



**The Restricted Growth Association (RGA) is a UK based charity that provides vital information and support to people with restricted growth (commonly known as dwarfism) and their families.**

There are over 400 different forms of skeletal dysplasia that can cause restricted growth. ("Dysplasia" basically means an abnormality of development.) Whilst the difficulties that a person with dwarfism faces will depend partly on the specific diagnoses that they have, there are some features that are common to most people with disproportionate dwarfism, resulting in many shared experiences and challenges which need to be overcome.

Common features include, but are not limited to:

- Disproportionate shortening of the arms, legs and/or trunk.
- Malalignment of the joints of the lower limbs (resulting in either 'bow legs' or 'knock knees').
- Curvature of the spine (kyphosis or scoliosis).
- Shortening of the bones of the hands.
- Relatively large head size (in achondroplasia- one of the commonest types of dwarfism).

Common experiences (compared to the general population) as a direct result of these features include:

#### *Difficulties with self-care*

- People with dwarfism often struggle with the act of cleaning themselves after toileting, particularly if they have short limbs. This can be socially disabling and may lead to problems with constipation, as the person will refrain from going to the toilet until they are in a safe environment with support from a family member or care giver.
- People of restricted growth also have problems with washing and bathing, because of reduced limb length and due to reduced joint and spine mobility. Some people also have reduced dexterity and hand strength.
- These difficulties are made worse by the fact that proper access to normal sized toilets, wash basins, sinks and taps is often prevented due to the person having short arms. This puts an onus on the toilet owner/provider to make physical modifications to solve the problem, ranging from provision of steps to stand on, to more sophisticated and expensive equipment options. It is of note that the adaptations made in 'disabled' toilet facilities often involve raising the height of the toilet seat, which may actually reduce access for those people with restricted growth.

#### *Difficulties with dressing themselves*

- People with dwarfism often struggle with:
  - holding trousers and stepping into them.
  - pulling up trousers and dresses.
  - reaching over their head and pulling items of clothing down.
  - reaching buttons, zips and clasps on the side and back of garments.
  - reaching socks and shoes to put them on.
  - tying laces or fastening buckles on shoes.
  - using clasps, buttons, zips, laces and buckles.



## *Difficulties with eating, drinking and food preparation*

- When independently preparing a snack, meal, or drink, a person with dwarfism faces greater difficulties in reaching necessary items; such as cups, glasses, cutlery, items of food from a fridge, or cupboard handles and water taps.
- Further difficulties due to the disproportionately short digits of the hand are experienced by some people in holding cups or glasses, buttering bread, opening bottles and jars, as well as pouring from bottles.
- It is important to recognise that problems arise for people of restricted growth not just because of their reduced total height, but also as a result of reduced arm length and, in some cases, reduced elbow extension. This makes standard counter depths inaccessible to many people with dwarfism, even if they are able to reach the height of the counter.

## *Difficulties with balance, walking and physical activity*

- Due to the slightly enlarged head and reduced leg length common to some skeletal dysplasias, people with dwarfism may have an altered centre of gravity and a greater tendency to over-balance, when compared to an average member of the general population. These features may also affect the gait of a person with dwarfism, particularly in childhood.
- In adulthood, some people (particularly those with achondroplasia) will develop neurological symptoms due to spinal stenosis, which can result in reduced mobility, reduced walking distance and reduced walking speed. Those who have conditions which affect the formation of the joints (e.g spondyloepiphyseal dysplasia) have joint pain, which can be severe, and a gait which is commonly described as a 'waddle'.
- Shorter limbs result in a different distribution of the biomechanical forces exerted by the muscles, tendons, ligaments and the bones, when compared to the average person of 'normal height'. This causes a person with dwarfism to experience fatigue, discomfort and pain when they perform any physical activities (including walking), even in the absence of the spinal stenosis described above. The walking pace of a person with dwarfism is affected by the differences in their biomechanical structure, as well as the duration and distance that can be walked before a rest is needed.

## *Difficulties with social, emotional and psychological well-being*

- Research carried out by Newcastle University in collaboration with the RGA (*A Small Matter of Equality – Living with Restricted Growth*, 2007) found that people with restricted growth still experience negative stereotyping and stigmatization as a result of their condition. The research report emphasises the disabling effects of these behaviours on individuals of restricted growth.

Skeletal dysplasias cause lifelong abnormality of bone growth and of bone, joint and connective tissue function. Even with the support of physical aids and organisations like the RGA, those who have dwarfism face challenges on a daily basis which are well above and beyond those of the average statured population. Thank you for fully considering the above evidence provided by the Restricted Growth Association.

**Stephen Martin**

RGA Benefits Advisor and Charity Trustee