

Joint Trust Guideline for the Management of: Sharing bad news with parents

A Clinical Guideline recommended

For Use in:	Paediatrics and neonatal care.
By:	Doctors of all grades.
For:	Parents or carers of children with newly diagnosed neurological; impairment or disability or other severe chronic or life threatening illness.
Division responsible for document:	Women and Children Division
Key words:	Breaking bad news, Sharing the news
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Date of approval:	5 th September 2022
Ratified by or reported as approved to (if applicable):	Clinical Safety and Effectiveness Sub Board
To be reviewed before:	15 th September 2025
To be reviewed by:	Dr Bina Mukhtyar
Reference and / or Trust Docs ID No:	1169
Version No:	3.1
Compliance links:	None
If Yes - does the strategy/policy deviate from the recommendations of NICE? If so why?	N/A

This guideline has been approved by the Trust's Clinical Guidelines Assessment Panel as an aid to the diagnosis and management of relevant patients and clinical circumstances. Not every patient or situation fits neatly into a standard guideline scenario and the guideline must be interpreted and applied in practice in the light of prevailing clinical circumstances, the diagnostic and treatment options available and the professional judgement, knowledge and expertise of relevant clinicians. It is advised that the rationale for any departure from relevant guidance should be documented in the patient's case notes.

The Trust's guidelines are made publicly available as part of the collective endeavour to continuously improve the quality of healthcare through sharing medical experience and knowledge. The Trust accepts no responsibility for any misunderstanding or misapplication of this document.

Version History:

Version	Date	Author	Reason/Change
JCG0325v1	21/08/2014	THCGAP	Change of header & footer to joint hospital version. On JPUH version change to contact details.
JCG0325v2	05/07/2016	THCGAP	Reviewed by Dr Mukhtyar, no clinical changes.
JCG0325v3	15/07/2019	THCGAP	Reviewed and updated by Dr Mukhtyar. Line Manager changed, and phone numbers amended.
JCG0325v3.1	September 2022	Dr Bina Mukhtyar	Line Manager changed and phone numbers amended

Distribution Control

Printed copies of this document should be considered out of date. The most up to date version is available from the Trust Intranet.

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1. Quick reference guideline/s

1.1 Preparations

- The news should where possible be given by a consultant.
- Both parents should be seen together. (*See 'Who should be present' below.)
- If a parent is alone, then it is preferable if another family member is present.
- Allow sufficient time without interruptions – usually at least 30 minutes.
- Arrange a quiet and private room.
- Support staff should be present. (* See 'Who should be present' below.)

These are fundamental to good practice. Every effort should be made to meet these 6 criteria. There will of course be exceptions: single parent families, one partner not available within a reasonable time frame, urgent medical need etc. In these circumstances the event should be planned modifying these criteria as necessary. If bad news is broken by a non consultant in an emergency the consultant on call should be informed at once.

1.2 Which staff should be present

- A member of the specialist nursing team who will be able to support the family both at the initial interview and in subsequent home visits.

Roles and contact details for specialist nurses as follows:

The Nurse Adviser for Children with Special Needs (this post is based at the Community hospital).	(01603 508 943
Oncology Outreach Nurse:	(01603 287 852 Mon-Fri 9-5pm; or (01603 286 286 and pager number 0507
Respiratory Outreach Nurse (children with cystic fibrosis.)	(01603 286 851 or (01603 286 286 and pager number 0534
Neonatal Outreach Nurses/Family Care Team3	(Family Care Team: 01603 645 489

- If the nurse adviser is not available then another nurse or midwife should be present – preferably someone known to the family.
- Trainees. It is acceptable for the consultant to be accompanied by a trainee – usually one who knows the case and is known to the parents

2. Objective/s

- To ensure best practice by Doctors when breaking bad news.

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3. Rationale

Hearing bad news about children is of course difficult and stressful. Families will remember the occasion with distress, particularly if the news is given carelessly. These guidelines seek to ensure that the practicalities of news breaking are correct. Guidelines cannot hope to replace training and experience in communication skills.

4. Breaking the news – some principles

- Prepare carefully. Make sure you know the case in detail.
- If you have not already met make sure you are talking to the correct parents!!
- For babies have the baby with you and the parents. In the case of older children they may be present or can be spoken to separately
- Warn the family: *“I have asked to see you because we are worried.....”*
- Find out or confirm what the parents already know.
- Summarise the story so far.
- Be simple and direct: *“We think George may have a condition called Downs Syndrome”*.
- Check back: *“Do you know anything about Downs Syndrome?”*
- Take time – go at the parent’s speed – there is no point in delivering a lecture on Downs Syndrome to weeping parents who are in shock.
- Don’t be too gloomy – find something positive to say.
- Don’t be foolishly optimistic.
- Allow silences.
- A hand on a shoulder or other physical support may be appropriate.

5. The aftermath

The parents will probably be shocked so:

- Acknowledge this. *“This must be a shock for you.....”*
- Offer time. *“Would you like to sit quietly for a time before you set out for home?”*
- Offer traditional comforts – tea etc.

The staff team may also be shocked and a debrief over a cup of tea is good practice.

6. Pass on the news

The following people need to know immediately by phone or fax if continuity of care is to be maintained:

- The General practitioner (GP).
- The Health Visitor or Midwife.
- The nurse adviser for children with special needs if she was not present at the initial interview. This is best done immediately by phone or fax.

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7. Confirm the information to the family

- Arrange early follow-up – within 24hrs for in-patients and 2 weeks for out-patients. Usually, specialist nurses can do an early follow up visit.
- Make sure parents get booklets etc. if available.
- Give parents information about appropriate parents groups. Leaflets, phone numbers and web sites are useful.
- Often a letter to the parents is helpful.

8. Broad recommendations

As recorded in quick reference guidelines.

9. Clinical audit standards

- a) The news is given by a Consultant.
- b) Both parents are seen together or a parent with another adult family member.
- c) Support staff are present.
- d) The GP and Health Visitor or Midwife are informed within 12 hours.
- e) A letter is written to the family within 2 weeks confirming the news.

10. Summary of development and consultation process undertaken before registration and dissemination

The authors listed above on behalf of the paediatric guideline development group, which has agreed the final content. During its development it has been circulated for comment to: Paediatric nurses, paediatric outreach nursing team, paediatric consultants. Relevant comments have been incorporated into the guideline. This guideline was reviewed in July 2016 by Dr Mukhtyar as still clinically accurate. It was reviewed in 2019 and minor changes were made see version control box below.

This version has been endorsed by the Clinical Guidelines Assessment Panel

11. Distribution list / dissemination method

- Intranet.
- Guidelines folders in paediatrics, neonatal care and post natal wards.

12. References / source documents

<http://rightfromthestart.org.uk>