

Improving Practice In Bereavement Care For Families,  
Children and Carers.



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# *Children and Families What Matters?*

# **hello** my name is...

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# Bereavement Matters

- In 2012 over 3,000 babies died before age one and over 2,000 children and young people died between the ages of one and nineteen
- Over half of deaths in childhood occur during the first year of a child's life, and are strongly influenced by pre-term delivery and low birth weight; with risk factors including maternal age, smoking and disadvantaged circumstances
- Suicide remains a leading cause of death in young people in the UK, and the number of deaths due to intentional injuries and self-harm have not declined in 30 years
- After the age of one, injury is the most frequent cause of death; over three quarters of deaths due to injury in the age bracket of 10-18 year olds are related to traffic incidents.

# Bereavement

If *bereavement* is what happens to  
you,  
*grief* is how you feel and react.

# Supporting Families and Children

- How do you already support families and or children pre and post bereavement?
- How does your organisation currently support families and children pre and post bereavement?

# Trends in Deaths

| LA                        | Total Deaths |         |         |         |         |         |         |
|---------------------------|--------------|---------|---------|---------|---------|---------|---------|
|                           | 2008/09      | 2009/10 | 2010/11 | 2011/12 | 2012/13 | 2013/14 | 2014/15 |
| Bolton                    | 38           | 28      | 24      | 32      | 35      | 15      | 19      |
| Salford                   | 33           | 29      | 26      | 27      | 18      | 16      | 27      |
| Wigan                     | 29           | 19      | 21      | 17      | 23      | 26      | 17      |
| Salford, Bolton and Wigan | 100          | 76      | 71      | 76      | 76      | 57      | 63      |

# Key issues

- Prematurity
- Parental smoking
- Low birth weight babies
- Life limiting conditions

# Where We Are Now?



# Pre Bereavement Support

- Pre bereavement to support staff and help to communicate with families and children
- Support staff in communicating my care with children
- Support family following the death
- Liaise with outside agencies - police, health visitors, community services, charities
- 1:1 support families and siblings
- Referral and sign posting to other bereavement services if required



# What Matters To Children and Families Pre Bereavement?

- Open honest conversations
- To receive reassurance
- Symptom control
- To have family and friends present
- To be allowed to have time to grieve
- To be offered **options** of support

# What Does Support Look Like?



# What Matters?

- Asking “What Matters to You”
- Personalising care
- Offering choices
- Ensuring that families have an opportunity to talk to health practitioners who have provided care for their child and family

# Factors That Affect Children's Reactions To Death

- Who?
- How the person died – expected , sudden, suicide, murder.
- What was the relationship?
- How do the family and community express their feeling and emotions?
- The child's age and understanding, their resilience to loss and events at the time of death.

# What Matters To Me?

Children see and hear many of the same things adults do. However, their understanding of what these things mean may be quite different.

- Grandmas body is in the cemetery, where is her head?
- If you are taking all granddads clothes to the charity shop, is he naked in his grave - aged 5 years
- My daddy's been crying because my dog is dying, my grandma said some of her heart will die when the dog dies I don't want my grandma to die – aged 6 years
- Grandad Hill has died, it ok because Granddad Tom lives across the road so I still have a Grandad – aged 5 years
- Its not my fault he died, so stop blaming me – aged 14 years

# Conversations - What Matters To Me?

Is being dead like sleeping?

What do you think dead is like?

Does dying hurt?

What do you think?

Why can't doctors and nurses make people better?

How do you think doctors and nurses can help people ....?

Will I die?

Do you know anyone who's died..?

Is it someone's fault?

What do you wonder about...?

What happens to the persons body at the funeral?

what do you think?

# What Matters To Children and Families Post Bereavement?

- Open honest conversations
- To receive reassurance
- ~~Symptom control~~
- To have family and friends present
- To be allowed to have time to grieve
- To be offered **options** of support

# Preparation

Whenever possible talk to the family first.

- You need to know what the child has already been told.
- You need to know what beliefs (religious or otherwise) the family has about an afterlife.
- You must reinforce what the child will hear later.



# Preparation

If the child is going to see the person who has died or is dying, make sure they are properly prepared.

- Explain medical equipment when appropriate.
- Use pictures first if possible.
- Listen for concerns and misconceptions.

# Language

- Use clear and concise words when telling the child what has happened. Misconceptions are common among children.
- Do not use terms such as the person “went away” or “went to sleep”.
- Make sure the child understands it is not their fault that the death has happened.

# Expression of Emotion

- Let the child know that expressing emotions and asking questions is okay.
- Encourage them to remember good things about the person who has died.

# Communicating With Children

- **Pace** – let children show their feelings, show your feelings
- **Pause** - avoid forcing the issue but be clear – *‘lost, sleeping, gone away’*
- **Acknowledge** that these conversations can be difficult – creative activities
- **Continue** to invite the child to talk, check their understanding
- **Support** older children by identifying adults / others that they can talk to

# Communication

- Children usually know much more than we think.
- The evidence shows that children and families cope better with death when there is open communication.
- Children have the right to have their questions answered honestly.
- Talking about illness and death allows them time to express their fears and feelings and reduces their sense of isolation.

- One year since gran died

# Rachael

Rachael is 22 years old and Matt is 20. Their baby Thomas was born with an undiagnosed heart condition and is not expected to live more than a few weeks. He is allowed to go home from hospital with health care support. You have worked with Rachael for the last 4 months, she struggled with the responsibility of the pregnancy and took a lot of time to make decisions.

# Questions

How do you already support parents who have experienced a loss?

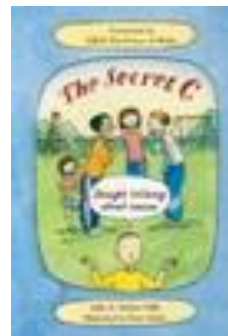
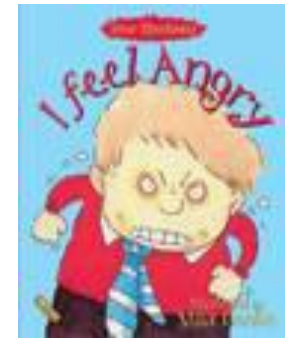
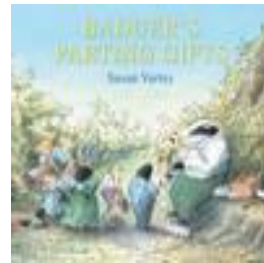
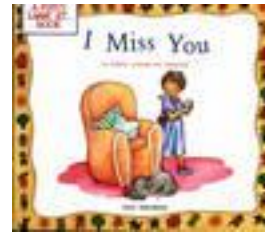
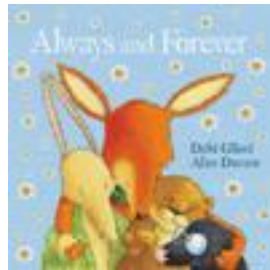
What support can be provided for Rachael and Matt?



# Family Support

- Engage – involve in, invite the conversation support decisions, active listening, CCN, GP, local hospice, palliative care services, coroners
- Mental health services – anxiety, grief, stress, anger, guilt
- Practical – finance, funeral costs, chaplaincy
- Relationships – offer reassurance
- Memory boxes, letters, poems

# Choices



# Useful websites

- Child Bereavement UK - [www.childbereavementuk.org](http://www.childbereavementuk.org)
- Winston's Wish - [www.winstonswish.org.uk](http://www.winstonswish.org.uk)
- Child Bereavement Network - [www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)
- Child line – [www.childline.org.uk](http://www.childline.org.uk)
- The Alder Centre – alderhey children's hospital 0151 228 4811
- Child Death Helpline – [www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)
- Together for short lives - [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)
- Hope Again – [hopeagain@cruse.org.uk](mailto:hopeagain@cruse.org.uk)
- Onceuponasmile - [www.onceuponasmile.org.uk](http://www.onceuponasmile.org.uk)
- Dying Matters - [www.dyingmatters.org](http://www.dyingmatters.org)
- Children of Jannah – [www.childrenofjannah.com](http://www.childrenofjannah.com)
- Sands - [www.uk-sands.org](http://www.uk-sands.org)
- SIBS - [www.sibs.org.uk](http://www.sibs.org.uk)
- Sesame Street: when families Grieve – [www.sesamestreet.org](http://www.sesamestreet.org)
- Mummy's Star – [www.mummysstar.org](http://www.mummysstar.org)
- Miscarriage Association – [www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)
- WAY – Widowed & Young - [www.widowedandyoung.org.uk](http://www.widowedandyoung.org.uk)
- [www.gmsafeguardingchildren.co.uk](http://www.gmsafeguardingchildren.co.uk)