



Babies and the Early Years



Restricted Growth Association

Working to benefit people with restricted growth and their families



BABIES AND THE EARLY YEARS

This booklet is written primarily for the parents of children with restricted growth, their family and friends. The information it contains will also be useful for health practitioners who have to advise and inform parents of children with restricted growth.

This booklet will answer many of the questions parents have when they are told of their child's restricted-growth condition:

- What should I do now my baby has been diagnosed with this condition?
- What sources of support are available to help both my child and me?
- How will my child develop in the coming years?
- How will my child's condition affect the care I give?
- How should I answer my child's questions about their size?

Diagnosis

'On a sunny June morning my daughter lay in her hospital bassinet, sucking in her sleep, dreaming whatever it is babies dream on their third day of life. "We think she has achondroplasia, a form of restricted growth," the doctor said without actually meeting my eye. The word sounded sort of pleasant – mellifluous, non-threatening. But achondroplasia forever defined my daughter as different.'

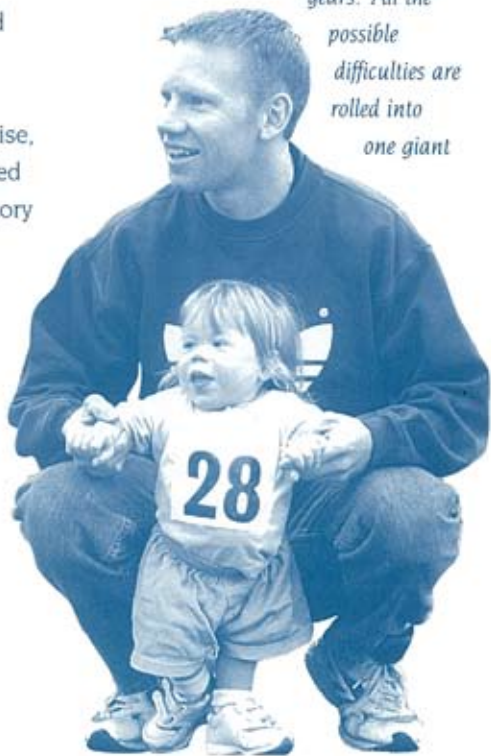
Lisa Abelow Hedley,
'A child of difference', *New York Times*,
12 October 1997

When babies are born with a condition that includes restricted growth, parents' reactions vary greatly. For some parents, their child's diagnosis will be no surprise, for example if they are of restricted growth themselves or have a history of the condition in their family. Indeed the diagnosis may be what they were expecting and hoping for.

For most parents, however, such a baby will come as a surprise – for example, 80% of children with achondroplasia are born to parents of average height with no history of the condition in their family.

Parents unprepared for the diagnosis experience strong emotions when they first learn of their baby's condition. Most feel a sense of shock, mixed with grief, and many need a lot of support to help them develop a positive attitude towards their child and his or her future – support that will help them to sort out their initial reactions and resolve to give their baby the best possible start in life.

- 6 *When your baby is diagnosed with restricted growth, you do not really know what it means. You think only of all the problems they will face in future years. All the possible difficulties are rolled into one giant*



mountain instead of being a series of small molehills. You need to learn to take one day at a time and his personality will shine through. 9

- 6 *When we finally learnt to enjoy our child for who he was, we found we had the happiest, most beautiful baby in the world. 9*

What many parents of babies with restricted growth say they most needed at the time of diagnosis is:

- good, accurate information about their child's diagnosis and its implications
- emotional support and help in gaining a positive perspective.

Getting information

When a diagnosis of restricted growth is given, as parents you need the opportunity to learn all you can about your child, their condition and its implications. A good social worker or health visitor may be able to provide this information, as well as contact numbers for organisations that can help them. One of the best sources of information is parents of children with the same condition. They can be found through support

organisations such as the Restricted Growth Association (RGA).

Many parents assume that their child's restricted growth condition will involve medical complications. While there are some clinical problems linked to particular conditions, complications are the exception, rather than the norm. It will be important, though, for your child to have certain tests to ensure that they are healthy. An accurate diagnosis of your child's condition at an early stage should ensure the best medical treatment.

Books and libraries

There are some resources available to parents who want to find out more about their children's restricted growth condition.

Detailed information relating to particular conditions can be found in the RGA's **What is...?** booklets. The titles in the series are listed on the back cover of this booklet – contact the RGA to be sent a copy of any booklet relevant to you.

As well as local libraries and bookshops, an important source in the UK is the RGA's Mary Lindley

library, which holds a collection of books and videos of relevance to people with restricted growth and their families. Membership is open to Members of the Restricted Growth Association who can borrow materials for up to three months.

The Internet

An increasingly important role is being played by the Internet or worldwide web (www). This is a vast storehouse of information, ranging from clinical information for health professionals to discussion and support groups for people with a restricted growth condition. For example, the Little People of America website has a Parents' Forum section which provides invaluable – and often inspirational – information written for and by people bringing up children of short stature. A word of caution, however: there is no control over what is put on the Internet and so it also includes information which is incorrect or misleading. Try to assess how reliable is the source of the information by comparing it with information from other sources. Medical information may

be difficult to understand and is not usually written for a lay audience. Above all, do not try to diagnose your baby's condition from the Internet. Diagnosis can only be done by experienced, skilled health professionals.

Practical and financial help

Various forms of practical and financial aid may be available to children of restricted growth from national and local resources. In the UK, the government's Department of Social Security and the Benefits Agency offer some assistance to families with disabled children requiring any special provision. Grants for home adaptations and rate rebates on the adaptations may be available from the local authority. However, for a child of restricted growth, you will probably not require any adaptations in the early years. If you do need to find out what is available and whether your family is likely to be eligible, try the following sources of information:

- your GP
- your local Citizens' Advice Bureau

- the local Department of Social Services
- the Restricted Growth Association – carries information about benefits in its Information Magazines and has a member who can pass on advice
- RADAR (The Royal Association for Disability and Rehabilitation), 12 City Forum, 250 City Road, London EC1V 8AF – publishes a guide on meeting the cost of adaptations to housing
- Parentibility, NCT, Alexandra House, Oldham Terrace, Acton, London W3 6NH.
Tel: 0181 992 2616 – is a National Childbirth Trust Network supporting pregnancy and parenthood, aimed more at disabled parents than able-bodied parents with a disabled child.

Finding support

Professional support

Nowadays babies born with a restricted growth condition usually get excellent care and support. Sometimes it is the parents who get overlooked, especially once you have transferred back home from hospital. However, besides support

from other parents (see 'Informal support' on the next page), the sources of professional help include:

- hospital doctors, including:
 - paediatricians (specially trained in medical matters relating to children)
 - geneticists (specially trained in diagnosing conditions that have a genetic cause and giving information relating to inheritance)
- your GP
- your health visitor
- social workers
- trained counsellors.

It is important to make the most of these resources. If you feel your needs for support are not being met, don't be afraid to say this to your GP or health visitor. If you find you need more information than the professionals give you, the sources of information listed in this booklet will be of help to you. You may then be able to pass on information back to the professionals!

6 *I quickly became an expert on my baby's condition – I had to, since getting information from the doctor was like getting blood out of a stone.*

Soon there was nothing I didn't know about hypochondroplasia. In fact I ended up giving my health visitor notes! It became a standing joke between us — that she was coming for her "lesson"! 9

Informal support

Invaluable support can also come from informal contact with other parents. Meeting other families who have faced the same situation helps to break down the sense of isolation that many parents feel.

Talking to other parents can help you to explore your own feelings and understand how your family is coping.

Talking about feelings can make them less worrying. It can also make painful feelings more

manageable. Other parents can also be a mine of information and will be happy to share ideas.

You can also help other people — partners, children, relatives, doctors. Talking may help them understand. It gives them permission to say how they feel.

Life can be physically and emotionally taxing, particularly in the early years, and parents may feel too tired or too busy to make contact with others. However, making the effort to get in contact can make an enormous difference.

6 *For ages we felt as if we just couldn't get any information. Then we found out about the Restricted Growth Association. Through them we got the chance to meet another couple with a child of restricted growth. They were kind enough to open their home to us, introduce us to their three-year-old daughter, and share with us their personal experiences. What we discovered was a happy, well-adjusted family, with a healthy and very beautiful little girl. That afternoon we began to learn the truth. 9*

Getting to know other families can also help allay fears.



6 I was finding it very difficult to adjust after Amy's birth. Then we went to the RGA National Day. There I saw numerous delightful children of restricted growth running around and enjoying themselves. I said to myself: "What are you worrying about?" Suddenly, everything fell into perspective. 9

The Restricted Growth Association and similar organisations in other countries are always pleased to help you make these sorts of contacts. Through social activities, these organisations also enable parents to meet a wide variety of children and adults of restricted growth.

If you do get an opportunity to meet other families at a social gathering of people of restricted growth, be prepared for the 'mirror image' experience. People of restricted growth describe this as the jolt of seeing yourself in other people and realising how other people must see you. This tends to be easier for children to deal with than adults, which reinforces the importance of allowing your child to mix with other children of restricted growth from an early age.

Giving a diagnosis: a message for maternity staff

Parents with no history of restricted growth in the family rarely even think about the possibility of having a short-statured child. Sometimes parents recognise that something is physically unusual at the time of birth – some may be alerted by the fuss being made by medical staff for no apparent reason. Others are upset by staff who seem embarrassed to answer questions.

For parents, even when they suspect something is different, the diagnosis still comes as a huge shock. Maternity staff know that the way that the diagnosis is given can have an immense effect on how parents react. Even so, medical staff sometimes give parents the diagnosis in an inappropriate manner, whether out of ignorance, insensitivity or just pressure of work. This can have serious repercussions, affecting a child's entire life: sometimes babies are rejected by their parents or even given up for adoption.

These are all real experiences of parents of short-statured children:

“The trouble was that the doctor made it sound like a tragedy had hit us. When he spoke it was all phrases like “suffering from” — “unfortunately” — “handicaps”. Now I really wish I could take my handsome, clever, healthy son to see that doctor and show him just how wrong he was. What I needed then was his support, not his pity.”

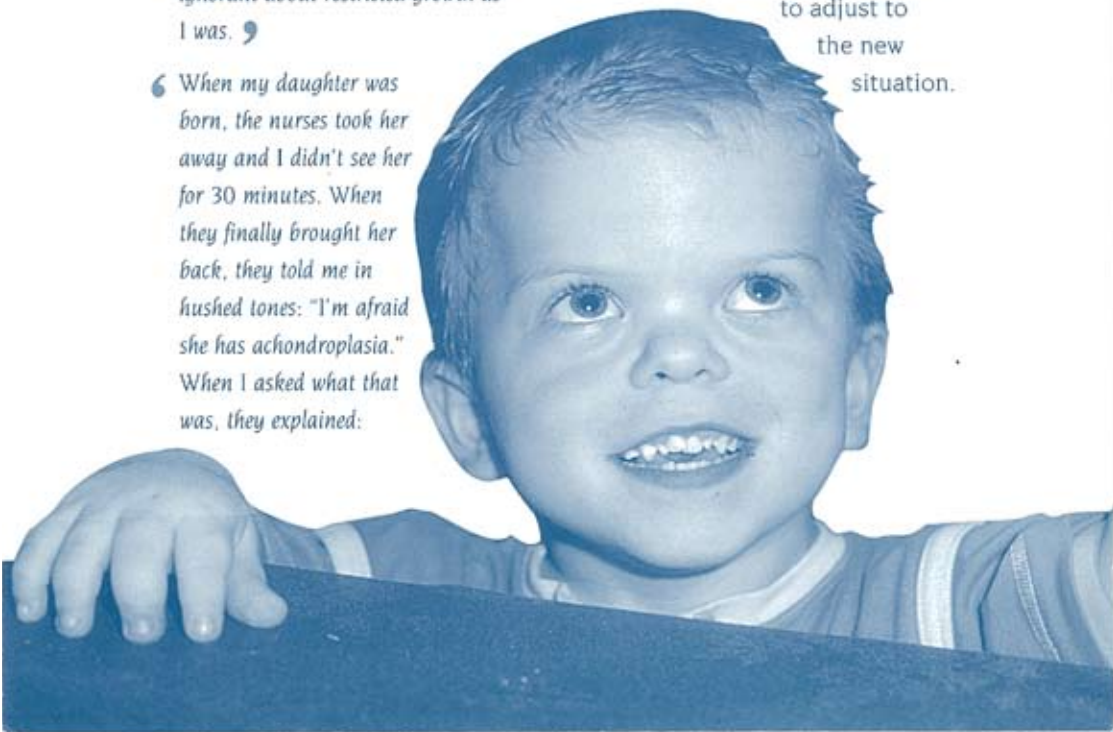
“When I was first told, I didn’t really understand what the doctor was saying, and it didn’t help when he came out with “I’m afraid your child’s a dwarf — you know, like in the circus.” Perhaps the doctor thought he was being helpful, but it gives you totally the wrong idea. I think he was as ignorant about restricted growth as I was.”

“When my daughter was born, the nurses took her away and I didn’t see her for 30 minutes. When they finally brought her back, they told me in hushed tones: “I’m afraid she has achondroplasia.” When I asked what that was, they explained:

“She’s got short arms and legs.” She was presented to me wrapped up in a blanket and I thought: “Oh my god, she’s got no arms or legs.” I wouldn’t have her near me for many hours. If only they’d thought more carefully.”

“The medical staff told us she had the condition, achondroplasia. At the time it was a shock. They told us nothing about the condition, only that the layperson’s name is “dwarf”. I fell to pieces at that point because of that word.”

Fortunately, attitudes have changed to some extent and medical staff are trained to give diagnoses in a more supportive way. That can make a big difference in learning to adjust to the new situation.



- 6 *Looking back, I think the hospital staff handled it really well. The doctor didn't try to hide the facts, but she was so positive about my baby's future which really helped, especially later, after I'd got over the initial shock. The nurses were great too, making such a fuss of him and saying how grand he was. Everyone seemed to make time for me and John – and that was so important.* 9

Understanding your reactions as parents

Even when the diagnosis is sensitively given, it can be a traumatic event which arouses strong emotions of grief. Some of the most common are:

- **Shock** – Initially you may be stunned and feel nothing. The shock is sometimes mixed with relief if you have been worrying about symptoms which now have a known medical cause.
- 6 *I suspected there was something different about my baby. As a mother you just know. Then I really started worrying in case she was mentally disabled. When the diagnosis of a growth disorder came, my first reaction was huge relief.* 9

Your brain may need time to take in what it has heard. It will protect you from too much distress. As a result, it is not uncommon for parents to believe that the medical staff have not given them all the information. But the truth is that you may have only heard as much as you could cope with. Medical staff are trained to return on a later occasion to repeat the information when you may be readier to manage it.

- **Denial** – Refusing to accept the realities of the diagnosis is a normal reaction. It can last a long time and can lead parents to seek a variety of medical opinions, hoping that the first diagnosis was a mistake.
- 6 *My husband began with the blindly optimistic desire, rooted in denial, to fix the "problem": bone lengthening, gene therapy. It wasn't until he accepted the little girl who is our daughter that he was able to simply let her be.* 9
Lisa Abelow Hedley, *A child of difference*.
- 6 *I came home from the hospital after 25 hours. I felt if I could get her home then her arms and legs would grow properly.* 9

■ **Anger** – Many parents feel very angry – at the hospital, the GP, the doctor who gave the diagnosis, or directed inwardly at the family. Sometimes it is the partner who has to bear the brunt of these feelings until they pass. It can be destructive to relationships if anger is directed at those who themselves need support. It is better to ask someone else to accept your anger and absorb it like a pillow. Some parents later redirect the energy of their anger into activities such as campaigning or fundraising.

■ **Guilt** – Many parents feel guilty that they have produced a child which is not 'perfect'. Others feel guilty about their reactions to their child. Guilt is irrational, but a normal reaction.

“ I couldn't help feeling I was somehow to blame for John's condition. Was it my gene that was faulty? Was there something I could have done to make him perfect? But you can't live your life looking backwards. ”

■ **Loss** – A restricted growth condition can represent a loss of a 'normal' future for your child. Many parents need to mourn for

the child they had hoped for and learn to accept and love the one they have produced.

“ At times I wanted to lock myself away from the world outside. ”

It's important to realise that these strong emotions are understandable: for example, denial is a way of blocking off our own feelings, while anger and blame are ways of transferring them to others. People also often experience a see-saw of emotions: some days they are able to talk about it openly, while on other days they want to deny it.

“ When I commented on how well she was coping, she was surprised. "But I'm constantly crying." I pointed out that that was healthy and normal in the exceptional circumstances. It would be worrying if she was not displaying emotion of some kind. "I'm so glad you said that", she replied. "I thought I was going mad. It gives me space to mourn." ”

Many parents then go through a stage of despair and helplessness as they think about 'What do I do now?'

“ The inevitable question is "Why us?" There are no satisfactory answers to cosmic accidents. Then there are

logistical questions: how do we refer to her condition? ... I reject the word 'special'. All my children are special; this one is just a different, more complicated kind of special. ♪

Lisa Abelow Hedley, *A child of difference.*

Don't forget your own parents...

When a child of restricted growth is diagnosed, not only will you experience strong emotions, but so too will your parents, brothers and sisters, and other relatives. They have the disadvantage that they probably do not receive first-hand information from the hospital. They have to adjust too, but it may not be clear to them what they are adjusting to. You may feel unable to support them at this time.

6 *I'm very distressed. My daughter has had a baby. It has a condition with an unpronounceable name. It sounds something like "spondi..." I don't know what it is and my daughter won't talk about it. I feel as if I'm walking on eggshells.* ♪

Your parents need to have your permission to contact the social worker for information or you can give them copies of these booklets from the RGA.



Living without a diagnosis

Finding out that your child has a restricted growth condition can make you feel very uncertain about your child's future. For some parents there is the additional uncertainty of not being given a precise diagnosis, i.e. not knowing which condition the child has. This may be because the condition is difficult to diagnose or because the medical staff you have had contact with are unfamiliar with restricted growth. Parents in this situation describe it as being highly unsettling:

6 *We just didn't know how to react or how to behave. We wanted to move forward, but didn't know in which*

direction we were going. I felt powerless, just rattling around waiting for someone to tell us what to do. And that made me quite aggressive. I wish I could have used my energy more positively. ♡

If the restricted growth condition has a genetic origin, rather than a hormonal one, then you should certainly seek genetic testing as soon as possible. Your GP should be able to refer you to your local Regional Genetic Centre (the Restricted Growth Association has a list of these in its main Office). Some GPs may need reminding of the availability of genetic testing services.

In any case it will be important to talk about your feelings with your GP or other health professionals, both for your own sake and in order to impress on them the difficulty of living without a diagnosis.

Early development and child care

Depending on the child's precise medical condition, early physical development may proceed at a different pace from what popular books on baby care might class as 'normal'. So-called 'gross motor' milestones (such as sitting up, standing and walking) may be delayed compared with average-height babies. This is, in some cases, because of the combination of a heavier head with shorter arms and legs. Short-statured babies also may be more floppy than average-sized babies. No one knows the exact reason for this but it is normal and resolves with time. Talking may also be delayed whilst the child concentrates on becoming mobile, but this is no reflection of intelligence.

There is no need to worry about these things as long as you can get expert medical advice when you need it. Most specialists will tell you not to push your child to achieve milestones at the same pace as other children; let your child develop at their own pace.

Special growth and development charts have been produced for some restricted-growth conditions.



These enable parents and health professionals to compare a child's progress with what is usual for someone with their condition. Health visitors too will find these development charts useful. Those that are available are included in the relevant **What is...?** booklets.

When it comes to intelligence, children of short stature should fall within the standard range for all children. Their restricted growth condition should not affect their intellectual capabilities.

How will your child's size affect the care you give?

“If you ask me what it's like bringing up a baby with a growth condition, I can tell you it's no different from bringing up any baby – scores of dirty nappies, sleepless nights, constant demands for attention and endless hours of pleasure.”

Different restricted growth conditions do bring with them some practical and social considerations. The RGA's **What is...?** booklets contain more information about issues relating to particular conditions, but some general points common to most conditions are included below.

“As your child gets older, you find you gain more confidence and learn to take a flexible attitude, tackling problems as they arise. Above all, don't panic if something doesn't work out! You can't get it right all the time. And there's no book that can give you the 'right' answers for every situation.”

This is where talking with and learning from other families can be particularly helpful. The difficulties you face will have been met and coped with by many other families before you. Remember, too, that you will have ideas and experiences to offer to others.

Handling a very young baby

You need to take great care to support your baby's head especially if they have achondroplasia where the head is quite large compared to the body, and the neck muscles take longer to be strong enough to support the head.

If your child has achondroplasia, your GP or paediatrician should monitor your child's head circumference and compare it to charts specific to achondroplasia (available from RGA). Any enlargement greater than that normally expected in this condition

can then be picked up and your baby referred to a specialist (see the booklet *What is Achondroplasia?*).

Sleeping position

Babies who are too young to turn themselves and have no spinal deformity may be laid in whatever position seems most comfortable to them, usually on the back. If your baby has problems involving the spine, such as kyphosis, it is better to nurse them on the side.

Snoring or noisy breathing is very common in babies with achondroplasia and they may adopt an unusual sleeping position to help with breathing. If you are concerned about breathing difficulties, especially when they cause problems with feeding, you should seek medical advice, as early intervention may help.

Looking after backs

The curvature of the spine associated with many restricted growth conditions means it is especially important to keep young children's backs well supported. It is best to avoid unsupported sitting or any activity that involves being in a curved position for any length of time. One solution adopted by

many parents is to make a horseshoe out of foam rubber. This supports the back as well as providing a raised surface on which the child can put their hands to push themselves up and balance. Remember that for children with short arms, the floor is further away than for the average child. Buy a chunk of foam rubber roughly 2 ft (60 cm) square and 5 inches (12.5 cm) deep – about the depth from the child's lower waist to the floor. Market stalls are often a good source of foam rubber.



Does your child have short arms? Help them sit up and support themselves with a foam rubber horseshoe. With this they can reach down to hitch themselves up.

Another practical (and economical) idea is the use of a cardboard box as a kind of mini-playpen. With plenty of cushions strategically placed, the young child can be both supported and contained.

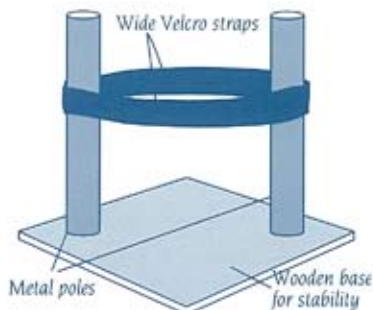
Similarly, plastic crates make excellent paddling pools or baths for small babies.



Weight-bearing and mobility exercises

In children of short stature, developing muscle strength and weight bearing are especially important in order to ensure maximum strength and mobility. This is something that should be discussed with an occupational therapist or physiotherapist, especially when it comes to the use of items such as bouncy frames or floor walkers. These often don't have adequate back support, but may have their place when used under strict supervision. A standing frame can be used to support the child in a standing position, allowing play and also developing weight bearing. At the same time, the child should not undertake any

activity which puts strain on the back. Jumping onto hard surfaces in a way that jolts the spine should also be avoided.



Massage may be encouraged for both relaxation and muscle development.

“Because our child's world was so restricted, we found his fine motor skills became very advanced. The occupational therapist encouraged things like painting, jigsaw puzzles, activity centres, touching dried pasta/beans/pulses, etc. – all under supervision.”

Going to school

Eventually your child will reach the age when he or she is ready to go to playgroup, nursery or to school. The RGA has produced another booklet in the **Lifestyles** series, called *Going to School*, which will help you prepare for that important event.

Encouraging independence

When children meet problems, it is very tempting for parents to step in and protect them, especially when your child is of short stature. As parents, it is important to resist the temptation to be overprotective. Instead encourage your short-statured child to be as independent as possible. While they may need help with certain tasks, they will not benefit if they learn to rely completely on you.

Some useful tips for encouraging independence include the following:

- Use simple gadgets, such as portable stools, steps and reaching devices, which will enable a child with short arms

and legs to become independent in the bathroom, bedroom, kitchen and everywhere else. Objects like this – whether bought or homemade – should become familiar aspects of family life.

- Always give your child encouragement, e.g. when they are climbing onto steps to reach the sink or struggling to dress or wash themselves. Never show pity or allow them to become the butt of family jokes.
- Don't let your child's short stature restrain them when playing. Within reason, allow your small child to climb trees, play on swings and slides, and so on.



- 6 *I try to treat all my children the same. Karen, who is short, knows her height won't protect her if she's been naughty. Yes, I do sometimes have to stop myself being indulgent, but it's not fair on her or her taller brothers if she gets special treatment. They all get treated according to their age and not their height. 9*

Answering your child's questions about their size

Once your child becomes aware of the reactions of other people to their size, you may be asked such questions as: 'Why am I small?' and 'When will I grow?'

Some parents have found that these questions resolve themselves naturally – their child comes to realise that short stature is for life without the need for lengthy explanation. If this doesn't happen, you as parents will need to take the lead.

- 6 *There's no easy way of handling this. I think whatever you do, you have to stress that all people are different from each other, some short and some tall; we all have our place in the world and can all be fulfilled, happy and respected. 9*

It is important that children of restricted growth should know from the outset that their families value them for their individual qualities and that their height is not significant. That security will help them to cope when people stare at them in the street or when other children make cruel remarks. Until society learns to accept all individuals for what they are, this sort of response from outsiders is, sadly, inevitable. It is not only upsetting for the children themselves, but can be as painful for brothers, sisters and other family members.

There is no magic formula for dealing with it. Some people recommend a clever, cheeky response, such as answering the question 'Why are you so small?' with 'Why are you so stupid?' Others feel it is inappropriate to teach children to be unpleasant and that the sensitivity of the people involved should be respected. A smile and a polite reply may be all that is needed, while in some cases just ignoring comments is all you can do.

When you or your children are faced with someone being persistently unpleasant, a more direct approach may be needed. Go up to the person concerned and talk to them. Explain to them about restricted growth – in many cases their comments are made out of fear and ignorance. Try to make them understand what it feels like to hear hurtful comments about your size – then they are more likely to empathise with you. Above all, be friendly and pleasant, so that you can both inform the person and make them feel confident. This approach should prevent any further expression of that kind of behaviour.

This booklet was written by Hugh Hillyard-Parker with the help of the many members and their families who have contributed their experiences towards this booklet. Their contributions were compiled by RGA Information Officer, Ros Smith.

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The RGA encourages members to share information and sources of help.

Other RGA publications

What is...?

The **What is...?** series looks at particular restricted growth conditions or issues. The titles in this series are:

Achondroplasia
Hypochondroplasia
Pseudoachondroplasia
SED
MED
Diastrophic dysplasia
Rarer syndromes

Lifestyles

The **Lifestyles** series focuses on particular aspects of living with a restricted growth condition. The other titles in this series are:

Babies and the Early Years
The Teenage Years
Careers, Employment and Education
Having a Baby
Adoption
The Later Years
Driving a Car
Bikes, Trikes and Ride-on Toys
Sporting Opportunities
What Shall I Wear?
Limb Surgery



Produced by
Communication Resources
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