

STANDARD 5: Sharing information and keeping parents and children consistently and fully informed and involved in all decisions.

‘Health care providers, organizations and individual health workers, share a responsibility to advocate for children and to reduce the fear and suffering of children and their families by ensuring that they keep parents and children consistently and fully informed and involved in all decisions’

Supporting criteria

1. The wearing of name badges by all health workers who also introduce themselves to children and families:
2. A system for making children and families aware of their rights to information:
3. Policies, systems and/or practices that ensure children and families are given sufficient understandable information about:
 - Their specific health problem/s
 - Any changes in their condition
 - Investigations and procedures(these make it easier for them to contribute to decision making, to give fully informed consent and to share any necessary special care)
4. Giving information to children and families about the ward facilities and routines, and about relevant general health issues:
5. Interpreters who are available, and used when necessary
6. Systems to investigate and address complaints, positive comments and to seek the opinions, views and ideas of all health workers, children, their parents and families
7. The sharing of healthcare related information by health workers in a way that enables consistency of information giving to children and families, confidentiality, and clinical effectiveness
8. Ways of sharing non-clinical (general) information between health workers that are effective.
9. Having and using communication tools, appropriate for the circumstances, to aid effective communication (information sharing), especially for summoning help urgently

Discussion

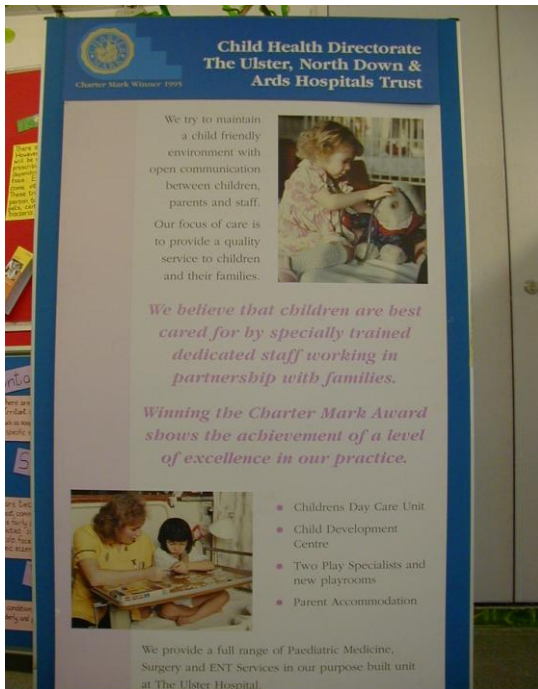
People who use health services need to know what to expect, how to use the services provided, who to complain to if something goes wrong and how to do this, and to be fully informed in a way that they understand about anything that might affect them. These issues are best covered in a written statement that is prominently displayed in the healthcare environment

Successful organizations are good at sharing information, ensuring the participation of all their employees and clients and of meeting their clients' individual needs. This culture for information

Ward rules



sharing minimizes misunderstandings, mistakes, disappointments and complaints. To provide the 'best possible' healthcare, information needs to be shared effectively with parents/carers and children so that they understand what will happen to them, and are able to share in the decision-making and fully participate in the healthcare needed.



An example of a mission statement

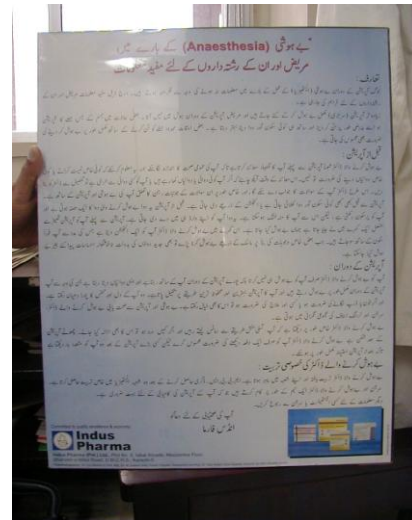


Early morning meeting in Moldova for all senior health workers to share information.

To share information effectively, it is necessary to have:

- A culture in the healthcare environment that encourages the sharing of information and enables participation
- A chain of responsibility and accountability that prioritises information sharing
- A positive attitude to sharing information (the desire to share), and to work together with colleagues (team working) in partnership with children and parents
- The skills to share information effectively (so that it is fully understood) and consistently
- A system that keeps sensitive information confidential. Protecting confidentiality is vitally important unless this is not in the child 'best interests', or you have permission from the child and/or their parents to break this.
- Different methods of information sharing for different circumstances
- 'Job aides' for use as reminders, such as 'how to break bad news'
- Tools to aid information sharing, such as information boards, telephones, pager systems etc
- Privacy, mutual respect, compassion, time, and patience.

Health workers know the names of their patients and their families. Children and families want and have a right to know the names of the health workers looking after them. Best practice is therefore for all health workers to wear identification (such as name badges) and to introduce themselves to the child and family.



Information for parents about their child's anaesthesia and what will happen after surgery

The information health workers give to parents/carers and children may not be understood for a variety of different reasons. These include:

- The language is not the first language of the child or parent receiving the information
- The information content is not understood as knowledge of the subject matter is limited
- The format and/or words used are not easily understood
- The parent/carer or child does not want to hear what is said or is not ready to hear this
- The parent/carer or child is partially deaf
- Too much information is given at once
- The recipient is distressed, anxious or upset and therefore is not receptive (does not 'hear')
- There is not enough privacy

To avoid these problems, best practice is for health workers to have education/training opportunities for learning communication skills, about the importance of protecting confidentiality and about the evidence based suggestions for giving information, particularly for transmitting bad news.

These 'rules' include:

- Privacy and no interruptions such as a telephone ringing, a knock on the door and other interruptions.
- Introducing yourself, say who you are and what your role is
- Making sure the child or parent/carer has a close family member or friend with them if possible
- Having a second health worker present (a doctor/nurse combination works well)
- Explaining what information you intend to share and finding out before giving this what the child or parent/carer already knows
- Giving information honestly and kindly in the child or parent/carer's first language (via an interpreter if necessary)
- When it is appropriate, trying to give any positive or reassuring information first, before giving information that children and families will find difficult
- Using words that child or parent/carer is likely to understand without being patronizing. Use of pictures or mime or sign language may be helpful
- Getting regular feedback by asking child or parent/carer to tell you what you have said
- Giving the recipient the opportunity to ask questions
- Remembering that small amounts given at frequent intervals are better than too much at a time or large time gaps without information
- Backing up with written or pictorial information whenever possible
- Arranging a time to give more information

- Asking if there is anyone else in the family the child or parent/carer would like you to share the information with
- Showing compassion but remaining in control of your own emotions
- Getting permission to share with others as necessary

Children and families need to feel confident about the abilities of those who look after them. Loss of this confidence can cause much anxiety and distress.

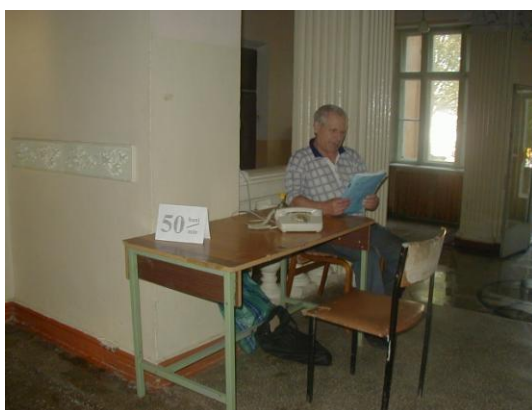
Some individual health workers can feel protective about the families they look after. While this is usually good, it can sometimes create a dependence that causes families to lose confidence in the care given by other health care providers. This is made even worse if a competitive atmosphere develops between different health workers and health care environments, especially when one undermines the care of the other. Such undermining makes it difficult for families who may need the care that can only be provided by the denigrated health workers or health facility at some future time. It is therefore important for health workers working in different situations to support and communicate well with each other, to share and promote consistent good practice and to be positive about all who contribute to providing healthcare for children and families, even if mistakes have been made.



A simple way of telling mothers they are welcomed and supported to see their babies, also a hand washing reminder

Communication tools vary depending on the technologies available and the task. Even basic low cost tools such as hand bells for summoning help and hand made hospital signing systems will achieve objectives. The important priority is to identify what needs to be communicated and then to decide what method or tool to use. It is up to individuals to employ the technologies available in the most appropriate way. A well-sited communication board for sharing non-clinical information may be as effective as individual more expensive handouts. The important issues are that the information is put on the board, the board is easy to see, the information is understandable and in large enough print for people to read, or in pictorial format for families unable to read.

It is also important for parents/carers to be able to share information about their child with other family members and friends. The resources for and a system to enable this are of paramount importance, especially for distant family members.



A low-cost private 'manned' telephone in a children's hospital in Eastern Europe. This enables parents/carers to contact their friends and relatives. Until the retired health worker in the picture persuaded the authorities to allow him to install the telephone, parents/carers had no secure way of contacting their relatives.

Finally best practice is to audit compliance with the policies and systems for information sharing and participation to make sure they are achieving their objectives.

References

United Nations General Assembly: Convention on the Rights of the Child. Articles 9,12,13, 17 New York: United Nations; 1989 available from <http://www.unicef.org/crc/crc.htm>

Leavitt L. When Terrible Things Happen – A parent’s Guide to Talking with Their Children. American Academy of Pediatrics, Johnson & Johnson Pediatric Institute LLC. Available from www.jjpi.com

Gillick competence. Gillick v West Norfolk and Wisbech Area Health Authority [1985] 3 All ER 402 (HL).

Flatman D. Consulting children: are we listening? Paediatr Nurs. 2002 Sep;14(7):28-31.

Richman N, Save The Children Fund. Communicating with Children. Helping Children in Distress. London: Save the Children; 1993.

Richman N. Helping Children in difficult circumstances-a teacher’s manual (Save the Children, Development Manuals). London: Save The Children; 1996.

Reddy N, Ratna K, editors. A journey in children’s participation, Bangalore: The Concerned for Working Children;2002. Available from www.workingchild.org

Silverman J, Kurtz S, Draper J. Skills for Communicating with Patients. Abingdon: Radcliffe Medical Press; 1998

Misteil S. The Communicator’s Pocket book. Management Pocket Books Laurel House, Station Approach, Alresford, Hants, SO24 9JH. UK; ISBN 1 870471 41 5