Developing communication skills in medicine

Telling parents their child has severe congenital anomalies

Steven Ryan

Summary
A large number of potential malformations exist, but the key skills in communicating with the parents of a malformed baby are the same. Dissatisfaction is common in this situation and has prompted a national initiative in improving standards of disclosure of disability and malformation – the Right from the start strategy (see appendix).

Key skills include keeping the family together, ie, not removing the baby unnecessarily, knowing how parents like to be informed, listening, checking that parents have understood, being non-derogatory and, most importantly, emphasizing the positive side of their newborn child.

Keywords: communication skills, education, congenital anomalies

Background
The birth of babies with major congenital anomalies is becoming less common in the UK. The reduction in incidence is due to the identification of malformed fetuses by medical screening in early pregnancy and their subsequent termination, but in some conditions, such as spina bifida, there has been a fall in the conception of affected fetuses. Many expectant parents feel that there is no chance of their baby having a malformation and many will not have considered such an outcome.

There has been a major change in attitude over life-saving treatment for children with life-threatening malformations. For instance, infants with Down’s syndrome are now more likely to be offered corrective surgery for antroventricular septal defects and duodenal atresia.

When are abnormalities detected?

Some parents will have been made aware that their unborn child has a major abnormality, but they may have chosen to continue with the pregnancy despite this. The involvement of a paediatrician before birth allows the condition and its natural history to be better defined, parents’ questions answered and plans made for the delivery and postnatal care. The parents can visit the neonatal unit. A description of the most likely postnatal course will be helpful for the parents and, if surgery is contemplated, so will an interview with the surgeon. Videotapes of interviews with parents of children with malformations have been prepared as an aid to antenatal counselling. Parents shown the film described it as useful and accurate; more so than genetic health visitors who also saw it. The authors used this discrepancy to call for a more balanced and non-directive approach from professionals involved in antenatal counselling.

When a major malformation is identified at birth, all efforts should be made to keep the baby with his or her mother. There is a natural reaction, born of apprehension, to remove the child for assessment to another room or to the special care baby unit. This interferes with the natural bonding process with the mother. For example, a child who is immediately put to the breast has an increased chance of successful breast feeding. It is unnecessary for every baby with a malformation to be removed to the special care baby unit, individual assessment being required. The chances of parental rejection are increased if the mother and baby are separated. Babies with cleft palate or Down’s syndrome can frequently be nursed on the postnatal ward with their mother.

When first talking to the parents, the baby should be present, firstly allowing important physical signs to be shown and secondly to remove the element of the unknown. The parents’ imagination may suggest a more ‘horrifying’ malformation than actually exists. When a child has been born with a cleft lip or other external abnormality, in addition to demonstrating the physical features, showing the parents pictures of other babies before and after surgery can be very reassuring. If possible a selection of pictures of varying severity of lesions should be available.

A baby with an important malformation may appear normal to his or her parents. This may be the case in the parents of a child with Down’s syndrome. Frequently however, such parents later admit to noticing that their child is different, but have said nothing because it has not been confirmed by the birth attendants. In other situations, the staff’s unusual reaction to the delivery alerts the mother to some problem. Occasionally malformations which look similar can have very different prognoses. Exomphalos (figure 1), for example, is associated with a number of other potentially serious malformations, whereas gastroschisis is not.

Figure 1 Exomphalos

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When to interview the parents

If a malformation is evident or strongly suspected, the parents should be told as soon as possible. Where they express a preference, most parents say they wish to know as soon as the staff suspected a problem.6 It is sometimes suggested that confirmatory diagnostic tests should be completed prior to talking to the parents. In fact informed consent is required to obtain samples for diagnostic tests. For example, in a baby with suspected Down's syndrome the clinical diagnosis is usually certain. The karyotype is analysed for conformation of the diagnosis and also to detect the small number of cases which are inherited by chromosomal translocation.

Previously, it was suggested that parents should be told as soon as a definitive rather than suspected diagnosis was made, and, if there were any uncertainty, to await confirmation or the parents' first approach.7 Nowadays the norm is to keep the parents informed, even in the presence of uncertainty.

The interview

Perhaps as many as 50% of mothers are dissatisfied with the way a disability is disclosed or discussed with them,8 a finding not dependent on the profession of the teller. The earliest opportunity should be taken, when both parents are present and when a senior clinician is available, to conduct an interview. If one of the parents or such a clinician is unavailable, the pros and cons of breaking the news to the mother alone by a more junior doctor have to be weighed up. In any event, where a malformation is obvious, this should be discussed immediately. When confirmatory tests are required parental consent is required, so the reasons for the test must be explained to the parents.

The most effective form of communication with parents, as in all situations,8 involves listening and answering questions. The least effective form of communication is to bombard the parents with a mass of medical facts. If one stops to consider, it is apparent that one is trying to get parents to understand concepts we only expect medical students to grasp after intensive study. In the uncomfortable situation of breaking 'bad' news, it is easy for the health profession to lapse into a lecture. This often helps us cope with the situation and fills awkward silences. But silences are not awkward; they are signs of effective communication and allow time for thought. They allow time for questions. Common problems with doctor–patient communication are shown in box 1.8 Some solutions are shown in box 2. These are general principles of communication, but apply equally to this situation.

One way to deliver such news is to make a first statement which is bold and simple: "I think that your baby has Down's syndrome", "Your child has a serious heart disorder". Parents appreciate a direct approach – 'not beating around the bush'. At that point remain silent. The parents may immediately react in an emotional manner or may simply ask you "What is Down's syndrome?". By allowing the parents to 'drive' the interview you can go at their pace and at their level of understanding.

Try and avoid long lists of medical words. Avoid medical jargon. At this early stage, you are just trying to communicate the main points. For instance with Down's syndrome you should be allowing the parents to understand that their child is likely to have learning difficulties and may have associated malformations. You do not need to bog them down in minutiae such as the requirement for thyroid function screening in later life. It is also important that the parents continue to perceive themselves as the main decision makers in matters concerning their child. It is easy to overlook this role in complex situations.8 Choices should be made by parents, based on clear understanding of medical issues.

The direct approach also avoids the trap of asking the parents to make the diagnosis by revealing physical signs to them. Further information on parents' needs during these early interviews is contained within another article in this series.9

Parents are unhappy if they are told abruptly and without apparent sympathy or concern, cannot understand what has been said or if they feel they have been misled or fobbed off. Features of the disclosure which make mothers more satisfied are shown in box 3. The key elements which mothers rated the most highly were the professional's manner, adequate information, and the opportunity to ask questions.

A single interview is unlikely to be adequate, so that at the end of the first, follow-up interviews should be arranged. On subsequent occasions the parents should be encouraged to bring a list of written questions with them, since it is easy to forget important points when others are being discussed at length. The
primary nurse or midwife for the parents and child should also be present. At the start of second and subsequent interviews it is useful to ask the parents to recall what they already understand. This is especially useful if the earlier interview was conducted by a colleague.

Cunningham and colleagues set up a 'model service' to inform parents that their newborn child had Down’s syndrome (box 4). This model service significantly improved the satisfaction of parents with disclosure. The Right from the start strategy working group (see appendix for address) has also produced a template of skills and attitudes which provide a philosophical and practical guide to disclosure.

Parents feel happier if they are presented with a positive image of their child. This is helped if the child is with them when they are interviewed. By not initiating the interview with the phrase such as “I have some bad news for you”, a more positive outlook can be initiated. Other positive messages include the potential which all children have, and the positive efforts which health and other services will undertake to secure the child’s maximum potential, emphasising the value which we place on the child’s future. Even accurate information, delivered in an unduly pessimistic way may elicit anger in parents. Early support, which allows parents to feel they can help their child to develop towards their full potential from an early stage, is crucial.

Understanding the emotional impact of the situation upon the parents and understanding that failure to produce a good outcome occurs despite our best efforts, augments the physician’s ability to communicate. It also removes from the physician the responsibility for the emotional suffering which is itself inevitable and natural. The nature of the parental emotional response has been well described and is summarised in box 5. Box 6 lists ways in which this emotional response may manifest. The seeking of a second or further opinion by the parents is not a sign of failure on the part of the doctor.

The parents will almost certainly want to ask why their child has the problem and, if it is only discovered postnatally, why the panoply of modern antenatal care did not detect it. Such a question could be directed to the obstetricians or midwives involved in antenatal care.

Commonly the parents, and especially the mother, may feel personally responsible for their child’s malformation. In virtually all circumstances this feeling is unreasonable and inappropriate. Since most parents experience this feeling at some time, it is worth seeking out with a direct question if it has not been previously mentioned, so that guilt may be allayed.

### Other information sources including referral

What caused the malformation? Will it happen in future pregnancies? The initiating event in most malformations is still unknown, but is being increasingly described for a variety of malformations. The field of clinical and molecular genetics is moving so rapidly, that it is wise to seek the opinion of a clinical geneticist, so that the very latest information is available for the parents. (More detailed information in this area will be given in a future article in this series by Dr Ian Ellis.)

If the parents are contemplating future pregnancies and the risk of a further malformed child is increased, they will wish to know what specialised antenatal care will be available, particularly with respect to antenatal diagnosis. The parents should be referred to a consultant obstetrician with special experience in fetal medicine. This allows the couple to contemplate a further pregnancy with reassurance.

If treatment, including surgery, is contemplated, this will need to be discussed. In the acquisition of informed consent, the nature of the problem, its natural history and the risks and benefits of the proposed intervention will need to be covered. If time permits, a number of separate interviews will ensure good communication and fully informed consent. Sometimes urgent life-saving treatment is required and a single interview must suffice. Written information is very useful in such circumstances. Parent information documents can be produced for the more commonly encountered conditions, detailing the points above. The advent of good quality printers and readily available personal computers allows such documents to be produced when needed rather than gathering dust and getting lost. Videos are particularly well understood by parents.

### Other sources of information

There are a number of other sources of information available. Medical texts may give useful information to the parents, but do require vetting. Be particularly...
careful with older textbooks, which contain inaccurate information, particularly regarding prognosis. Their views are frequently based on selective groups of patients, seen before the advent of modern screening methods. The best information is usually found in recent state-of-the-art reviews in medical journals. You should consider reviewing the article with the parents to answer their questions and to decipher the medical language for them. Most parents appreciate having the information, and it reveals the doctor’s willingness to share fully his information. Such documents may contain references to difficult areas, such as the risk of leukaemia in Down’s syndrome. The doctor needs to be aware of the presence of such information and be prepared to deal with questions on it.

Some information sources are specifically designed for parents and carers. They are frequently produced by organisations and charities formed to represent the interests of children and their carers. SOFT UK (Support Organisation for Trisomy 13/18 and related disorders) is an example (see appendix). Since the doctor has usually not been in the situation of having a child with the malformation, he/she is unlikely to guess all the parents concerns and questions. Other parents, however, are likely to have many common experiences and questions and these organisations draw on this valuable resource when compiling information documents. Local branches of such organisations may be able to arrange for the parents to meet other parents who have a child with the malformation. They may also be able to offer practical help. MENCAP (Royal Society for Mentally Handicapped Children and Adults) is a UK organisation which provides nursery placement for such infants (see appendix).

Most of these organisations provide introductory pamphlets, useful for both parents and professionals alike (figures 2 and 3 and see appendix). It is worthwhile obtaining as many as these pamphlets as possible, for future use. Many of these organisations are large, multimedia champions for particular treatments. They often find out about new advances before the busy doctor. It is easy to feel threatened in such circumstances. Ask for the information and time to digest it before responding.

Of course, some malformations are rare and have no such organisation. Parents of such children can feel left-out in the company of parents with children with more common conditions, especially if no cause has been identified. In such cases it is worth stressing that, whatever the malformation, all children’s needs vary and are met on an individual basis.

The child’s future

Rejection of the newborn malformed child occurs in only a minority of cases. In this situation the doctor should adopt a non-judgemental role. Rejection is more likely if the baby has been separated from the mother, a reason for avoiding unnecessary separation. Rejecting parents often state that they wish to forget all about their baby. This course can lead to severe emotional trauma manifesting even years later. Counselling should be offered on an open basis to such parents, although the offer is frequently rejected.

Parents appreciate a clear outline of the services their child will receive and express dissatisfaction if the interviewer has a lack of knowledge about medical speciality referrals or community services. This problem can be overcome by preparation prior to the interview or by clearly identifying someone who will be able to give the parents all of the necessary information. This outline will include hospital medical services, community medical services, social services, and assistance from voluntary organisations. The amount of information the parents may need to absorb is large, especially if the child has multiple malformations. It is important to identify a key worker in this situation, to whom the parents can turn for advice and who can co-ordinate these services.

The relatives of the child will need to be told of the situation. The parents may wish to do this themselves, but an offer to tell them by the doctor is usually taken up. If the relatives are interviewed in the presence of the parents, consistency of information is ensured, questions can be answered, misunderstandings prevented, and medical confidentiality is ensured.

Discharge

By this time the parents should have had all of their questions addressed and have a clear understanding of their child’s condition and what plans have been made. It is important that the primary care team are informed and are invited to discharge planning meetings.

Many infants are subsequently readmitted to a different ward or hospital. If the parents have been given their own copy of the initial discharge summary, this can allow the admitting doctor to assimilate complex information quickly and act
appropriately. Parent-held child health records of a more general nature are also useful in this regard.

**Training**

Training can be achieved by experience. Initially you can observe a senior colleague breaking such news and discuss key points afterwards. I and many of my colleagues appreciate having a junior member of the team in the room. They give support, ensure the information given to the parents is disseminated to the rest of the care team and they can provide useful feedback on clarity and effectiveness.

A video ‘Shared concern’ has been produced under the guidance of the Kings Fund Centre Informal Caring Support Unit. This gives an excellent overview of the area. It is accompanied by a small booklet which summarises key points, contains a list of references and also a list of voluntary organisations. The video is most useful when watched by a small group followed by a discussion.

Groups wishing to enhance their communication skills in this area can also use role play and this can include the use of professional actors taking the role of parents. Recording such consultations on videotape can then be used for detailed analysis. It is also possible to videotape real and role-played consultations for assessment of consultation skills. Reproducible and reliable instruments of assessment have been generated for analysis of such interviews, although adaptation of the instrument will be required for different scenarios.

It may also be possible to arrange a visit to a nursery of infants with special needs and listen to parents reporting how the news was broken to them. The value of such direct learning has been emphasised by others.

4 Kranz GL, Hallum A, Kinne C. Are there good ways to give ‘bad news’? *Pediatrics* 1993; 91: 578–82.
12 Society of Parents Helping in Education. Shared concern: breaking the news to parents that their newborn child has a disability. Informal Caring Support Unit, Kings Fund Centre, 126 Albert Street, London NW1 7NF.

**Appendix: Useful addresses in the UK**

**Cornelia de Lange Syndrome Foundation UK,**
‘Tall Trees’, 106 Lodge Lane, Grays, Essex RM16 2RU. Tel: 01375 376 439

**Down’s Syndrome Association,**
155 Mitcham Road, Tooting, London SW17 9PG. Tel: 0181 682 4001

**MENCAP (The Royal Society for Mentally Handicapped Children and Adults),**
MENCAP National Centre, 123 Golden Lane, London EC1Y 0RT

**Right from the Start Campaign,**
c/o SCOPE, 12 Park Crescent, London W1N 4EQ

**SAFTA (Support After Termination for Abnormality),**
29–30 Soho Square, London W1V 6JB. Tel: 0171 439 6124

**SOFT UK (Support Organisation for Trisomy 13/18 and Related Disorders),**
Tudor Lodge Redwood, Ross-on Wye, Herefordshire HR9 5UD