Making a difference...a work in progress...

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Location of deaths over the last 5 years (2013-2018)

- 532 reported deaths
- 33.6% (**179**/532) child deaths occurred at the BRCH
- 27.6% (**147**/532) at St. Michael's Hospital
- 12.2% (**65**/532) at hospitals within North Bristol NHS Trust (Southmead and formerly Frenchay Hospitals)
- So **73.4% (391/532) of all child deaths occurred in hospital**

- 5.8% (**31**/532) died in a hospice

- 9.9% (**53**/532) died at home or at a relative's residence

- Of the children who died at home or at a relative's residence,
  - 68% (**36**/532) were **unexpected** deaths
  - 32% (**18**/532) were **expected** deaths
  - 8.6% (**46**/532) died in other hospitals and
  - 2% (**11**/532) died in other locations

Source: WOE CDOP Annual Report April 2017 – March 2018

The aim of the work is to leave families with what can only be described as a "good enough" memory of the life, dying and death of their child or in some cases children...

Empowering who is the question…

Professionals or families
Or
Is it both?

Empowering…

- This is the key across all settings if we are to build a sustainable service which offers families and professionals:
    - Well-coordinated services
    - Well-informed families
    - Able to exercise real choice…

The main work is with clinicians...

"It is about helping them to see palliative care as a positive option that needs to be everyone's business and needs to be reintegrated into everyday care on the wards..."

The Local Champion model....!!!

Introducing palliative care…

This should not be seen as nothing more can be done or come across as a sense of giving up.

Palliative care is not a diagnosis or single intervention; it is a philosophy of care. It can be seen as a thread that weaves through the lives of all children with a life limiting illness alongside active interventions and treatment.

What is palliative Care…

- **Paediatric Palliative Care is** care that maximises the comfort, wellbeing and quality of life of children with a life-limiting illness, and of their family and carers. It is very different to End-of-life care.
- Palliative care does not begin at the end of life but is involved from the time a child is diagnosed with a life-limiting illness.
- **End-of-life care** is the end stage of palliative care where the child is very close to death.

So we might say…

We have come to talk about maximises the comfort, wellbeing and quality of life of your child and family and we call this palliative care…

Common themes...

- Communication…
- Parallel Planning…
- Inter-professional working...
- Location...
- Similarities and differences...
- Caring for self...
- Boundaries...
- Bereavement starts at diagnosis...
- Siblings...

Three key questions....

- What is palliative care for you?
- What are your concerns around palliative care?
- How do you look after yourself and your team in the doing of this work?

Concerns around Palliative Care from staff…

- Timing
- Staff
- Safety
- Misconception – Palliative Care vs End of Life
- How to start conversation with parent – what to tell them
- Out of date plans
- Age of child – parental responsibility

What are your concerns around children's palliative care...

- What do the family want...
- What to say…
- What can I ask…
- Best interest of the child...
- Prolonging life or Prolonging death…
- Withdrawing and withholding treatment?
- Ethics review
- Suffering...
- Being alongside in uncertainty
- Total pain...
- Total care…
- End of life care plans...
- Boundaries...

What is Palliative Care for you?

- Symptom control
- Comfort
- Pain relief
- Communication with family
- Quality of life
- Care for life limiting condition
- Escalation/ceiling of care
- Support
- Rationalising treatment

Themes from Parents...

- Practical help & Support
- Help to create good memories
- Empathy
- Time & Space
- Communication with parents
- Sensitivity
- Accurate record keeping & Communication
- Photos & Human touches
- In utero
- Support afterwards

What are we talking about…

An ***active and total*** *approach to care,* ***from the point of diagnosis*** *or recognition,* ***throughout the child's life, death and beyond.***

It embraces ***physical, emotional, social and spiritual*** *elements and focuses on the enhancement of* ***quality of life*** *for the child and* ***support*** *for the family.*

It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. (ACT 2009)

A parent…

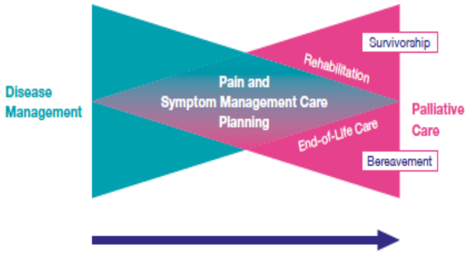
“I thought ‘palliative care’ just meant pain relief at end of life! Then I thought it meant withdrawal of treatment – ‘giving up’. The best part of it in reality was parallel planning – enjoying the moments we had. Preparing for an uncertain future”

‘Parallel Planning’…

- It is often **hard to predict** what the future holds for baby / child requiring palliative care... Although children may be assesses as deteriorating or approaching the end of their life, it is sometimes the case that **children survive these episodes**.
- Parallel planning for life while also planning for deterioration or death allows a babies full potential to be achieved and **primes the mobilisation of services and professionals where necessary** (The Core Care Pathway, 20130 page 12 TfSL’s).

Parallel Planning…

Fig. 2: Parallel planning for disease-directed alongside palliative care can be represented in the ‘bow-tie’ model[4]



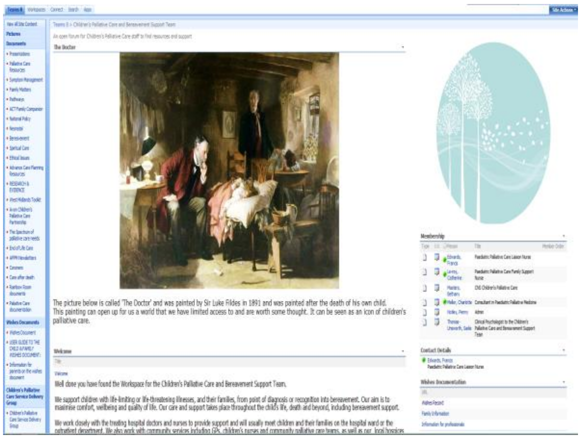
‘Parallel Planning’…

A parent...

‘Parallel planning opened up many opportunities for us as a family. We hoped and hoped for the outcome we all wanted but also had in mind that the dream outcome we all wanted for little Ava may not come true, therefore made her time with us as special and as unforgettable as possible.’

‘We created memories’

‘We were then granted my one wish, to take our little girl into the sunshine for a big cuddle and kiss before saying goodbye ...’

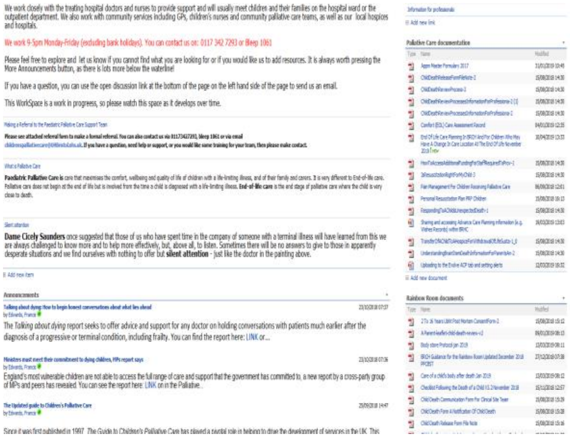


The picture below is called 'The Doctor' and was painted by Sir Luke Fildes in 1891 and was painted after the death of his own child. This painting can open up for us a world that we have limited access to and are worth some thought. It can be seen as an icon of children's palliative care.

Welcome

Well done you have found the Workspace for the Children's Palliative Care and Bereavement Support Team.

We support children with life-limiting or life-threatening illnesses, and their families, from point of diagnosis or recognition into bereavement. Our aim is to maximise comfort, wellbeing and quality of life. Our care and support takes place throughout the child's life, death and beyond, including bereavement support.



We work closely with the treating hospital doctors and nurses to provide support and will usually meet children and their families on the hospital ward or the outpatient department. We also work with community services including GPs, children's nurses and community palliative care teams, as well as our local hospices and hospitals.

We work 9-5pm Monday-Friday (excluding bank holidays). You can contact us on: 0117 342 7293 or Bleep 1061

Please feel free to explore and let us know if you cannot find what you are looking for or if you would like us to add resources. It is always worth pressing the More Announcements button, as there is lots more below the waterline!

If you have a question, you can use the open discussion link at the bottom of the page on the left hand side of the page to send us an email.

This WorkSpace is a work in progress, so please watch this space as it develops over time.

Making a Referral to the Paediatric Palliative Care Support Team

Please see attached referral form to make a formal referral. You can also contact us via 01173427293, bleep 1061 or via email childrenspalliativecare@UHBristol.nhs.uk. If you have a question, need help or support, or you would like some training for your team, then please make contact.

What is Palliative Care

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Silent attention

Dame Cicely Saunders once suggested that those of us who have spent time in the company of someone with a terminal illness will have learned from this we are always challenged to know more and to help more effectively, but, above all, to listen. Sometimes there will be no answers to give to those in apparently desperate situations and we find ourselves with nothing to offer but **silent attention** - just like the doctor in the painting above.

Announcements

Talking about dying: How to begin honest conversations about what lies ahead 23/10/2018 07:37
by Edwards, Francis

The *Talking about dying* report seeks to offer advice and support for any doctor on holding conversations with patients much earlier after the diagnosis of a progressive or terminal condition, including frailty. You can find the report here: LINK or...

Ministers must meet their commitment to dying children, MPs report says 23/10/2018 07:36
by Edwards, Francis

England's most vulnerable children are not able to access the full range of care and support that the government has committed to, a new report by a cross-party group of MPs and peers has revealed. You can see the report here: LINK on in the Palliative...

The Updated guide to Children's Palliative Care 25/09/2018 14:47
by Edwards, Francis

Since it was first published in 1997 *The Guide to Children's Palliative Care* has played a pivotal role in helping to drive the development of services in the UK. This

It may be helpful to ask yourself the following questions...

The surprise questions....

Diagnosis or recognition

- ❖Would you be surprised if this baby / child died as a result of this condition or problem?

Death before adulthood

- ❖Would you be surprised if this baby/ child died before adulthood (18th birthday)?

Increasing instability

- ❖Would you be surprised if this baby / child died in the next few months to years?
- ❖Would you be surprised if this child died in the next five years?

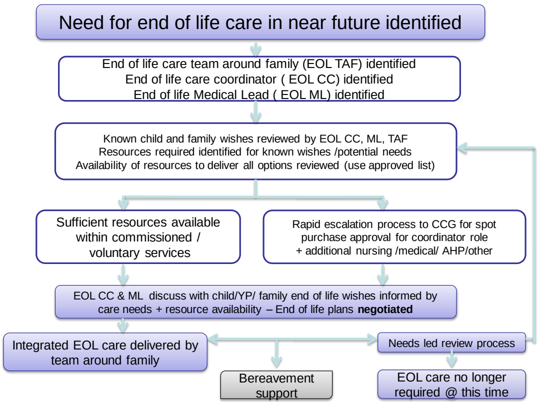
Critical illness or end of life

- ❖Would you be surprised if this baby / child dies in the next few days / weeks?

If your answer is NO to any of these questions you should be thinking about palliative care for this child or young person

Making a difference **: well-coordinated services, well-informed families, able to exercise real choice**

High level end of life care delivery pathway



Need for end of life care in near future identified

End of life care team around family (EOL TAF) identified
End of life care coordinator (EOL CC) identified
End of life Medical Lead (EOL ML) identified

Known child and family wishes reviewed by EOL CC, ML, TAF
Resources required identified for known wishes /potential needs
Availability of resources to deliver all options reviewed (use approved list)

Sufficient resources available within commissioned / voluntary services

Rapid escalation process to CCG for spot purchase approval for coordinator role + additional nursing /medical/ AHP/other

EOL CC & ML discuss with child/YP/ family end of life wishes informed by care needs + resource availability – End of life plans **negotiated**

Integrated EOL care delivered by team around family

Needs led review process

Bereavement support

EOL care no longer required @ this time

Francis May 2019

The purpose of this guidance is to...

- Offer guidance to hospital professionals who are caring for a baby, child or young person who has been identified as approaching the end of their life and so likely to require end of life care in the near future.
- This may follow a period of acute illness or a child who may have been on a palliative care trajectory...

Three sections...

- Care for baby, child or young person requiring **end of life care in Hospital**...
- Care for baby, child or young person with palliative care needs in need of **rapid discharge from hospital...**
- Care for the baby, child or young person being **extubated in different settings...**

Approach taken...

- Care before death
- Care at the time of death
- Care after death
- Bereavement support

Approach taken...

1. What needs to happen and be in place before the child dies?
2. What needs to happen and be in place at the time of death?
3. What needs to happen and be in place for after the child has died?
4. Who is doing the bereavement support…

Getting it right...

Making a difference **: well-coordinated services, well-informed families, able to exercise real choice**

Brief work......

Making a difference **: well-coordinated services, well-informed families, able to exercise real choice**

Getting it right...

Making a difference **: well-coordinated services, well-informed families, able to exercise real choice**

Nice Quality Statements 2018

- Statement 1 Infants, children and young people with a life-limiting condition and their parents or carers **are involved in developing an advance care plan.**
- Statement 2 Infants, children and young people with a life-limiting condition **have a named medical specialist** who leads and coordinates their care.
- Statement 3 Infants, children and young people with a life-limiting condition and their parents or carers are given **information about emotional and psychological support, including how to access it**.
- Statement 4 Infants, children and young people with a life-limiting condition **are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team**.
- Statement 5 Parents or carers of infants, children and young people approaching the end of life **are offered support for grief and loss when their child is nearing the end of their life and after their death**.
- Statement 6 Infants, children and young people approaching the end of life and being cared for **at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care**.