

**Angus gene chapter**  
**Genetic testing of children**  
**Talking to children - and talking with them**

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When the princess kissed the frog, he turned into a prince and they lived happily ever after. Well quite happily - as the sequel tells. The frog had an identity crisis. Was he a frog or a prince? He set out to find his true identity.<sup>1</sup> Like all great stories, the frog prince deals with the eternal questions.

How much are we trapped by biology, limited and defined by our bodies, our genes, and how much can we live beyond these seeming limits?

How much can we achieve by our own efforts and with other people's help, and how much do we have to rely on other powers - science, genetics or magic?

How much does our state at birth determine who we are and will become?

How much does our behaviour, even our appearance, reflect the attitudes of other people, such as love or rejection, and their beliefs about us?

There are many stories of ugly lonely 'beasts' who, when they are loved turn into handsome heroes. How much are we really our 'worst' or our 'best' sides?

**Words and meanings**

Everyone tells stories - their versions or accounts of raw experience. Science is often seen as a way of escaping from stories and telling neutral 'truths' or 'facts'. But like all other accounts, scientific ones have to use language which is loaded with complex meanings and values as much as fairy stories are. Genetic 'information' or 'facts' are complicated by:

- \* uncertainties - about how pronounced the condition might be;
- \* speculation - about the way each child's life might be affected by a genetic condition or by other influences;
- \* value judgements about which lives are worth living, and who counts as a human being, such as in the efforts put into developing and marketing the triple test;
- \* 'geneticization'<sup>ii</sup> a great emphasis on biology and technology - genes, mapping the genome, antenatal screening and selection, hopes of genetic engineering, methods of controlling and preventing 'problems' - with under attention to relevant social concerns;
- \* anxiety about risk and responsibility, control and blame, and sometimes irrational guilt about genetic events which are beyond our control;
- \* under-estimation of human resourcefulness and community, when we jointly confront and live with difficulty and disability - as we almost all have to do in old age;
- \* a tendency to inflate genetic influences - many genetic disorders hardly affect daily life, many are extremely rare, with many defects only a few of the people that have them are severely affected. Yet it is often implied that genetic disorders are extremely numerous, and generally very severe, and each affects large numbers of people. Among the general public who do not belong to genetic interest groups or work in genetics but have quite serious genetic disorders, how many of them think of themselves as having faulty genes like defective machines? How many carriers think of themselves as carrying a time bomb waiting to explode in later generations? Do people generally perceive themselves in these consciously technical mechanistic terms?

All these complications can affect the way people talk about genetics with children - and with anyone else of any age. Most of this chapter applies to all age groups. Complications may be highlighted when talking with children but they are not unique to them. This is not a 'how to' chapter or a manual, which could imply that talking with children, like baking a cake, will turn out right if you follow the recipe. Instead, they are very varied and unpredictable agents in their own right, partners in discussions even when they refuse to talk. This chapter is mainly about stepping back and looking at some of the underlying complications which have to be dealt with at some level, especially when talking with people who are very intimately affected by genetic conditions. The main areas covered in this chapter consider communication in relation to risk, contradictions, timing and content, children's competence, and methods and barriers when talking with children.

### **Risk in talking with children**

As discussed in a later chapter (Genetics and the social context) certain strong themes in the way we think about genetics resonate with many other aspects of life, including the task of talking about genetics with children. Some of these themes can heighten concern about risk. There is the feeling that 'we ought to get it right', that complex information should be clear and also correct, that information will raise the child's anxiety. Yet at the same time there is also the feeling that anxiety should somehow be managed and relieved. Besides coping with these contradictory aims, the adults' hopes to 'get it right' are inevitably accompanied with worry about 'getting it wrong', about being incorrect, or giving too much or too little information for the child's good.

Subconsciously, other trends in genetics might increase the informant's anxiety: quests for high standards of research and knowledge, and for the 'perfect child'; the assumption that some pregnancies should be terminated because coping with the consequences would be too hard for the parents and potential child; the desire to protect people from suffering; lack of confidence in their ability to cope with difficulty. People who are strongly guided by such assumptions are likely to see talking with children as risky.

Adults with greater confidence about sharing knowledge with children are less worried that there is a 'correct' method. They are less anxious about taking risks and making mistakes, trusting that they will learn from children's responses and with them work out appropriate ways of sharing knowledge, recovering from blunders, and coping together with confusing, uncertain and distressing information. They have confidence in children's resilience and resourcefulness.

Decades ago, when four (fictional) children wanted to go camping and sailing on their own, their father agreed saying, 'Better drowned than duffers, if not duffers, won't drown'.<sup>iii</sup> Today he would probably be imprisoned for negligence. Western society is becoming increasingly anxious about risk, blame and litigation; it is almost impossible to have an accident when every event can be seen as someone's 'fault'.<sup>iv</sup> Starting with a nominal range for 1970, Figure 1 shows each decade moving more activities into the careful, cautious or fearful categories, increasing ascriptions of responsibility and potential blame.

### **Figure 1. A more risk-conscious society**

When talking with a child, adults need to reflect on how they feel about and present, for example, the possibility of the child as a carrier passing on a genetic condition to the next generation: as fearful and to be avoided at all costs, or as requiring caution, or as a risk that is worth taking and acceptable whatever happens. When parents say that one benefit in warning their teenage son about genetic risk is that it will inhibit his sexual relationships, is

this really in their son's best interests, now and in the long term, that he should be controlled by fear, rather than by his own sense of responsibility? What might the effects be on his sense of his present and future identity? Do warnings that place information in the right hand column (in figure 1) serve parents' interests rather than their child's?

## Contradictions

Figure 2 shows how modern genetics is caught within social ideals which contradict and yet also reinforce one another. People grappling with these conflicts can feel that their aims and values are being pulled apart by opposing forces, yet they are also curiously reaffirmed by these pairs of opposites. This can make explanations about genetics still more complicated, such as in the choice of words and emphases and presentation of options.

### Figure 2. Contradictory ideals

1. The first opposition is between social utility and personal worth: some people increasingly measure things and people for their utility, their commercial worth, and the way they contribute to or detract from efficient industry. Defective and disabled people in this light are seen as a net loss. Consumerism encourages people to expect the 'perfect' child and to reject the 'imperfect' fetus. As one US expectant couple said, 'If he can't have a shot at being president we don't want him'.<sup>v</sup>

2. The second dimension of opposing views relates to how a child with a genetic condition is seen as a case of disease to be rooted out, or as a person requiring social support. It is said that one reason for the rising divorce rate is that people are encouraged to expect higher rewards than ever before from close relationships as a haven from a hard world; mothers are exhorted to keep their children clean, safe, busy, stimulated and achieving.<sup>vi</sup> Mutual satisfaction within families is very highly valued, sometimes in consumer terms of parents and children expecting love to be expressed and rewarded - with gifts or high achievements.

3. The second pair, of medical versus social concerns, also involves contradictions and reinforcements. Medical technology enables us to consider treating genetic patterns and selecting and terminating affected pregnancies. Some doctors now talk of 'eliminating' a genetic defect. This can lead to less tolerance of disability and disfigurement, and higher expectations of treatments and cures.

4. However, advanced technology also produces the aids and practical support which alleviate disabilities, and enable severely disabled people to lead fulfilled lives, integrated into society in ways that were previously not imagined. The contradictions arise in the ways technology is used - to exclude or to aid inclusion, to 'eliminate' people with cystic fibrosis or to alleviate their condition and greatly extend their lives. 'Integration' includes the global interest in disability rights, equal opportunities and tolerance or celebration of diversity, all of which can be aided by new technologies.

In the past few decades, possibilities have expanded, and values have become more diverse. So, for example, a child with Down's who might scarcely be noticed as different in many earlier societies can now be seen as either too great a misfit and burden on the state, or else as a highly valued, loving and loved person,<sup>vii</sup> either as a problem for health professionals to prevent or to treat (plastic, cardiac or ENT surgery, speech therapy, and so on), or as someone with much to offer when fully accepted into society.<sup>viii</sup> This acceptance can be aided by, for example, effective treatment of the heart conditions which many Down's children have, and which would be treated without question in other children. When 3 and 4 complement one another, the same principles are applied equally to everyone, and there is

positive allowance for their differences.

Figure 2 shows how each of the four positions are pulling apart, yet can reinforce one another. Explaining the more severe genetic conditions to a child involves making sense of these contradictory forces - as far as possible.

### Timing and content

Talking with children affected by a genetic disorder raises questions about what, when and how to tell them. It also involves listening to them and learning from them. Each child, and each child-parent relationship is unique. There is a limit to how helpful general ideas can be when talking with the individual child. So much depends on each relationship and on how freely and comfortably the child and adult talk about many other things.

It may be assumed that parents should have an orderly plan, gradually unfolding information as the child 'develops'. Life is not like that. Some children understand long before the textbooks say that they can, others want to talk years after that 'stage'. They ask unexpected questions at awkward times. Parents have to think of quick responses. One mother described how she was preparing her daughter, who had a mucopolysaccharide disorder, for major surgery. Her daughter asked 'might I die?' The mother said that she hesitated, and she knew that the hesitation expressed far more than any follow-up words, so she decided to explain more than she had expected to. She worried that her young daughter would not cope well with the alarming news. The girl wrote a story about heaven, and although distressed at the time, she did seem to come to terms with the information.<sup>ix</sup> Apart from deciding to initiate discussions, adults are perhaps best advised in the timing and extent of their talking by the child's own questions and other cues.

Genetics involves words loaded with good and bad news: 'bad genes' or 'incorrect, impaired, wicked, naughty genes'. 'Make it right or better', and so on. How can the 'right' words be found? One way is to find out the words which the child or teenager uses, their questions and concerns, what they think their friends will or do think, their 'ascertainable wishes and feelings' in the words of the Children Act 1989. This includes trying to sense how much they want to talk, when and whether they want to talk. Sharing complex and potentially distressing knowledge with people of any age is not easy. The main difficulties arise when adults try to 'talk down' to children.

There are barriers to communication, especially in busy clinics, limitations of time and space, the lack of confidence and skill for some adults. There are problems of language with young children, people with learning difficulties and those who speak little or no English. Communication goes beyond words in tone of voice (optimistic, anxious, nervous or authoritarian) and in facial and body language which can be more expressive than words. Careful listeners pick up many cues from pauses and unspoken responses when giving and receiving information. More important than practical barriers are those of attitudes - prejudice that it is unwise or unkind to inform children or to trust them to make decisions, the 'adult alliance' which assumes that adults must be in control and that to defer to children is to betray both this alliance and also children's reliance on adults. There is anxiety about intruding on children's privacy, or burdening them with unwanted anxieties.<sup>x, xi, xii</sup> How can reticent children be respected yet not excluded from discussions? Geneticists and counsellors may have 2

different agenda from their clients, while assuming that they have the same concerns and order of priorities. All these barriers can affect discussion with adult clients. Attempts to create special skills for talking with children risk belittling and demeaning them. It is more worthwhile to practise sensitive ways of relating to each individual and clear appropriate ways of sharing information with them whatever their age or circumstances.

## Competence

Talking with children is frequently discussed in terms of assessing their competence to understand and to make decisions, such as to agree to a predictive genetic test. Some people advocate waiting until young people are 18, and 'competent'. Others believe that some children want to have answers, to sort out misunderstandings, and sometimes to make decisions at a much younger age. There might seem to be a contradiction between the two views, raising the age for involving children in one case and lowering it in the other. They are reconciled when attention is paid to competence and it is not identified with a specific age.

Competence to make decisions means understanding the relevant information, having the wisdom or discretion to evaluate it in the light of one's best interests, and having the confidence to act with some independence and, if necessary, to take responsibility and accept blame. Few if any adults fully understand, or have complete discretion and independence, or want to have such extreme capacities. Competence is a relative not an absolute quality, and higher standards should not be expected from children than from adults, or from the parents who may decide for them. As mentioned earlier, genetics is complicated with many uncertainties.

Assessments of competence usually attend wholly to the child's capacities. Yet the context also needs to be assessed. For most patients, their competence partly depends on how clearly they are informed by health professionals, and how much their discretion and independence are respected by all concerned. Besides relationships between the individuals, the more general social context affects competence, such as how far experts understand the condition and treatment concerned, how new or risky the treatment is, how much time and space is allowed in the hospital for quiet discussion, the adults' beliefs about children's abilities, and many other factors.

This entails moderating assessments of the child in the light of the setting, for example whether the parents are used to sharing knowledge and decisions with the child or not. This moderating can be done positively or negatively. If the family tends to keep secrets and reserve power to the parents, a negative approach would assume that the child is immature and incompetent. The context would be reflected back into the assessor's view of the child. In a positive approach, the assessor would consider whether, despite the constraints and perhaps initial signals that the child does not and cannot want to be involved, this is not inevitably the case. Further discussion might clarify the child's wishes about being involved and the parents' willingness to reconsider. The context can be used either as a further constraint, or towards a more fair and careful assessment. The two approaches partly depend on whether the assessor works in psychological traditions of taking the individual as a somewhat static unit of analysis, or else sees people within a network of dynamic relationships and experiences.

When the competence of younger children is respected, they are treated with the same respect accorded to adults. 1) Adults cannot be tested against their will in order to inform or benefit others. 2) Their results are confidential. 3) An adult who very much wants to have a test which is often done for other people would not be refused.

The onus should be on those who want to set different standards for non-urgent interventions for children and for adults to justify this. Respect for children can expose them to the dangers of unwanted tests and interventions. It is important to check that they are not being unduly pressured to consent, and that they understand any risks and disadvantages - as in counselling adult patients. Many adults feel ambivalent about tests for serious conditions, and undertake them partly to inform their relatives. So to look for complete

conviction and freedom from family pressures in the child would be as unrealistic as to expect this in all adults. It is a question of a reasonable balance between the child deciding as an individual and as a member of a family, and this is not always easy to discern.

One great difference is when children either have or do not have knowledge based on personal experience, perhaps of a close relative having severe effects from the condition. In the latter case, however mature and intelligent they are, their understanding and wisdom are likely to be much more limited. Children with experience of serious illness or disability and treatment, even if they are well below average at school, can have high levels of competence concerning decisions about their health care. During interviews with children in schools for physical, sensory, emotional and learning difficulties, we have found children who are far more competent and aware than generalisations about their disabilities assume.<sup>xiii</sup> This finding has two important implications for talking with children about genetics. A much broader range of children may be able to be informed than has previously been supposed, and overly pessimistic descriptions and decisions about some genetic disorders must be reconsidered.

One unpublished description of a working class family, in which two younger children have severe genetic conditions, assumed that the elder sister aged 16 knew nothing about the disorders and should not be tested for her carrier status, because the family did not know the numbers of the affected chromosomes. But of course, the sister had profound experience of the effects of the disorders which were far more relevant to any decisions she might make than formal genetic knowledge would be. There are other valuable sources of knowledge, such as through the mass media, and their impact is discussed in the chapter on the social context.

Competence has four levels,<sup>xiv</sup> and the first two have no threshold of age or ability. One year olds can exchange information and views, resist or accept interventions, and react positively to explanation and persuasion and negatively to coercion. The levels are:

to be informed

to express views

to influence a decision

to be the main decider about proposed treatment or care.

The United Nations Convention on the Rights of the Child 1989, and the Children Act 1989 advocate the first three levels, the third one in accordance with the child's ability. Law Lords in the Gillick case, 1985,<sup>xv</sup> advocated the fourth level for children who can understand the relevant information, make wise decisions and are competent to do so in the judgement of the doctor treating them.<sup>xvi</sup>

Assessments of competence are difficult and contentious. There are no clearly agreed methods and criteria. Psychological testing tends to be biased by outdated developmental theories which under-estimate children's abilities. A solution to these problems is to assume that school aged children are competent to influence personal decisions affecting them, and that anyone who thinks that their informed views should not be taken seriously would have to demonstrate that the child is not competent.<sup>xvii</sup>

## **Conclusion**

Some geneticists are concerned about the technical imperative, the belief that it is better to do something than nothing, better to act now than to wait and see. They have reservations about the rush to have genetic tests for later onset disorders for which there is no effective treatment or prevention. Some are concerned about pressures either to give alarming information to children, or to withhold it from them leaving them in frustrated uncertainty.

Because of these pressures, it is not helpful to make rules about specific ages when children should be informed or involved in decisions. So much depends on individual cases.

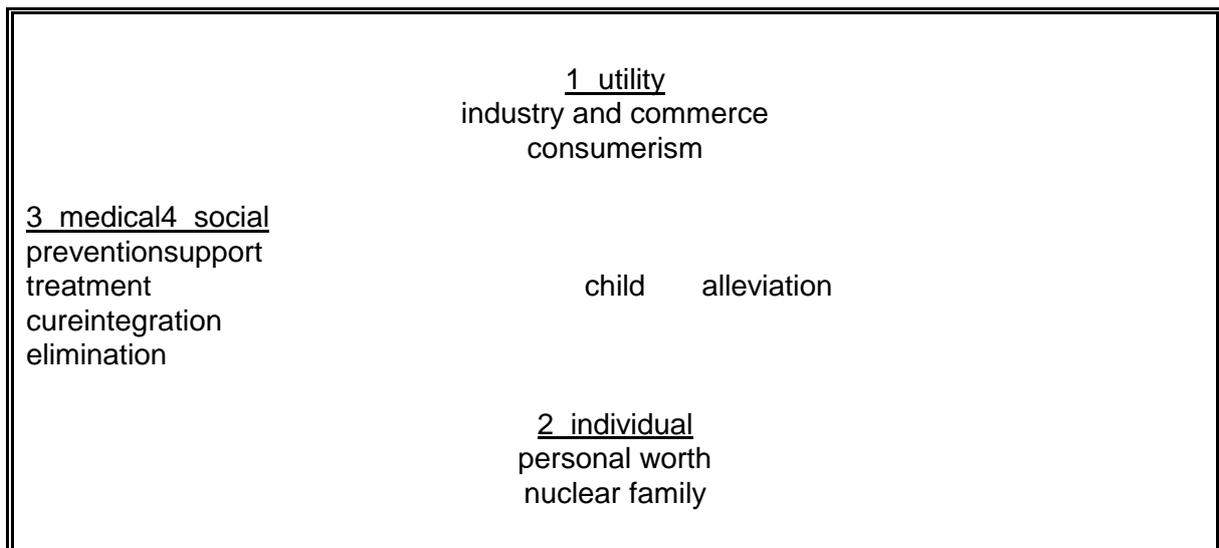
Instead of being a 'how to' manual, this chapter is intended to help people to reflect on underlying questions and contradictions, and to think about what they know and do not know before deciding what to do. This is in the hope that by unravelling some of the questions, they may find it easier to respond to children's enquiries and to respect their interests.

Through talking with children, we can learn from them how to do this, and we can reduce problems of coercion, fear, ignorance and resentment. Talking can help to clarify mutual understanding while, whenever possible, adults and children work together towards the best, or the least harmful, decision for that child.

**Figure 1. A more risk-conscious society**

1970				
carefree	risk-taking adventurous	careful sensible	cautious timid	fearful
1980				
carefree	risk-taking adventurous	careful sensible	cautious timid	fearful
1990				
carefree	risk-taking adventurous	careful sensible	cautious timid	fearful

**Figure 2. Contradictory ideals**



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