief & Bereavement Resources for people in the Banbury area

8.1. Numbers of people affected by a bereavement

The number of people affected by a bereavement is difficult to quantify. For the sake of establishing national targets, Cruse considers that, on average, one person per death would seek help, meaning that, for example, in Cherwell, with 1268 deaths per year, Cruse should expect to respond to 127 people seeking support. Of course in some families, and depending on factors such as the nature of the death, this figure could be much higher. Prigerson et al (2009) estimates that each person dying from cancer leaves behind 4 survivors. We have taken one person per death for the purposes of making some numerical analysis of the figures in this report.

8.2. Lawrence Home Nursing Service they refer to Katharine House for bereavement support for families but estimate for most of their patients (c 50 a year) that 2-3 family members are supported by the nurse during the end of life care process.

8.3. Current provision bereavement services in Oxfordshire and Banbury

In Oxfordshire as a whole and Banbury bereavement services are provided by a mix of statutory and voluntary agencies. Appendix 1 summarises the services available to people living in the Banbury area.

National guidance recommends that the services provided have 3 components.

Dr Relf's detailed review of Oxfordshire services in 2012 concluded that Oxfordshire offered all three components but that there are gaps in provision.

9. Data on referrals in Banbury

All organisations in table 8 provide components of bereavement care, but were not all able to supply data mainly because their referral systems do not collect the data or they did not respond to requests.

This data is a conservative figure as Talking Space have a counselling service provided by Principle Medical Limited, which includes counselling for complex grief; however, they do not collect this data on their referral form. Similarly, the Samaritans may talk with people with complex grief but they do not identify this as a reason for referral.

Table 8: Referrals and/ or the people seen for bereavement services in Banbury area 2012/13 to 2014/15

Name of service	**Details**	**2013**	**2014**	**2015**
Cruse Oxfordshire	Number of referrals	45 (estimate)	36	26
Katherine House Hospice	Pre-bereavement and post bereavement service	77	124	91
Primary Care Bereavement Service Banbury	2013-2015 total service users seen 379 for complex grief NB. PBS only takes referrals from 8 of the 12 GP practices in NOLG.	c126	c.126	C126
Late Spring;	Peer Support Group Banbury Started Sep 2015	-	-	14
Late Spring:	Peer Support Group Chipping Norton, started 2013	14	14	14

Lawrence Home Nursing Service	Focus is on end of life care for patients and pre bereavement support for patient.	49	51	61
OUH FT	Bereavement provide IAG services, this require Freedom of Information request			
Way and Way Up	Way reported 11 people in the last 3 years	4	3	4
Mind Oxfordshire	Contacted but Andrew Agnew away until 20 June			
Sunrise Multicultural project	Contacted, no response, but don't deal specifically with death			
Integrated Locality Team (Community services) Oxford Health	Offer 1:1 meeting up to 5 weeks after a death; sign-posting and listening ear; often doubles with Katharine House and Lawrence Home Nursing; demand increasing			69

10. Banbury Based Services

Primary Care Bereavement Service (complex needs), Horsefair
01295 759122

Katharine House Hospice

Katharine House Hospice delivers healthcare called specialist palliative care, for patients and their families. It delivers this care in any setting including within the hospice building, within the patient's home and in the Horton Hospital: www.khh.org.uk

Tel: 01295 811866

Lawrence Home Nursing Team

Nursing Care at home for the terminally ill in the Chipping Norton area

www.lawrencehomenursing.org

Tel: 01608 641549

Samaritans (Banbury)
24 hour confidential telephone service for anyone feeling desperate or suicidal or experiencing a personal crisis such as bereavement.
Tel: 01295 27000

GP surgeries (12)
General Practitioners & District Nurses. GP may be able to help by listening, offering support, prescribing drugs for problems like sleeplessness or depression, by advising you about other sources of support or by referring you to a counsellor. The district nurse may make contact to ask about the patient's health and may be able to give advice about sources of support.

Banbury Health Centre
Bloxham & Hook Norton surgeries
Cropredy Surgery
Deddington Health Centre
Hightown Surgery
Horsefair Surgery
Sibford Surgery
West Bar Surgery
West Street Surgery
Windrush Surgery
Woodlands Surgery
Wychwood Surgery

Funeral Directors in Banbury

The Midcounties Co-operative Funeralcare
122 Middleton Rd · +44 1295 272207

Edd Frost & Daughters Family Funeral Directors
20 Horton View · +44 1295 404004

Humphris Funerals

32 Albert St · +44 1295 265424

R. Locke and Sons
Castle Hill, Upper Brailes, Banbury, OX15 5AZ
Telephone: 01608 685274

11. Oxfordshire-wide Bereavement Services

Acknowledgement
The information for the Oxfordshire section is taken from *Grief & Bereavement: Resources for Bereaved People,* April 2016. Compiled by
Dr Marilyn Relf (smsh.bereavementservice@ouh.nhs.uk)

Age UK Oxfordshire
Offers a range of services including befriending & a community information network that provides access to a range of groups & organisations offering practical & emotional support to older people.
Late Spring Offers bereaved people aged 60+ the opportunity to meet with others over tea & cake. Fortnightly meetings in across Oxfordshire.
0345 450 1276
www.ageuk.org.uk/oxfordshire latespring@.ageuk.org.uk

Archway
Provides a supportive, understanding & friendly environment & a range of activities for people feeling lonely & isolated. Activities include social evenings, befriending, drop-in café & group outings
01865 790552 www.archway.moonfruit.com
office@archwayfoundation.org.uk

BLESS Bereavement, Loss & Emotional Support Service
BLESS provides 1-1 support for Jewish people (& people with Jewish connections) living in Oxfordshire.
07503 650710 bless@ojc-online.org

Chipping Norton Friendship Club
Social activities for bereaved people - monthly meetings (Sats), lunch outings & coach trips.
Telephone: Pat Smith 01608 678456

Cruse, Bereavement Care Oxfordshire branch – for all bereaved adults
A national organisation with a local branch covering Oxfordshire. Provides individual & group support, counselling, social 'friendship' groups, a group for people bereaved by suicide (in collaboration with Survivors of Bereavement by Suicide) and runs a project working with homeless people in hostels and supported housing in Oxford.
Telephone helpline: 01865 245398 (10.00-13.00 weekdays) www.oxfordcruse.co.uk
admin@oxfordcruse.co.uk

Footprints
A monthly bereavement support group under the umbrella of Christ Church, Abingdon. Held monthly on second Tuesday, 10.30-12.00 in the New Barn Café, Northcourt Road.
01865 682350 www.cca.uk.net

Helen & Douglas House Family Support Team
Individual & group support & counselling for families of Helen or Douglas House patients.
01865 794749 www.helenanddouglas.org.uk

Katharine House Hospice Bereavement Service
Offers support & counselling to families & friends of Katharine House Hospice patients.
01295 811866
www.khh.org.uk Srinder.Singh@khh.org.uk

Maggie's Oxford - for those affected by cancer
Offers bereavement support to those affected by cancer through support groups & individual counselling. National website hosts an on-line facilitated bereavement support group.
01865 751882
www.maggiescentres.org oxford@maggiescentres.org

Oxford University Hospitals NHS Foundation Trust Bereavement Service Provides a compassionate administrative & signposting service to support families cared for in the John Radcliffe, Churchill, Horton & the Nuffield Orthopaedic Hospitals in the immediate period after a patient has died. Facilitates opportunities for recently bereaved people to ask questions about the care given by the Trust. Provides a rapid response service for families who have experienced a sudden child or adult death & to assist families in meeting their cultural & religious requirements for funeral arrangements or repatriation. Also offers bereavement resources following pregnancy & neonatal loss & the options for funeral arrangements for babies dying at, or near, the time of birth. Helpline 01865 220110 www.ouh.nhs.uk/patient-guide/bereavement-service .

Oxfordshire County Council
Helpline 0845 129 5900 www.oxfordshire.gov.uk

SANDS (Stillbirth & Neonatal Death Society) Oxfordshire
National charity for people affected by the death of a baby during pregnancy or after birth. Oxfordshire Sands holds informal meetings every two months where individual stories can be shared & support & practical advice offered. Run by volunteers who are all bereaved parents. Information & recommended reading available on website National Helpline: 020 7436 5881 Local befrienders:
07513 295504 befriender@oxfordshiresands.org.uk
www.oxfordshiresands.org.uk info@oxfordshiresands.org.uk

Sobell House Bereavement Service
Offers individual, group support & counselling to families & friends of Sobell House patients.
01865 225878
www.sobellhouse.org.uk smsh.bereavementservice@ouh.nhs.uk

Talking Space Oxfordshire
Talking Space is part of the NHS Improving Access to Psychological Therapies programme offering help to people (age 18+) with depression or anxiety. Access via GPs or by self-referral. 01865 901222 talkingspaceplus@nhs.net www.talkingspaceoplus.org.uk

The Loss Foundation
The Loss Foundation is a charity run by health professionals offering support groups & social events in London & Oxford for people who have lost a loved one to cancer. Offers opportunities for people to share stories; to talk, listen, eat cake, or simply be. 07732 070 972 www.thelossfoundation.org

The Way Ahead
A social group for bereaved, single & retired people. Meets monthly in Oxford, arranges trips, meals & other social gatherings. 01865 559081 (Joyce) or 01865 880634 (Diane)

WAY Foundation (Widowed & Young)
Helps young widowed people (up to age 51) through social events. Run by young widowed volunteers. Organises holidays, website provides information, a chat room & on-line support groups & has an active local branch in Oxfordshire. 0300 012 4929 www.widowedandyoung.org.uk info@widowedandyoung.org.uk

WAY UP
WAY UP is a mutual help group created to support the needs of anyone (over the age of 50) who has lost a long term life partner. Provides a national web-based group & offers meetings & events all over the UK, including Oxfordshire. www.way-up.co.uk info@way-up.co.uk

YoungDementia UK
YDUK offers support services for younger people with dementia (under 65) & their families. Offers individual support both before & after a bereavement. 01865 794311 www.youngdementiauk.org mail@youngdementiauk.org

General services

Employee Assistance Programmes
Many companies offer Employee Assistance Programmes which provide employees with free counselling sessions. Ask your manager/human resources department for information

Independent counsellors & therapists
To find registered psychotherapists & counsellors in your area visit the following websites. Costs vary. Many therapists have their own websites giving further information.
www.itsgoodtotalk.org.uk (British Association of Counselling & Psychotherapy)
www.psychotherapy.org.uk (UK Council for Psychotherapy)

12. Telephone/Web based Support and National Groups

Bereavement Advice Centre

Helpline & web-based information service offering support, information & advice about what to do after a death & the practical issues & procedures that people may face.
Helpline: 0800 634 9494 (9.00-5.00 Mon-Fri)
www.bereavementadvice.org info@bereavementadvice.org

Child Death Helpline
Offers a confidential telephone listening service offering emotional support to all affected by the death of a child. Helpline staffed by bereaved parents who are trained & supported by professional staff.
0800 282 986 or 0808 800 6019 www.childdeathhelpline.org.uk

Cruse Bereavement Care
The national website provides telephone counselling, practical information about what to do after a death, links to useful organisations, on-line support, information about adult & children's grief & hosts a dedicated website for young people 0844 477 9400 0808 808 1677 (young people's helpline) www.cruse.org.uk helpline@cruse.org.uk
www.hopeagain.org.uk (for young people)

Compassionate Friends
The Compassionate Friends are bereaved parents who offer support & friendship to parents whose child has died at any age & from any cause. Support is also available for bereaved adult siblings (Support in Bereavement for Brothers & Sisters - SIBBS) & grandparents. The Shadow of Suicide group (SOS) can put parents in touch with other parents who have lost children through suicide. Contact via national helpline which is answered by a bereaved parent who provides support & information. There is an active group in Oxfordshire and Berkshire
Helpline 0345 123 2304 (daily 10-4, 7pm -10pm)
www.tcf.org.uk helpline@tcf.org.uk
Oxford group: 0118 940 3038 or 07970 611013 austenrobert@hotmail.com

Dying Matters Coalition
Aims to change societal attitudes to dying, death & bereavement. The website provides links to organisations providing help (Find Me Help section), a useful publications guide & leaflets such as 'Telling Others About a Death', 'Looking After Yourself' & 'Coping with Grief'. www.dyingmatters.org.

London Friend
A gay, lesbian, bisexual & trans charity offering counselling & support including bereavement support. Helpline 020 7833 1674 www.londonfriend.org.uk

Lullaby Trust (Formerly the Foundation for the Study of Infant Deaths) Trained bereaved parents offer a befriending service by phone or email. 0808 802 6868 (bereavement line) 0808 802 6869 (information line) www.lullabytrust.org.uk support@lullabytrust.org.uk

Miscarriage Association
Offers information & support to people who have been affected by miscarriage, ectopic pregnancy or molar pregnancy.
01924 200 799 (Mon-Fri, 9am-4pm) www.miscarriageassociation.org.uk
info@miscarriageassociation.org.uk

RoadPeace
Provides emotional & practical support to those bereaved or injured in a road crash (RTA). Helpline staffed by volunteers who themselves have been bereaved or injured in a RTA. Also offers befriending, a resilience building course & specific guides & information sheets on the legal procedures that follow a road death
Helpline: 0845 4500 355, 9am-5pm, Mon-Fri www.roadpeace.org
helpline@roadpeace.org

SCARD (Support & Care After Road Death & Injury)
Provides emotional & practical support & counselling to those bereaved following a road crash.
0845 123 5542 (9.00-9.00 daily) www.scard.org.uk

Service Children's Support Network (SCSN)
SCSN is a network of education & welfare professionals working collaboratively with the service community to facilitate support to service children & their families in recognition that they may face experiences that are different from those faced by civilian families including operational deployment, trauma & bereavement. 01296 625779
www.servicechildrensupportnetwork.co.uk

SSAFA Forces Help
National charity helping serving & ex-serving men & women & their families. 0800 731 4880 10.30-7.30 weekdays www.ssafa.org.uk

Sudden Death Association
Sudden is an initiative by Brake, the road safety charity, focusing on bereavement from any type of sudden death, whether it's through a road crash, suicide, disaster, war, accident, or undiagnosed medical reasons. Provides support literature for bereaved adults and children and supports best practice and resources among professionals who work with suddenly bereaved people. www.suddendeath.org

Survivors of Bereavement by Suicide (SOBS)
SOBS is a mutual support organisation that exists to break the isolation of those bereaved by the suicide of a close relative or friend. Provides emotional & practical support through a helpline, chat room & forum, group meetings & residential events. 0300 111 5065 (9.00-9.00 daily)
www.uk-sobs.org.uk Sobs.support@hotmail.com

War Widows Association of Great Britain
Gives advice, help & support to all war widows & their dependants. 0845 241 2189
www.warwidows.org.uk

The National Association of Bereaved Services
20 Norton Folgate London, E1 6DB Tel: 020 7709 9090 (24 hours, with answerphone)

13. 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[2] , One Chance to Get it Right[3] and taking into account of NHS England publication Actions for End of Life Care 2014-16[4] 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.

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2 End of Life Care Strategy: promoting high quality care for adults at the end of their life, Department of Health, 16th 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

3 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

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

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.
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.

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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 year6 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)[5] 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.

[5] http://www.ons.gov.uk/ons/dcp171778_317495.pdf

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

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 study 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 the list of 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

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. **study 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 patient's 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 5years 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 continuous 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:
    - 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 study 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

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