

## **SUPPORTING CHILDREN WITHIN THE FRAMEWORK OF THE LCP**

### **PROJECT OVERVIEW**

**THE ROYAL SOCIETY OF MEDICINE  
21.06.10  
ALISON GERMAIN**

### **Current Role**

- **Children and Families counselling service at the Marie Curie Hospice, Liverpool (Pre and Post Bereavement support)**
- **“Long Arm” Professional support to Community staff with the PCT**
- **Adult Bereavement Service**
- **Developing the LCP within the Marie Curie Palliative Care Institute Liverpool.**

### ***Background to project...***

- Literature review of children's needs pre bereavement
- Focus Groups with clinical staff
- Interviews with clinical staff in different areas and contexts of care e.g. acute, hospice, intensive care, community
- Review of existing resources produced
- Exploration of parent/carer needs/concerns

### ***Aims of the Project:***

- To provide information and guidance to parents/carers in explaining about the imminent death of a close relative to children
- To provide age-appropriate resources information to help children in their understanding of the dying process
- To “sign post” to services and resources for ongoing bereavement support

- To provide clinical staff with a framework to ensure that families receive appropriate advice and support when a patient is dying.
- To develop prompts and goals for the LCP generic version 12 to incorporate the needs of children and families.
- To develop learning and teaching within the LCP package to include children's needs
- To develop the end of life care module to include children and grief



### **National Steering Group**

- *To support implementation of the project aims and objectives*
- *Membership of the Group to reflect the activities of the project including of palliative care and child development issues*
- *Representation from national child bereavement agencies and paediatric services*
- *To ensure project's success through the sharing of best practice and the development of a robust framework to support children and families.*
- *To provide endorsement of resources and materials produced by the MCPCIL*
- *To ensure that resources produced are evidence based*

## ***CBN Regional conferences***

- **Consultation exercise at 4 Regional conferences (300 Members) obtaining feedback on draft documentation.**



## ***The clinical staff...***



**“ It’s difficult enough talking to the adults in the family and breaking bad news, I’m a bit scared to ask about the children... it could open up a can of worms and I don’t feel that I have the training or the time to support the children as well.”**

**Words of a Registered Nurse**

**“ It’s an Intensive Care Unit... it’s scary enough for adults so it must be even worse for children. I try to think of ways to explain about the equipment and the machinery to children so they are not so frightened but it’s hard. We have only just got a room where we can talk to families and tell them when a patient is dying...”**

**Words of a Registered Nurse**

## ***Why do Health Professionals exclude children?***

- We may assume parents/carers are supporting the children.
- We feel children should be protected
- We assume that children will not understand (Adams & Deveau 1984)
- We want to delay upsetting children until we have no choice
- We feel that we don't have the skills or speciality

## ***The Parents...***



**“ How do I tell her? She knows that her dad is ill, she knows that it’s serious but how do I find the words to tell her that he is dying when I don’t want to accept it myself?”**

**Words of a mum**

**“ I haven’t told them anything, he was only diagnosed three weeks ago and they don’t even know that he has got cancer. How do I tell them that their dad is about to die?”**

**Words of a Mum**

**“ The older ones know, they’ve known from the start, but the babies?... They’re only 5 and 7 , how do I talk to them I wouldn’t know how to begin...”**

**Words of a Dad**

### *Concerns for the Parent/Carer?*

- **What do I say?**
- **Will they understand?**
- **When should we tell them?**
- **Should we delay telling them and upsetting them?**
- **What if I get upset or tearful?**
- **I MAY NEVER SEE MY CHILD/REN GROW UP.**
- **I FEEL GUILTY THAT I AM ABANDONING THEM.**

**“ What children are told  
will be limited by their  
maturity and their  
ability to understand”**

**(RITTENBERG 1996)**



“I understand why parents are reluctant to tell their young children about a parent’s terminal illness. The hardest part for me was realizing that I couldn’t protect Rachel from the pain of her father’s death. It hurts to watch my child in pain. But then I realized that it isn’t a choice of whether she will hurt or not, but whether I will know about it.”

(From “Healing Children’s Grief”  
Grace Hyslop Christ 2000)

## Words of the Children ...



**“If someone had told me that mum was going to die I would have gone to visit her... I just thought that she would be coming home again.**

**That’s what makes me sad.”**

**Sam (Age 7)**

**“I think it’s my fault that dad died ...  
I kept asking him to play football with  
me, so his back never got better.”**

**Thomas (Age 6)**

**“Everyone knew she (mum) was going  
to die, but they just couldn’t be  
bothered to tell me.”**

**Charlotte (Age 17)**

**“I knew mummy was very poorly but when she died it was a very big shock, they all kept saying that she would get better.”**

**Daniel (Age 5)**

**“I would of liked to give her a big hug and a kiss and said goodbye ..... But now I can't, it's too late.”**



**Jenny (Age 8)**

***Common responses to loss.***

- Difficulties at school- Frequent absences, lack of concentration and motivation
- Sleeping difficulties
- Eating disturbances
- Anti social behaviour
- Difficulty relating to peers
- Concern for well parent
- Fear of recurrence of disease (age 10 yrs +)
- Acting out behaviour
- Adolescent conflict- Stay with sick parent/independence.
- Fear of genetic implications of disease.

***LOSSES FOR THE CHILD  
DURING TERMINAL PHASE***

- Separation from sick parent.
- Separation from healthy parent (if present) whilst caring for partner.
- Potential loss of home, whilst cared for by friends/family).
- Loss of play time.
- Loss of support - Emotional  
- School work
- Loss of routine

“The terminal stage of cancer is a time of high psychological stress. Our experience indicated that the impact on families of the terminal phase of cancer was generally more dramatic and stressful than the period after the death.”



(Christ 2000)

## ***BREAKING BAD NEWS TO CHILDREN***

### **REMEMBER**

There is no script or template- what is said should be individual to each child's needs and understanding. Parents/carers should be willing to adapt or change what they were going to say in reaction to the child's response.

**What is said maybe;**

- A proactive disclosure- initiated by an adult. Can be planned. Often used when the child has no idea or little understanding, OR
- A Reactive disclosure- initiated by the child and in response to a child's question, behaviour or feelings expressed.
- (LINDSAY & ELSEGOOD 1996)

***Key Aims of Supporting Documentation:***

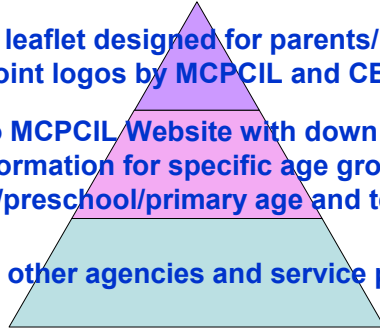
- To support children and families on the commencement of the LCP.
- To provide easily accessible information and guidance to parents/carers in explaining about the imminent death of a close relative to children
- To signpost to more detailed information for specific age groups on the MCPCIL website.
- To provide links to other service providers.

## **Pyramid of Support**

Short leaflet designed for parents/ carers  
joint logos by MCPCIL and CBN

Links to MCPCIL Website with down loadable  
information for specific age groups;  
Toddler/preschool/primary age and teenagers

Links to other agencies and service providers



## *Resources produced...*

- Brief information to support parents/carers in talking to children when a relative is dying, with links to MCPCIL Website to down load information on:
  - Supporting toddlers/pre-school children
  - Support when Mum is dying (5-11 yrs) (teenagers)
  - Support when Dad is dying (5-11 yrs) (teenagers)
  - Support when a close relative is dying (5-11 yrs) (teenagers)
- Other site links...
  - Support for young people with learning disabilities
  - Links to other agencies/support sites.
  - Winston's Wish helpline number

## ***Endorsement received from CBN***



## ***Additional work to be undertaken***

- **To develop learning and teaching within the LCP package to include children's needs**
- **To develop the end of life care module to include children and grief**
- **To develop resources for post death support including advise on children viewing the body and attending funerals**

**“ We talked a lot... I knew about his illness and how serious it was... I knew that he could die, I just hoped and prayed that he wouldn’t.**

**When he died, it hurt so much and knowing about it didn’t stop it hurting, but it did help me to understand, we talked a lot, I got angry and cried a lot, but we did it all together and I knew that I was not alone....”**

• Thank you!