

# Telling the Children

The following article was written by Shirley Dalby, Social Worker for the HD Association in the U.K.

Many parents and caring professionals find it hard to talk to children about HD. Nobody likes to be the giver of bad news, and although they may acknowledge they should tell, the actual information-giving and possible repercussions seem overwhelmingly difficult. This article attempts to explore some of these difficulties and hopefully help parents and professional caregivers alike.

## Reasons for Telling

When someone in the family has HD, be it parent, grandparent or other close relative, it will be difficult to avoid giving a child some sort of explanation. Small children are much more accepting of individual eccentricities than adults are, but this becomes less so as they grow older, and they do need to know that someone is actually ill in order to understand and accept certain behaviour. This becomes very important as time goes by, especially if it is a parent who is affected, so that the child can retain his affection and respect, and in turn be able to explain the difficulties to outsiders. Children are also very sensitive to atmosphere and if they realize that something is not being discussed, can become anxious and imagine all kinds of things as the cause of the family's 'secret'. They may, for instance, feel that they are in some way to blame - anxiety and guilt can be much more harmful than knowing the facts. Not telling can in some circumstances be damaging to the relationship between parents and child because of the anxiety gene-

rated by the parents having to keep the secret, and fearing being found out. This can also lead to inventing an explanation which is not true and which is bound to cause trouble later on. It is almost certain that children will find out the truth at some stage, perhaps through a relative or a magazine article or television program which may give the facts quite insensitively, and accusations and distress will naturally follow.

The other important reason for telling is that everyone has the right to know the major facts of their lives, of which being at risk for HD may be one. Not to tell means that we would be denying someone's right to this knowledge, and the right to make their own decision regarding the future which will take account of this. I have known a number of people who were not told until they were adults, and sometimes then only because of a parent being diagnosed. Many of these people felt angry and bitter that the information had been kept from them, especially when they had already taken major steps in their lives such as getting married and having children. Their partners may share the feeling, and there can sometimes be consequential marital problems.

## The Telling

Parents who know about HD themselves before deciding to have children and who are already used to open discussion may find it an easier situation than those who are having to face the facts themselves for the first time. Ideally, the 'telling' should be a 'gradual sharing' so that children can grow into a greater understanding made

possible by parents acting openly, naturally, and answering questions in a way appropriate to the child's age. How much to tell will depend a good deal on the child's age and development. Children seem to have an amazing capacity for realizing when adults are being evasive or dishonest, so it is necessary to tell the truth; but it need not, and probably should not, be everything at once. The younger the child is, the more basic the facts which will suffice - just that someone is ill, for instance, with perhaps the name Huntington's disease being given. Questions are pretty well bound to follow, if not then, at a later stage, unless the child realizes that information is deliberately being withheld. Again children seem to know how much they can cope with and stop asking and listening when the answers get too difficult. They may ask the same question a number of times to reassure themselves that they have got it right.

Perhaps the question most parents dread is the direct "Will Mummy or Daddy get it?" or "Will I get it?" My feeling about this is that one should be as reassuring as possible, without denying that that chance is there. Once a child has made the connection that a family illness has implications for his parents or himself then this truth has to be acknowledged.

When adolescence is reached the questions are likely to be more pointed and will very much involve the young person himself or herself. It may not then be possible to stagger the fact-giving, and the reaction is likely to be stronger, showing in some cases as distress, anger or withdrawal. What is really important is that there is an atmosphere at home and/or outside where a child or young person can safely discuss their feelings, negative and

positive, knowing they will be accepted and understood. Some need help with this - adolescence can be a time of mood swings, rebellion or depression anyway, and parents may have a teenager who refuses to discuss anything or allow that HD is a factor in their lives. Communication cannot be forced but channels need to be kept open so that when the time comes, he/she can express fears and anxieties without loss of face or causing harm to the family.

Anyone doing the telling needs to be aware of their own attitudes towards HD. These will be coloured by their own experiences and their particular situation - an HD sufferer in the family who has been lovingly cared for will obviously create a very different reaction from where there has been family breakdown. Again the situation is different where it is a grandparent rather than a parent who is affected. The teller's own fears, guilt, or denial of the problem can prevent communication and may need to be worked through beforehand. **Trying to give the facts without falling into the trap of being over-optimistic or over-pessimistic is difficult, but I think now, as never before, parents are justified in referring positively to the possibilities involved in research.**

From what I have already said, it seems clear that the younger the child is, the easier it is to tell them something about HD. Experience from work with children in other areas, such as adoption, has shown that any facts regarding a child's life are better given earlier than later. They can then be absorbed over a length of time and the shock element is avoided. There is no 'right' time to tell - I have met many parents who have put off telling because of their own feelings and fears - "They're too young to understand", "I don't want to spoil their

childhood", but then it can become a real problem with the stresses of identity, education and relationships that teenagers have and it becomes more difficult: "Adolescence is enough to cope with", "She's preparing for exams", "He's got a really nice girlfriend who might leave him", "I can't tell now, she's pregnant and will be so upset and angry".

It is claimed that some children never do ask, and so don't give anyone the opening to tell. This can happen, particularly if the child has been put off at some time, or senses that there is a 'secret', and the opportunity may have to be a planned one. **There are various ways of doing this - telling about an affected person, discussing and drawing a family tree, looking at photographs, etc.** Children often cope with bad news much better than adults, and many parents have been surprised at the matter-of-fact reaction they receive after gearing themselves up to talk about HD. Often, too, it turns out that the information only confirms what the child already suspected. **In some cases it can be a relief as a child may have been convinced that it was inevitable that he was going to get it, or was indeed already showing symptoms.** Knowledge about the late onset and the 50/50 chance of inheritance can be a distinct improvement on his secret fears. However, teenagers, and some children, may find it helpful to talk to someone outside the immediate family circle. This could be a relative, family friend, family doctor or a genetic counsellor. It is probably not a good idea for a young person to get the very first facts about HD from an unknown professional - this can indicate that the condition is too frightening for the family to cope with, but it

can be reassuring to have the information verified by someone knowledgeable, sensitive and calm. I have known a few families who take the children with them on a follow-up appointment at their genetic clinic, so that it becomes a familiar and trusted place to go.

## Who Can Help?

Having read this some parents will think that it all sounds easy enough but that telling in practice would be very difficult. Others may still have honest doubts that it is the right thing to do. Some may think that after my comments on telling as early as possible that they have left it too late - I do not believe it is ever too late as future generations have to be considered. In any of these circumstances people may like to get some help by approaching a genetic counsellor (a referral can be made by their family doctor), the HD association, or a local professional such as a family doctor or social worker, who could talk it over with them and then offer support. There may be members of the Association who have already dealt with this problem and who could be helpful. I believe that the best person to 'tell' is someone close to the child who is around enough to pick up further questions and give reassurance, but other people can also be involved. Grandparents can be good at this, or perhaps the school may be very caring - it is a good idea anyway for them to know that someone in the family is ill.

However difficult it all may seem, I am quite sure that the whole family will benefit in the long term by sharing information and facing the problem together.

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