BASIC MEDICAL SURVEILLANCE ESSENTIALS
FOR PEOPLE WITH DOWN SYNDROME

GROWTH

(Revised December 2015)

Short stature is a recognised characteristic of most people with Down syndrome.[1, 2] Average height of children with Down syndrome at most ages is around the 2nd centile for the general population. For the majority, the cause of growth retardation is not known.[1] Some conditions leading to poor growth - congenital heart disease,[3-5] sleep related upper airway obstruction[6], coeliac disease,[7-9] nutritional inadequacy due to feeding problems[10] and thyroid hormone deficiency[9,11,12] occur more frequently among those with the syndrome. Regular surveillance of growth, general health, nutritional and thyroid status should aid in early identification of pathological causes of growth retardation.

UK/Republic of Ireland growth charts for healthy children with Down syndrome from birth to 18 years are available and were revised in 2011.[13,14] These reference values are essential for assessing linear growth. However, as many older children and adults with Down syndrome tend to be overweight,[15,16] the reference values for weight may over-estimate the appropriate weight for the child and should not be used as a standard that children should aim to achieve. Instead, clinical observation and the body mass index (BMI) data included on the charts should be used to aid the assessment of those who are overweight and for the prevention of obesity.

Guidelines:

1. We suggest that it is good practice to record and chart accurate height and weight frequently in the first two years using the 2011 revised Down syndrome specific charts.[13] Thereafter, measurements should be recorded at least annually throughout childhood and at regular intervals in adult life. Regular measurements are likely to be sensitive early indicators of the many medical problems which are over-represented in this syndrome.

2. Children normally lose weight after birth but usually regain the weight lost by approximately day ten of life. Preliminary data suggest many babies with Down syndrome do not regain birth weight until around one month of age.[17] This is not reflected in the growth charts because of their cross-sectional nature and thus regular assessment is necessary from birth. This early failure to thrive is usually due to feeding difficulties, many of which resolve after the first few weeks. From one month, weight should increase parallel to the centiles. Failure to do so should be investigated. Breastfeeding should be encouraged and supported.[18,19] Preterm babies with DS (born before 37 weeks of gestation) have weights that are[20] similar to the general population and so the neonatal infant and close monitoring (NIC**A**M) chart should be used until term[21] and thereafter the DS charts should be used with measurements corrected for gestational age for at least a year.

3. Of those with measurements below the 2nd centile some will have major pathology but some may be failing to thrive for other reasons – e.g. feeding difficulties.[10] Such children should have their dietary intake evaluated and may need to be referred to a paediatrician or paediatric endocrinologist for assessment.[17]

4. The Down syndrome specific growth charts based on data from around 6000 measurements of 1100 children clearly reflect the tendency to excess weight gain among the children within the UK and Irish study sample particularly in later

childhood.[13,14] Hence clinical assessment together with use of the standard BMI charts, which are included on the growth charts, is required. We suggest that all those over age 2 years with weight above the 75th centile should be charted on these BMI charts. Those above the 91st BMI centile should be carefully monitored. Those above the 98th BMI centile should be encouraged to lose weight and further assessment and guidance should be considered.

5. Although there is a high prevalence of overweight/obesity among people with Down syndrome this is not inevitable.[15,16] As with the general population weight is influenced by environmental[16, 22] as well as biological factors.[23]

6. Appropriate anticipatory guidance regarding diet and physical activity should be given for all those with the syndrome.

7. Thyroid function should always be checked in those with accelerated weight gain.

8. In childhood, growth may fluctuate as in all children, but among children with Down syndrome these fluctuations may be more prolonged. They are not reflected in the smoothed curves of the current standardised growth chart.

9. The Down syndrome specific chart suggests an absence of pubertal growth spurt. Those with the syndrome do have an adolescent growth spurt, but it is usually less marked than in the general population. Puberty may occur at an earlier age and requires anticipation together with education and support for both parents and the child.[24,25] Early onset of puberty has a limiting effect on final height.

10. As with all children, head circumference should be measured regularly and charted on Down syndrome specific charts. If there is any cause for concern, subsequent measurements should be made.

11. The use of growth hormone in Down syndrome is still being evaluated. There is no evidence that it should be prescribed except in the unusual situation of concurrent primary growth hormone deficiency.[26-30]

12. The influence of parental height on target height appears to be variable.[31]

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