

ADDRESSING END OF LIFE CARE ISSUES IN A TERTIARY TREATMENT CENTRE

ROSIE MIDSON
END OF LIFE CARE MANAGER
GREAT ORMOND STREET
HOSPITAL LONDON

SETTING THE SCENE

- STATISTICS
- 2007
- TOTAL GOSH PATIENTS 455
- IN THE HOSPITAL 104
- PICU- 46
- NICU-15
- CCCU- 24
- OTHER WARDS -18
- OPD-1

STATISTICS

- GOSH PALLIATIVE CARE TEAM
- 115 DEATHS-HOME, HOSPICE, LOCAL HOSPITAL
- 22 IN GOSH

STATISTICS

- 82 IN HOUSE DEATHS
- CHILDREN NOT KNOWN TO PALLIATIVE CARE TEAM
- ARE THESE ALL ACUTE UNEXPECTED DEATHS?

TERTIARY CENTRE WORK

- NATIONAL and INTERNATIONAL referrals
- NO A/E facilities, so children stabilised before retrieval
- NO transfers in utero
- All admissions via local services or after outpatient assessment

PERCEPTIONS

- FAMILIES: “no-one else has been able to help my child but GOSH will make them better”
- STAFF: “ we have the expertise, resources, knowledge and skills, we expect to make children better”
- DEATH IS A FAILURE

Acknowledging Difficulties

- When and how should the possibility of death as an outcome be introduced?
- Intensivists as ‘gate-keepers’
- Withholding or withdrawal of treatment
- Ethical consultation
- Assumption: “we don’t do death very well”

BASELINE EVIDENCE

- Ask families about their experiences
- Conducting an audit of bereaved parents
- PROCEED WITH CARE

Audit Process

- Registration and oversight
- Sample selection
- Demographics
- Permission from families
- Time for careful listening
- Collating data
- Reporting back

AUDIT QUESTIONNAIRE

- Were you familiar with the hospital before your child's final stay?
- Did you have an identified member of staff coordinating your child's care?
- Were you given regular updates regarding your child's condition?
- Did anyone discuss with you the fact that your child was dying?

AUDIT QUESTIONNAIRE

- Were you given a choice regarding preferred place of death?
- Did you feel supported during the time of death?
- Were your other children included according to your wishes?
- Have your other children needed any particular support since your child died?

AUDIT QUESTIONNAIRE

- Were you offered appropriate spiritual support?
- Have you been contacted by the hospital since your child died?
- Did anyone prepare you for the practical aspects following your child's death?
- Have you and your family experienced local support since leaving the hospital?

AUDIT QUESTIONNAIRE

- Have you had a letter from the chaplaincy team inviting you to have your child's name in the Book of Remembrance?
- Did you receive an invitation to the Trust's annual memorial service?
- Would you have taken up the opportunity to come back for a follow up visit with your child's consultant?

AUDIT QUESTIONNAIRE

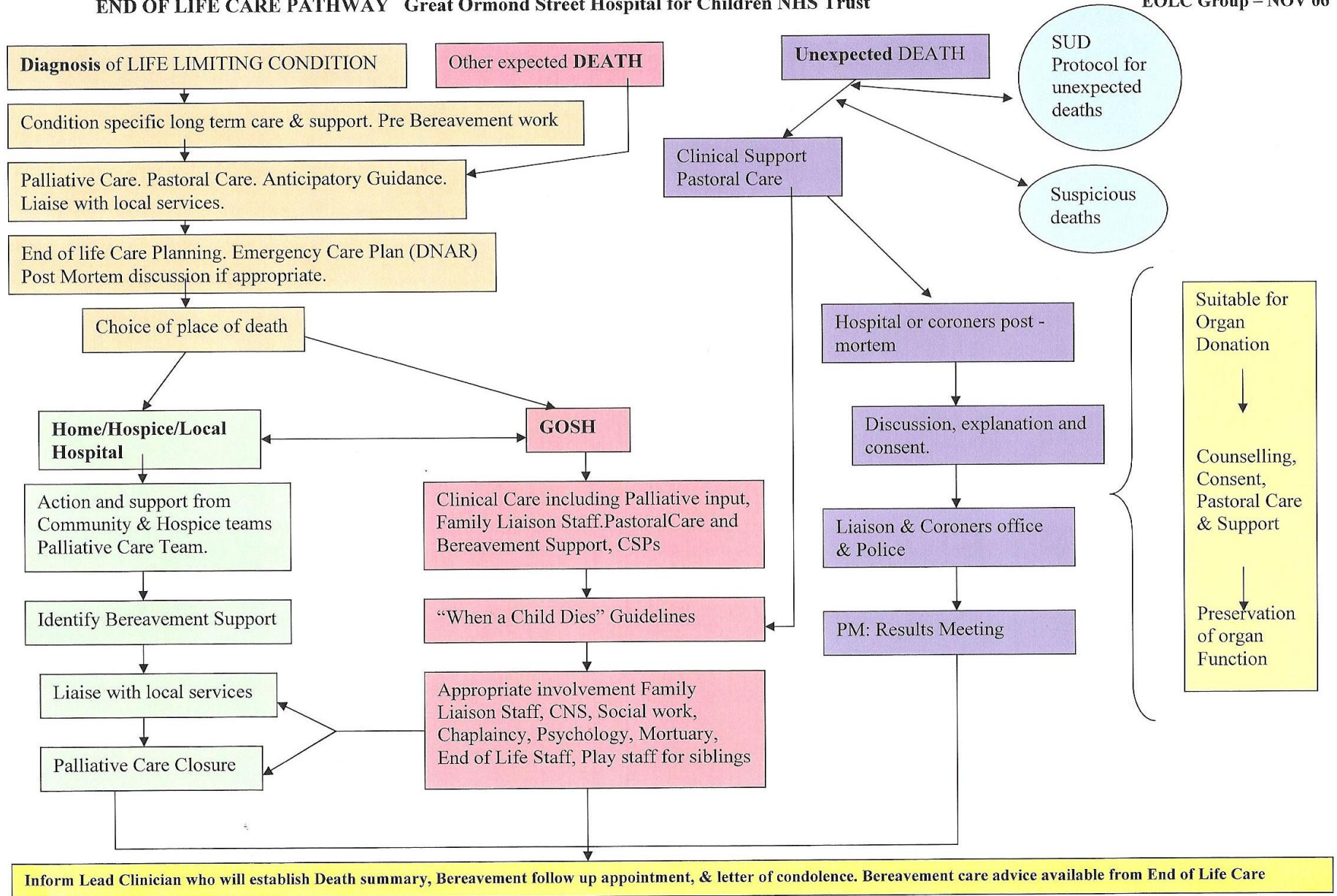
- Please tell us what made the situation worse for you.
- Please tell us what was helpful or what would have been helpful.

Introducing the pathway and tool

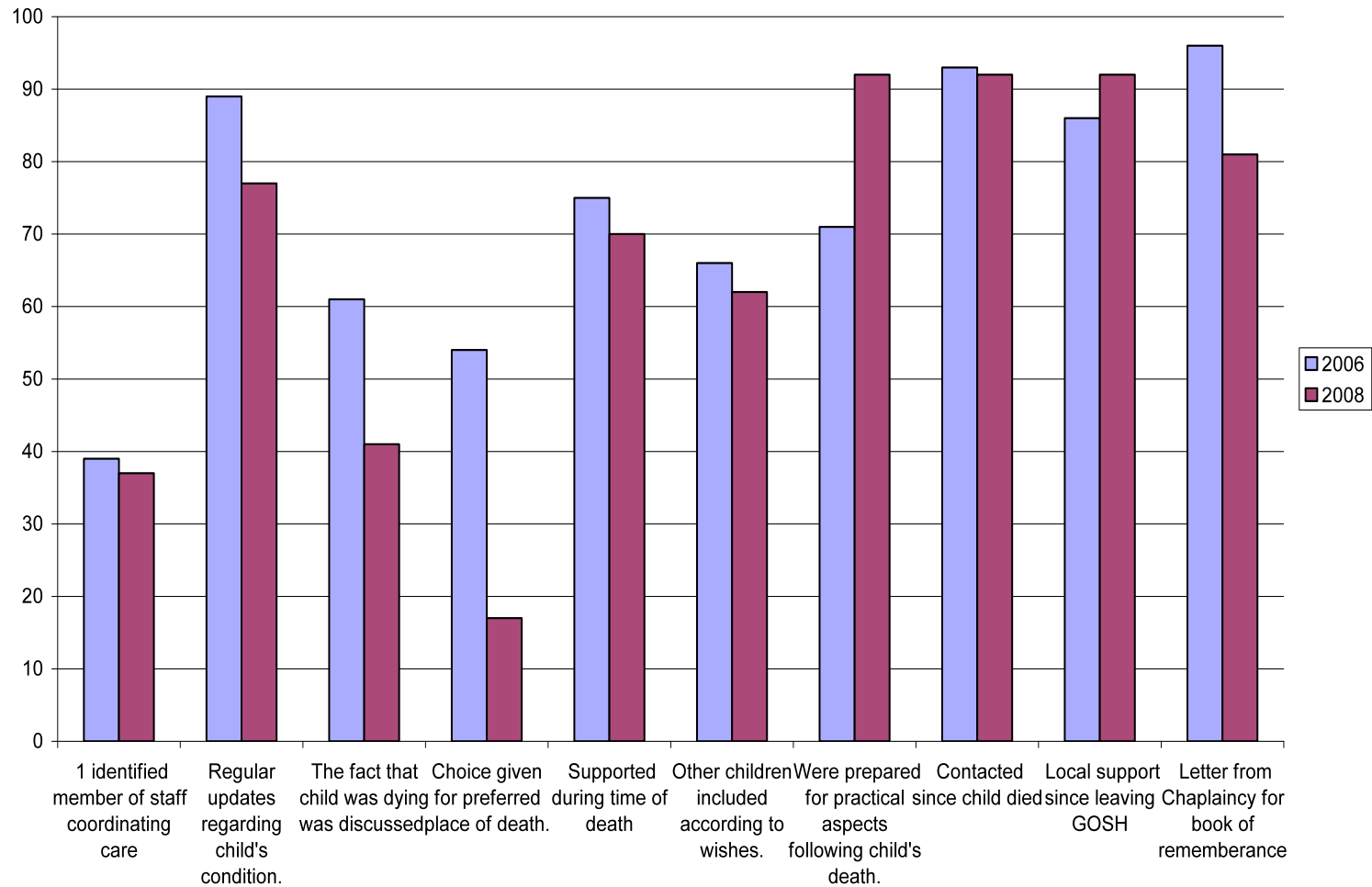
- Wide dissemination
- Raise awareness
- Teaching on how to use the tool

END OF LIFE CARE PATHWAY Great Ormond Street Hospital for Children NHS Trust

EOLC Group – NOV 06



Audit results comparison



Changing attitudes and culture

- Reluctance to talk about death and dying

The Barriers

- Lack of experience
- Fear of reactions
- Ownership of who should hold these conversations
- Uncertainty about timing
- Lack of services to support choices
- Lack of knowledge about existing services
- Unwillingness to acknowledge death as a likely outcome

The next steps

- Continuing education, particularly around communication skills
- Raising awareness of resources available to staff to support them in caring for families when goals of care change
- Enabling families to be empowered, providing information on what they might expect and who is available to help

GOALS

- Anticipatory guidance
- Timely discussions
- Enabling choices
- Effective planning
- Utilising available resources

- All the while listening to the child and their family and responding to their expressed needs