

Wiltshire Council

Health and Wellbeing Board

29 March 2018

Subject: End of Life Care Implementation Plan for Children

Executive Summary

- I. Following a multi-agency review of End of Life care for Wiltshire children against NICE guidelines, this paper summarises:
 - Priority areas of work to improve compliance with guidelines
 - Demand on end of life service for Wiltshire children
 - Next steps

Proposal(s)

It is recommended that the Board:

- i) Reviews the enclosed paper and notes the findings of the review and associated resulting actions.

Reason for Proposal

Following development of the Wiltshire End of Life Strategy for adult services, a request was made to better understand End of Life Care for children and any actions required to improve services for Wiltshire.

Susan Tanner
Head of Commissioning and Joint Planning
Wiltshire Council

Purpose

The need to review end of life care for Wiltshire children was highlighted following presentation of the Wiltshire End of Life strategy, which does not specifically address the needs of children, at the Health & Wellbeing Board. Opportunity for review also arose following publication of the NICE guidelines: End of life care for infants, children and young people with life-limiting conditions: planning and management, in December 2016 and their subsequent associated Quality Standard in September 2017. This paper aims to summarise the key findings from this review, as well as priority areas that have been identified for further action, and next steps. For the purposes of this paper the term 'children and young people' refers to everyone under the age of 18, including neonates and infants.

Background

No one provider or professional group is ultimately responsible for provision of palliative care for children and young people across Wiltshire. Instead there is a complex landscape of organisations which may be involved, to varying extents, at different points within the palliative care pathway. The principal organisations involved in provision of palliative care for Wiltshire patients have been summarised within Appendix 1. For the purposes of this review and ongoing work we have opted to exclude tertiary providers; Wiltshire patients predominantly feed into three tertiary centres, although some children will go on to access services from tertiary centres even further afield. Each tertiary centre will provide care to children from many counties other than Wiltshire and so it was not seen as feasible to request any significant involvement on their part, and instead tertiary centres will be kept informed of any changes to practice that may impact on them as a result of work undertaken within Wiltshire. All other identified organisations have been engaged with and representatives from each have been identified and invited to take part in an initial review of services and ongoing strategy work to address key priorities. The primary aims of the review were to:

- Develop an understanding of end of life care for Wiltshire children currently, the organisations involved and their respective roles and responsibilities within the overall context of delivering an optimum level of care for children and their families;
- Identify any gaps in service provision across Wiltshire or areas for further development;

- Understand whether services for children in Wiltshire are compliant against NICE guidelines;
- Enable networking and communication across organisations with a common goal of improving palliative care for children across Wiltshire.

Demand

In order to provide some context, the data from the Wiltshire Child Death Overview Panel report have been summarised within Appendix 2. In summary however, there are an average of 28 child deaths per year in Wiltshire. The majority of children are in their first year of life when they die (64%) and most child deaths take place in a hospital setting (average of 19 deaths per year). Further analysis of data has been identified as a key priority in order to better understand the potential demand for end of life care across Wiltshire and plan capacity accordingly. Existing data enables us to make assumptions around the proportion of child deaths that may have been as a result of life limiting conditions and so may have had the opportunity to receive end of life care outside of hospital, versus those that were a result of trauma or unexpected. For example, 28% of deaths were unexpected and so it is likely that these children would not have been on a palliative care pathway. Numbers of children requiring end of life care are thankfully small and provision is sporadic in its nature, the result of which is that our acute and community providers do not generally have designated capacity in place for end of life provision, but instead work to create capacity as and when it is required. Feedback is that when a family choose to go home providers will do all that is required to enable this to happen however it is acknowledged that this puts significant strain on services and we must do whatever we can to identify other resources that can support and make the best use possible of this highly specialist resource.

Review findings

Each provider was given the opportunity to present a summary of their service provision and any issues that they felt they have in relation to fulfilling the NICE guidelines. It was clear from this that there is significant variation in service models across providers, and there was acknowledgement that there can be differences in end of life provision for children within oncology services, which generally has a higher level of palliative care resource, than for children with non-oncological conditions. All providers felt that they were compliant with NICE guidelines for the elements for which they were responsible albeit in some cases as a result of staff going 'above and beyond' rather than it being within their job plans. Participants felt that it was very useful to hear more about how each service operates in order to best match the needs of the child and their family to the organisation. Some specific issues were relayed by individual providers however there was a strong consistency between all organisations and the group was able to agree a number of key priorities for provision of end of life care for children across Wiltshire:

1. Access to 24/7 medical cover:

The NICE guidelines state that children and young people receiving end of life care at home should have access to advice from a consultant in paediatric palliative care at any time (day and night). This is extremely challenging for providers to deliver against, both in terms of the specialism in paediatric palliative care at consultant level and the 24 hour provision. Whilst some hospices are able to offer 24/7 consultant medical telephone cover, other providers are unable to meet this expectation. With the numbers outlined in appendix 2 it is very difficult to make this provision viable and so as a county we need to explore other means of accessing medical support, particularly out of hours.

2. The role of the GP:

There were reports of variable engagement from GPs around children's end of life care. Some have been involved throughout a child's palliative and end of life pathway; often enabling care to be delivered at home if that is the family's wish, whilst others have not seen this as part of their role. GPs potentially have a vital role to play both in the delivery of some medical support for end of life provision out of hospital but also in the ongoing support of the whole family after the child's death, and the group identified the need to seek engagement from GPs in future work so that this role could be further defined. It was acknowledged that GP representation on the group had not been sought but was important and this has now been rectified with two GPs identified to participate in the working group going forwards.

3. Workforce planning & training:

In addition to the medical workforce children with life-limiting conditions or receiving end of life care need access to a number of other professionals with specialist palliative care experience including but not limited to: nurses, pharmacists, psychologists, allied health professionals, chaplains, social care and educational professionals. Within each of these staff groups, a specialism in palliative care is relatively rare and providers are often competing with each other for a relatively small staffing pool. In order to manage this situation the group needs to consider how it might communicate or even develop training and development opportunities in order to nurture staff with an interest in palliative care for the future. Some particular staffing groups, such as psychology, were identified as particular gaps by certain providers.

4. Data:

The Wiltshire and Swindon Child Death Overview Panel has been in place since April 2008 and it reviews the deaths of every Wiltshire and Swindon child under 18 years with a particular focus on whether there were any modifiable factors which may have contributed to the death and what, if any, actions could be taken to avoid future such deaths. Within this capacity they collect a significant amount of data on behalf of Wiltshire which would enable us to better understand how end of life care is currently being delivered and whether this was in line with

children and families wishes. This will in turn help the group to better plan services for the future and so the need to collect and analyse this data on behalf of Wiltshire patients was identified as a priority for the group.

Next steps

Strategically the group is keen to explore opportunities in working alongside the adult End of Life Programme Board to understand synergies and identify shared priorities. It is the view of the group that many of the high level strategic aims in end of life care will be shared between children and adults and the group is keen to find a way of aligning the strategic focus of end of life care as much as possible, whilst recognising that there will be some factors which are unique to provision of end of life care for children and young people.

The Children's End of Life Group has agreed to meet quarterly in the capacity of a 'working group' in order to progress against the priority areas outlined within the review findings above. NICE suggests that organisations work within clinical networks to develop and improve children's End of Life Care and the working group will be well placed to deliver against this recommendation. Below is an illustration of the actions that the group is currently working to:

Action	Status
Identify a GP representative to sit on the group	Complete
Identify a representative from the out of hours GP provider to join the group	Complete
Make contact with the Rainbow Trust and engage in future activities	Complete
Develop a directory of all services providing input to end of life care for children across Wiltshire, including geographical areas and patient groups covered	Complete, See Appendix 3
Schedule a meeting for February to begin work on identified priority areas of work	Complete
Develop list of exceptional data requests for CDOP	Complete
Explore option of developing a children's palliative care template within the GP system Ardens	May 18
Consider how children's 'fast-track' continuing care referrals might be aligned with end of life pathways	April 18
Agree how the children's end of life group will feed strategically into wider end of life discussions at the CCG	Mar 18
Agree process for sharing Advance Care Plans and Symptom Management plans with all relevant staff involved in provision of end of life care	May 18
Develop a simple 'off the shelf' guide for GPs and out of hours services on children's end of life pathways, key documents and principle providers	May 18
Compile a training directory for staff who may have an interest in this area, or who feel that it is an area in which they need further development. Also consider as a group of providers whether there might be some work that we can do together to upskill discreet groups such as the clinical hub within the 111 service	April 18

Appendix 1

Table of stakeholders:

Tertiary centres*	Bristol Children's Hospital (RUH tertiary provision)
	John Radcliffe Hospital Oxford (GWH facing)
	Southampton Children's Hospital (SFT facing)
Acute hospitals trusts	Great Western Hospital Swindon
	Royal United Hospital Bath
	Salisbury General Hospital
Hospices/ voluntary sector organisations	Naomi House & Jacksplace , Winchester
	Julia's House, Devizes
	Helen & Douglas House, Oxford
	Children's Hospice South West (Charlton Farm), Bristol
	Jessie May, hospice at home
	Rainbow Trust South West Family Support Team, Chippenham
Children's Community Services	Virgin Care
Primary Care	Family GP
	Medvivo (out of hours)

*A number of children may access tertiary services via other specialist centres for example Great Ormond Street.

Appendix 2

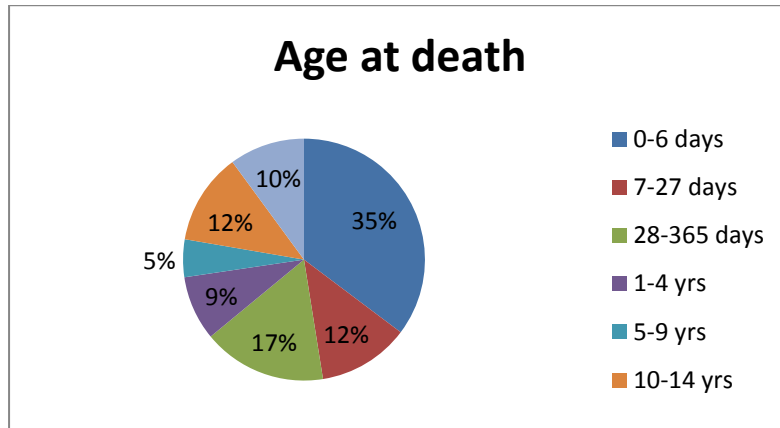
Some of the key data from the 2016/17 CDOP annual report are summarised below. Unless otherwise stated numbers relate to the period 1st April 2012 – 31st March 2017.

1. Number of child deaths notified in Wiltshire:

Year	Number of child deaths
2012-13	39
2013-14	32
2014-15	28
2015-16	17
2016-17	23
TOTAL	139

2. Age at death:

The greatest proportion of notifications (47%) were for babies dying in the neonatal period (under one month of age). This figure increases to 64% when all deaths under one year are grouped together.



3. Location of death

Home/ private residence	32
Royal United Hospital, Bath	15
Salisbury District Hospital	14
St Michael's Hospital, Bristol	14
Princess Anne Hospital, Southampton	13
Other hospital	13
Bristol Children's Hospital	10
Hospice	9
Great Western Hospital, Swindon	8
Southampton General Hospital	6
Other	5

Grouped locations:

Hospital- tertiary/ out of area	56
Hospital- in area	37
Home/ private residence	32
Hospice	9
Other	5

4. Expected and unexpected deaths

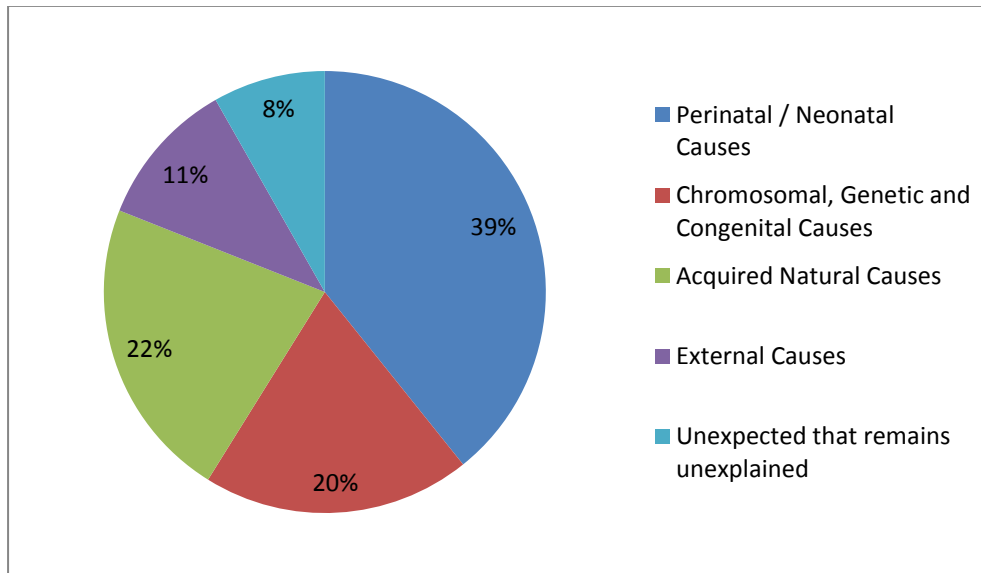
An unexpected death is defined as the death of a child which was not anticipated as a significant possibility 24 hours before the death or, where there was a similarly unexpected collapse or incident leading to or precipitating the events that led to the death. During the reporting period 2012 – 2017, 39 deaths (28%) of children were unexpected. The remaining 100 were expected child deaths of children with known illnesses or life-limiting conditions.

5. Categorisation of death for cases reviewed by CDOP

As part of the Child Death Review process each death reviewed by the panel is categorised by the most likely cause of death based on a set of pre-defined CDOP categories. As the numbers within these categories remain quite small despite the use of aggregate data, they can be grouped into wider categories as follows:

Pre-defined CDOP categories	Wider Category
Perinatal / Neonatal Event	Perinatal / Neonatal Causes
Chromosomal, genetic and congenital anomalies	Chromosomal, genetic and congenital anomalies
Malignancy Acute medical or surgical condition Chronic medical condition Infection	Acquired natural causes
Deliberately inflicted injury, abuse or neglect Suicide, or deliberate self-inflicted harm Trauma and other external factors	External causes
Sudden, unexpected, unexplained death	Unexpected that remains unexplained

The assignment of categories to child deaths across Wiltshire is summarised below. It is possible from this information to make some assumptions about what kind of demand there might be for hospices or end of life care at home. For the purposes of these projections it would be sensible to discount those deaths that are attributable to External and Unexpected causes, as in their nature these deaths are likely to have been sudden or not attributable to long term or pre-existing life limiting illness. These children account for 19% of child deaths.



Appendix 3

A summary of organisations involved in the provision of End of Life Care for infants, children and young people in Wiltshire with life limiting conditions.

Acute Providers:

In the first instance, the majority of children across Wiltshire will be managed clinically by one of three acute trusts: the Royal United Hospital Bath, Great Western Hospital Swindon and Salisbury Hospital. Children and families can exercise choice as to which trust they would like to access care from, however in the main the county splits fairly equally three ways depending on proximity to hospitals from home. If more specialist intervention or oversight is required then these three acute trusts will link into Bristol Children’s Hospital, Oxford Radcliffe and Southampton Children’s Hospital respectively. Other tertiary hospitals may be accessed as required by the child’s condition or as capacity, for example within paediatric intensive care, dictates. Acute providers outlined will support children with a range of life limiting or life threatening conditions, covering specialties such as: Paediatric oncology, neurology, respiratory, cardiology, and neonatal care. Children with complex needs may sit under a range of acute clinicians and specialties; however one primary clinician should be nominated as the lead for that child and their management. In most circumstances the acute trust will commence the child’s Advance Care Plan and Symptom Management Plan, and will be responsible for its ongoing review.

Community provider:

Our children’s community healthcare services in Wiltshire are provider by Virgin Care, who provide a range of services that may be involved in the delivery of care for children with life limiting of life threatening conditions including but not limited to: community nursing, continuing care, community paediatrics, integrated

therapies, speech & language and paediatric continence. Children or young people with life limiting conditions will have a lead community nurse, and the community nursing team will work closely with acute hospital to enable a family to go home to receive end of life care if that is their wish. This will involve establishing a rota for provision of nursing support in the home.

Voluntary sector organisations:

Below is a summary of the hospices and other voluntary sector organisations involved in provision of services for infants, children and young people with life limiting and life threatening conditions. It is important to recognise that within children's services involvement with these organisations is not limited to end of life care, but that children and their families may receive ongoing care and services throughout their lives. Hospices listed below are all able to provide care at the end of a child's life if that is the choice of the family or young person. As such, the organisations below all aim to work in partnership with other professionals and organisations surrounding the child and their family including acute hospitals, schools, social care and community providers. Referrals can either be made by professionals or the families themselves.

Children's Hospice South West (Charlton Farm, Bristol)

Charlton Farm Hospice will usually cover West Wiltshire and provides ongoing support for children up to the age of 18 and their families, including end of life provision. The hospice employs a multidisciplinary team including paediatric nurses, therapists, social workers, teaching staff and medical support through GPs and paediatricians. Referral information: <https://www.chsw.org.uk/what-we-do/our-care/make-referral>

Helen & Douglas House, Oxford

Helen & Douglas House most commonly receive referrals for families living in the North West area of Wiltshire, typically being managed via Great Western Hospital. The Hospice comprises Helen House, caring for babies and children up to the age of 18, and Douglas House, who look after young people and adults, aged 16 – 35. Referral information: <https://www.helenanddouglas.org.uk/our-care/how-to-get-help/>

Jessie May, Bristol

Providing nursing care at home for children and young people with life limiting conditions who are not expected to live beyond the age of 19. Nurses will go into the family home to provide care and support, providing parents or carers with some much needed free time. Referral details:

<https://www.jessiemay.org.uk/help-support/do-you-need-our-help/>

Naomi House & Jacksplace, Winchester

Predominantly taking referrals for children and families from the South of Wiltshire, Naomi House offers respite care, day visits and end of life care for children up to the age of 18. The multi-professional team is led by a specialist paediatric palliative care consultant. Jacksplace will accept referrals for young

people from 16 – 35 years. Referral details:
<https://www.naomihouse.org.uk/about-us/referrals>

Julia's House

Julia's House is a Children's Hospice caring for children from 0-18 years across the whole of Wiltshire. We provide practical and emotional support for families caring for a child with a life-limiting or life-threatening condition, providing frequent and regular support in their own homes, in the community or at our hospices where day and occasional overnight care can be provided- wherever it is needed. This can include 24 hour support for children at the End of Life. The family support service provides holistic whole family support enabling family members to build their resilience and confidence this includes specialist play and complementary therapy. <https://www.juliashouse.org/contact-us>

Rainbow Trust

The Rainbow Trust is a non-clinical organisation that provides outreach support to children, parent carers, siblings and grandparents where a child has a life threatening or terminal illness. This may include practical support for example with taking siblings to and from school or helping to prepare meals, helping to liaise with hospitals regarding appointments and advice as well as emotional and bereavement support. Referral information: <https://rainbowtrust.org.uk/support-for-families/ask-for-support>