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Dealing with the Disadvantaged

Problems of short stature

I—Adults

MARY LINDLEY

Adults of restricted growth are as varied in their personalities, occupations, and medical concerns as any other adults. They expect to be treated as such, and not to be mistaken for children, clowns, or creatures from another planet. Whether patients are 2.38 m (4 feet 10 inches) or 1.34 m (3 feet 5 inches), they naturally merit the same courteous treatment afforded to other patients, being recognised as individuals rather than interesting cases of rare syndromes. But their rarity may make special demands on a doctor's skill. Even if achondroplasia is a memory from student days, it is likely that many doctors have never come across any of the other forms of restricted growth. So when a very small person appears for a consultation, a doctor may have much to learn.

Understanding the problems

A general practitioner may find that a patient has already been diagnosed accurately, knows a great deal about the condition causing his restricted growth, and is in the regular care of a consultant. In such a case the patient will be grateful to feel that the general practitioner is interested in his progress and understands when special care may be needed. While patients of restricted growth mostly require only routine care, there is always the possibility that an apparently straightforward problem, such as chest infection, obesity, or a broken bone, is associated with or could be aggravated by the cause of the restricted growth. The patient's own knowledge may be valuable in such circumstances, and doctors should be prepared to listen. When referral is necessary, it is helpful to make sure that the consultant knows the full details of the restricted growth. When the underlying cause of the restricted growth is unknown and the patient understands little about his condition, it is worth suggesting that he should seek an accurate diagnosis so as to understand any special problems when they might arise. If needed, a specialist can be recommended by the medical committee of the Association for Research into Restricted

Growth (ARRG), a British self-help group that has been active for the past 10 years.

Family planning may entail more discussion than usual. Before deciding whether to have children, people of restricted growth should have the opportunity to seek the advice of a genetic counsellor so as to know what to expect. Much confusion and distress may be prevented by a clear explanation at this stage. Patients may worry unnecessarily if told that they "have bad genes," with no attempt to explain the simple link between a defective gene, a defective enzyme, and the reality of an inherited disease, whether the precise defect is known or not. A woman of restricted growth who becomes pregnant may require special antenatal care. On the other hand, adoption has been shown to be perfectly possible and may be worth pursuing.

Apart from medical care, people of restricted growth may need a doctor's support in seeking help with daily problems. They may, for example, wish to apply for a parking permit from the local authority or a mobility allowance from the Government, or they may wish to have financial help in modifying their homes. Such help may be the key to an independent life, enabling a very small person to play a full role in society. Those who have never thought of making use of some of the opportunities available to them may appreciate a doctor's encouragement and advice.

In the consulting room

When talking to patients of restricted growth, a doctor should remember above all that they are ordinary people who happen to be very small. The following simple recommendations may help to smooth the encounters.

- (1) If you have several chairs in the room, invite the patient to choose the most comfortable.
- (2) Talk to the patient as to any other adult, judging intelligence according to conversation, knowledge, questions asked, and so on and not according to appearance.
- (3) Do not ask, "Do you work?" ask instead, "What is your job?" Suppress your surprise when told that your four-foot-tall patient is a television producer or a managing director.
- (4) Do not refer to dwarfs and midgets in conversation but to people of restricted growth or short stature.
- (5) If practical difficulties arise and, for example, the patient

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cannot manage to open the door or is not visible over the receptionist's counter, offer the necessary help but do not fuss or consider other difficulties until they arise.

(6) If an examination is necessary, offer help on to the bed but do not lift the patient except by mutual agreement.

(7) Listen to the patient's suggestions and explanations because he may know more than you do about the condition causing restricted growth, which may or may not have a bearing

on the problem of the moment. Do not be too eager to deny a link.

(8) When prescribing a drug, remember that the patient's weight is likely to be less than average.

(9) Encourage the patient not to put on extra weight.

(10) More thorough information is available in the *Layman's Guide to Restricted Growth* and *Coping with Restricted Growth*, both published by ARR.G.

II—Children

VRELI FRY

The first way in which the doctor can help the unusually short child is to recognise that there is indeed a problem. So many parents are dismissed as being over-anxious when they are convinced that their child has grown inadequately for a period of time. The observation that shoe or trouser size has remained unchanged for an unusually long time is an important clinical clue. Proper assessment, including reference to a growth chart and allowance for parental heights, is essential. If there is still doubt after assessment, then the child should be seen and remeasured three to six months later to assess the growth rate and if necessary to take appropriate diagnostic steps. One of the major reasons for false reassurance is that many growth disorders do not affect general health and the children seem well and misleadingly normal.

A child with a recognised disorder of growth leading to short stature has various problems. These arise broadly from two aspects: firstly, coping with a world designed for children of average stature, and, secondly, the attitudes of adults and other children to them. Their reactions to their growth problems depend upon their likely medical progress. Children with a treatable disorder are usually optimistic and are often more able to cope with everyday problems. In contrast, a child with an untreatable disorder, with the corresponding pessimistic prognosis for final height, is much more sensitive to difficulties.

Doctors may contribute to their relationship with an affected child by a correct understanding of the child's true age and intellectual abilities. It is all too easy to relate a chronological and intellectual age to the child's size without recognising the fact that they are truly older and more understanding than one realises. It is fairly obvious that the child may resent being treated as younger than his years and as being less responsible than he feels he should be. What is not so obvious, but equally damaging, is that a child continually treated as younger than his age may indeed regress and behave as expected. Thus he will achieve less than he is capable of at school and consequently a future career might be compromised. The doctor should make the family aware of this problem. It is surprising how many parents themselves come to treat their child as if he were younger. If the parents are fully aware of this problem then they also are more likely to prevent the same pattern spreading amongst the more peripheral family, friends, and school.

Recommendations

The following are a series of particular recommendations that should be made to parents:

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(1) Always treat the child as much as possible as a normal human being, only making those allowances which are absolutely unavoidable.

(2) Try to encourage independence. If a child can't reach a tap or light switch encourage him to use a chair or stool rather than performing the operation yourself.

(3) In the context of the above, try to foresee such problems and have the necessary help immediately available. This avoids the embarrassment of the child having to ask and the frustration when you are not around.

(4) Do not allow your friends and family to talk down to the child and to treat him as a special case. Bring them into the picture about the child's height and make clear your feelings on how they react to the child.

(5) Do not allow brothers and sisters either to become over-protective or to adopt a bullying role. Include them in discussions of the problems of the short child and encourage an atmosphere of openness within the family.

(6) At school make sure that the staff are aware of the problems and of the child's need to be treated appropriately for his chronological or intellectual age and not according to his appearance. On the other hand, do not be bullied by the school into allowing the child to do quite inappropriate activities. Physical education, while generally perfectly good and safe for a short child, may sometimes demand quite impossible tasks. Small hands cannot always grip climbing frames, etc, and small bodies may not respond well to being thrown about by other larger individuals.

(7) Also in the school be alert to teasing, which may become cruel and psychologically damaging. It is equally important, however, to strive against mollycoddling, either by friends or members of the school staff. Being the school mascot may be fun at times but may also be cruel.

(8) With the older child and adolescent be aware of their frustrations with clothes. Sometimes the fashions that they wish to wear are unavailable in their small size. Although this may seem trivial it may be yet another way in which the child is singled out as different from his peers. This deficit may often be made good by careful shopping or home manufacture.

Finally, some of the above recommendations may lead the family into conflict with authorities concerning special provisions. The doctor must be prepared to support them with authoritative statements about the child's needs.

Useful addresses: Child Growth Foundation, 2 Mayfield Avenue, Chiswick, London W4.

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