The assessment of childhood short stature and why it matters: A healthcare professional's guide

Child Growth Foundation

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KEY LEARNNG POINTS

- Accurate evaluation of growth is a key assessment of child health.
- Short for age and sex is an often-overlooked marker of vulnerability and social deprivation and may be the only presentation of potentially serious underlying pathologies.
- Girls and ethnic minority children may be disadvantaged during growth assessment leading to inequalities of treatment as well as delayed or missed diagnosis.
- Opportunistic growth assessment should be undertaken where possible.
- The tools for undertaking growth assessments are: the height centile, the child's growth rate, and the mid parental height centile.
- The two growth parameters that are useful for identifying those who are more likely to have rare disease and require onward referral are:

  - a childhood height of below the 0.4th centile; and
  - a birth weight less than the 2nd centile.

- Rare disease is much more likely in children whose height is below the 0.4th centile. The shorter the child the greater the likelihood of underlying pathology.
- Rare diseases are often multisystem disorders with serious comorbidities which require lifelong surveillance.
- Early identification of short stature and referral improves outcomes.

ABOUT US

The Child Growth Foundation (CGF) is a UK charity, focused on the support, understanding and management of rare growth conditions and concerns.

We work to improve the lives of everyone affected by a growth condition. We support children, young people, adults, and their families – whether or not they have a diagnosis.

About this booklet

This booklet is intended for healthcare professionals. It is based on material presented in webinars delivered by Professor Justin Davies and Professor Helen Storr. They have kindly granted the CGF permission to adapt the content into this information booklet.

PHASES OF NORMAL GROWTH

A combination of factors affect growth, including genetics, the environment, psychosocial factors, and nutrition. Normal growth in children is a strong indicator of their health and well-being.

Human growth can be divided into three phases, infancy, childhood, and pubertal growth (figure 1).

The infancy growth phase is mostly nutrition dependent and is very rapid, up to 25 cm per year.

The childhood growth phase starts around 6 months of age but becomes predominant from around 3 years. Initially there's a slow deceleration followed by a steady growth rate which continues until puberty. The growth velocity is 4-8 cm per year and is more dependent on hormones, particularly growth hormone and thyroid hormones.

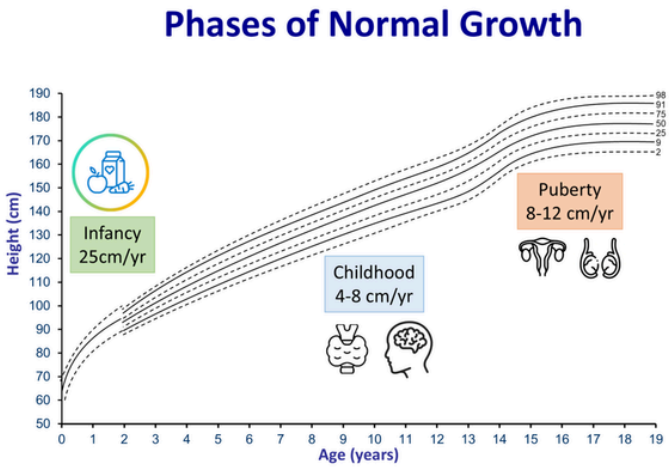

Figure 1: Phases of normal growth.

PHASES OF NORMAL GROWTH

The pubertal growth phase is led by growth hormone and sex hormones and is characterised by a dramatic increase in height velocity of 8 to 12 cm per year. However, this phase is variable between individuals and there are major differences between the sexes which account for the average height differences between men and women (see figure 2).

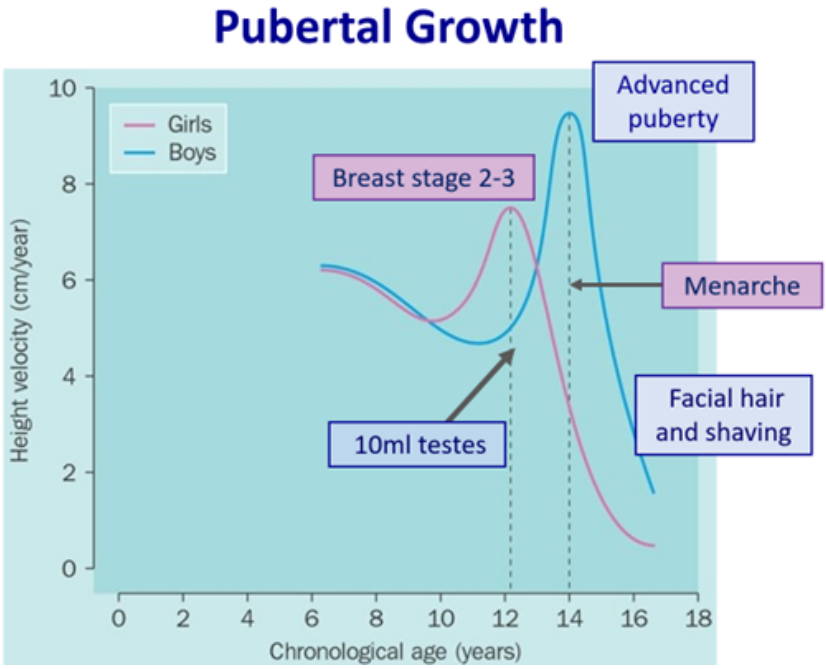

Figure 2: Pubertal Growth

PHASES OF NORMAL GROWTH

In girls, the puberty growth spurt occurs at a mean age of 12 years and, at its peak is 8 cm per year on average. This correlates with breast stage 2 to 3 in early-mid puberty. Once menarche occurs and periods are established, the growth spurt declines, and growth is nearly complete.

In boys, puberty is well established at the start of their puberty growth spurt, giving two more years of pre-pubertal growth compared to girls. A peak height velocity of around 10cm per year occurs at an average of 14 years and by the time they've established facial hair, their growth is nearly complete.

WHAT IS CHILDHOOD SHORT STATURE?

Short stature is common and is typically defined as those who have a height measurement below the 2nd centile. Accurate evaluation of growth is important and should be a key assessment of child health. This is because, being short for age can be the first and only sign of several underlying medical conditions, many of which are treatable.

Early diagnosis is important so that appropriate treatments or interventions can be initiated which give the child the best chance of good general health and achieving normal height.

Additionally, short stature is linked to poor nutrition and adverse socioeconomic circumstances, with increased incidence of poor childhood growth in areas of higher deprivation.

Overall, childhood short stature is linked to poorer lifelong health and education and can be a major concern for parents and children.

WHY IS IDENTIFYING CHILDHOOD SHORT STATURE IMPORTANT?

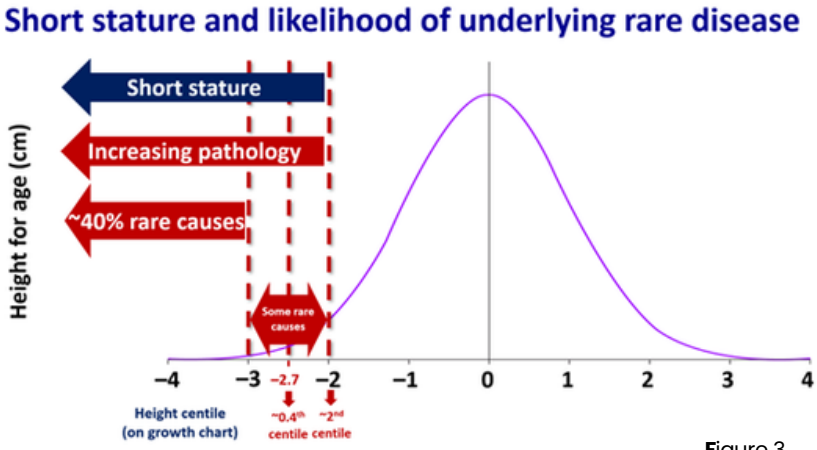

Figure 3

The shorter the child the greater the likelihood of underlying pathology, as shown in figure 3 above. Children whose height is below the 0.4th centile (approximately minus 2.7 standard deviation scores below the mean) have a significantly higher likelihood of a rare disease.

Children who have heights that lie between -2 and -3 standard deviations have an increased likelihood of a rare cause for their short stature.

40% of the children below minus 3 standard deviation scores will have a rare cause for their short stature.

Early access to growth assessment enables optimal health and growth outcomes. A diagnosis of the cause of short stature can inform the health surveillance strategy needed for that child, beyond growth management.

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SHORT STATURE AND LANGUAGE DEVELOPMENT

The Millenium Cohort Study showed that the children who had short stature at the age of 3 years also had language development scores that were consistently lower from ages 3-11 years compared to the rest of the study group (Freer, J. et al. 2022).

Children with short stature at age 3 who had catch up growth by age 5 did not have significantly different average language development scores than their peers but had a higher probability of being high performing when compared to children with persistent short stature.

This could indicate that early interventions may be beneficial for neurodevelopment in children and that short stature could be used as a marker to identify vulnerable children.

CAUSES OF SHORT STATURE

Normal Variant Short Stature - In approximately half of children, short stature is normal for them and there's no underlying problem. They will ultimately reach a height appropriate for their family.

Pathological Short Stature - This is short stature as a result of an underlying medical problem. Approximately one third of the children with pathological short stature will have a primary growth disorder which directly impacts the growth plate (the part of the growing bone where growth occurs). These include: chromosomal problems, such as Turner syndrome in girls; skeletal dysplasia (e.g. hypochondroplasia); and being born small for gestational age.

The remaining two thirds have a secondary growth failure where a wide range of secondary factors impact the growth plates. These include: nutritional problems, psychosocial issues, major systemic disease, and endocrine problems such as growth hormone deficiency.

SMALL FOR GESTATIONAL AGE (SGA)

Figure 4 shows the frequency of birth weight for a particular age and gender corrected for gestational age. 95% of babies will have a birth weight between minus 2 and plus 2 standard deviation scores.

Babies who have a birth weight below the second centile are defined as being born small for gestational age (SGA)

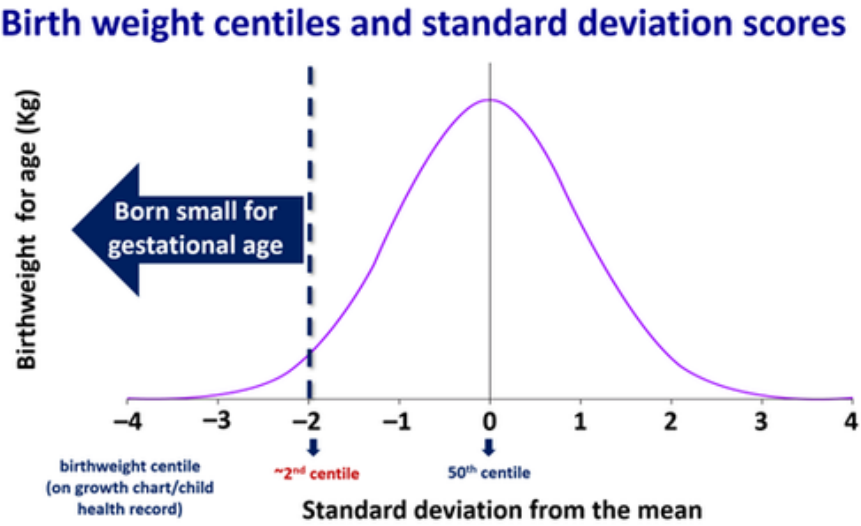

Figure 4: Standard deviation curve of birthweight corrected for gestational age.

SMALL FOR GESTATIONAL AGE (SGA)

Early identification is important as 10% of children who are born SGA do not exhibit catch up growth.

For these children, their height may remain below the second centile throughout childhood with many going on to experience an early puberty and finally a significantly short adult height.

Growth hormone therapy is available and is an effective treatment for optimising linear growth during childhood and improving final height prognosis.

Growth hormone is licensed for children born SGA who do not exhibit catch up growth by the time they are 4 years of age. These children will need referring for further monitoring and assessment

Always check what the child's birth weight was when carrying out a growth assessment

PREVALENCE, PATTERNS, AND INEQUALITIES

A study published in 2021 by Bart's charity and Public Health England (Orr, J. et al, 2021) mapped the prevalence of short stature across the country using data from over 7 million children aged 4-5 years. The results showed that shorter height was linked to areas of high deprivation, with regional hotspots found in the North, the Midlands and within East London in Tower Hamlets, Newham, and Hackney – see Figure 5

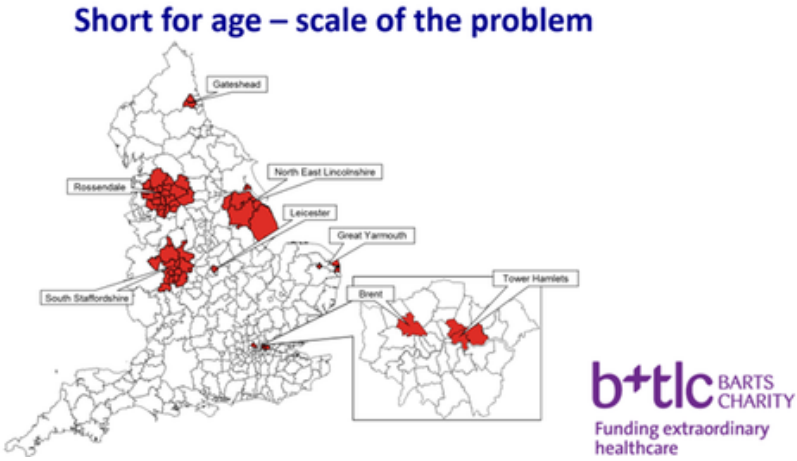

Figure 5

Short stature was highly associated with ethnicity and was also higher in girls compared to boys.

PREVALENCE, PATTERNS, AND INEQUALITIES

Inequalities exist because short stature can be considered less of a problem in women when compared to men and can vary between racial groups, especially in communities where short stature is more frequent. These biases can lead to variations in caregiver attitude and can impact upon the delivery of primary, secondary, and tertiary care.

The data shows us that:

- From primary care, girls are referred much less frequently than boys, and yet the frequency of short stature is the same in both sexes
- When compared to boys, girls have more severe growth failure at the time of presentation and are more likely to have an underlying pathology that is treatable and sometimes serious
- In secondary care, boys are twice as likely to be treated with growth hormone for short stature than girls despite there being no difference between the sexes with these conditions
- The degree of short stature determines the likelihood of offering growth hormone therapy in girls but not boys
- In a US study, black children were shorter at the time of referral and had lower growth hormone levels. The implication being that in this racial group, presentation is later and more severe
- Black children and girls of all ethnicities are under-represented in children receiving intervention for growth

GROWTH SCREENING

Unfortunately, child growth is a low priority in the UK and there's no systematic growth screening program. The UK National Child Measurement Program (NCMP) was established in 2005 for all children in state-maintained education. Single height and weight measurements are recorded at school entry (age 4 to 5 years) and at the end of primary school (age 10 to 11 years). These measurements are not a screening programme and used only to calculate body mass index.

This program has very high participation with national uptake around 95%. The guidance recommends referral of the shortest 0.4% of children (<0.4th centile on the growth charts) for growth investigation. However, children are not referred from this system because its primary focus is to monitor the rise in obesity (a child's BMI) not growth. Also, a single height measurement may not be very sensitive for the detection of growth disorders.

In practice, most children that are referred for growth assessment have not been picked up by any routine health check and instead are self-referred, usually driven by the parents or the child themselves.

To improve this situation we recommend that opportunistic height measurements / growth assessments should be undertaken whenever a child is seen in either primary or secondary care

CARRYING OUT A GROWTH ASSESSMENT

Measuring a child

Any equipment used should be calibrated at least once per year and regularly maintained according to specific manufacturer recommendations.

- A child's length should be measured until the age of 2 years using an infantometer or another purpose-built calibrated infant measuring device. Ideally you need two people to obtain an accurate measurement by ensuring that the head is up against the board and the legs are straight. Standing height is inaccurate and not recommended in this age group
- After the age of 2, standing height should be measured. The correct position is feet flat with the heels against the wall and the head straight. The child should be looking straight ahead in the Frankfurt horizontal plane (figure 6)
- All height and length measurements should be accurately plotted on an appropriate growth chart, to the nearest 1cm
- Height and length measurements should be converted to centiles in order to compare the child to other children of the same sex and age
- Weight and BMI are important, because they can give clues about nutritional influences on heights
- A head circumference should be included in at least the first assessment and particularly in babies and infants

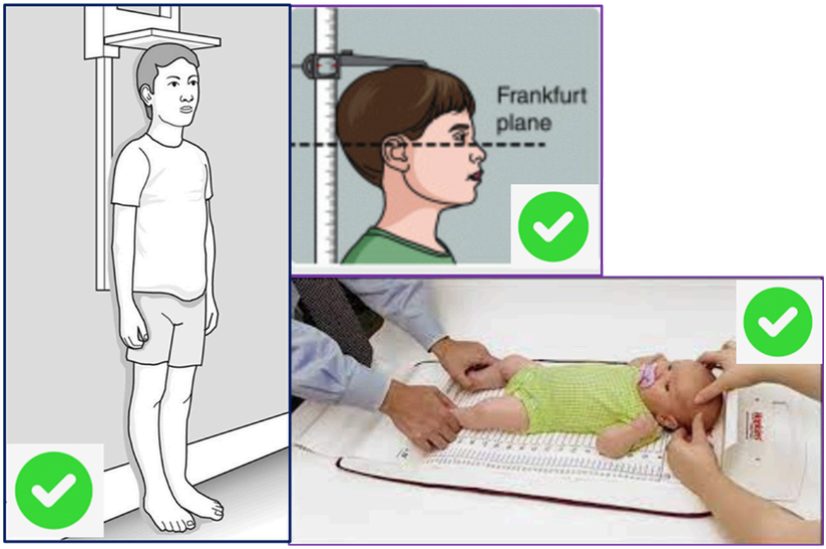

Figure 6: Height measurement of children and babies

MID-PARENTAL HEIGHT

Comparing the child's current height centile with the parent height centiles can show whether the child's growth is within expected parameters.

The mid parental height can be calculated by:

1. Plotting the parents' heights on the main chart at age 18 to 20, depending on the growth chart. If you are plotting on a girl's chart, correct the father's height by subtracting 13 cm. If you are plotting on a boy's chart, add 13 cm to a mother's height

2. Join the two points with a line. The mid parental height is where this line crosses the middle centile line– see figure 7

3. Compare the mid parental centile to the child's current height centile

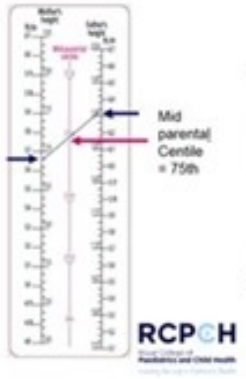

Figure 7: Calculating mid parental height

MID-PARENTAL HEIGHT

You can also calculate mid parental height using the following calculation:

Girl

$$\text{Target height (cm)} = \frac{\text{Mother's height (cm)} + \text{Father's height (cm)} - 13\text{ cm}}{2}$$

Boy

$$\text{Target height (cm)} = \frac{\text{Mother's height (cm)} + \text{Father's height (cm)} + 13\text{ cm}}{2}$$

RCPCH

Once calculated, the mid parental height can be plotted on the growth chart to enable comparison to the child's current height centile - see figure 8

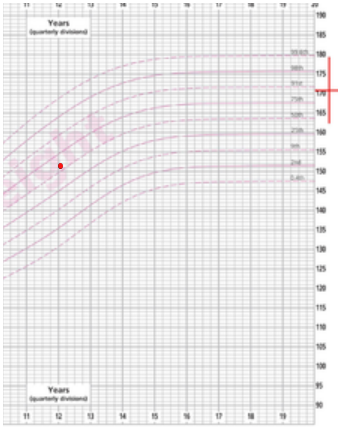

Figure 8

90% of children will be within two centile spaces of their mid parental target height, and 99% will be within 3 centile spaces. If the distance is greater than this, this could be a red flag for an underlying problem which is causing faltering growth

CALCULATING GROWTH RATE

Growth rate is calculated in centimetres per year. It requires more than one measurement, usually taken at least 4 to 6 months apart. This can be compared to the accepted ranges of height velocity for the three different stages of growth in childhood and adolescence (see figure 9). More simply, if a child is displaying a drop in height of more than 2 centile spaces, this is indicative of a poor growth rate and is a red flag. This should be taken seriously as long as measurement errors have been excluded.

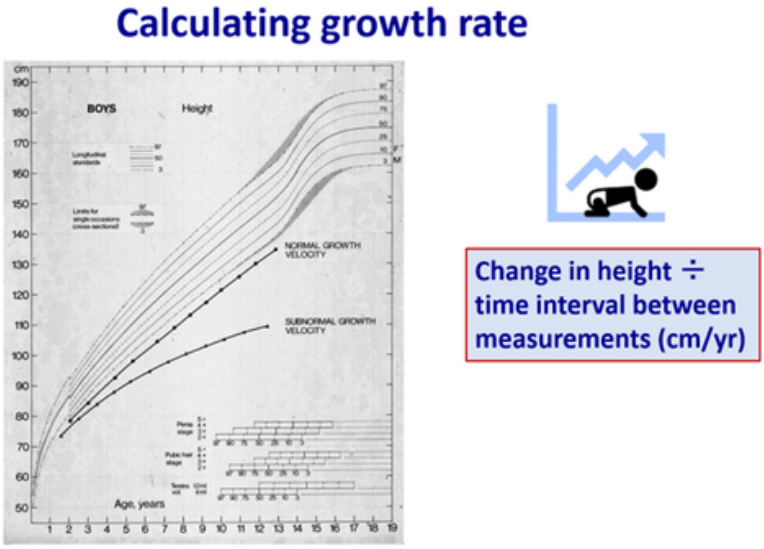

Figure 9

TAKING A TARGETED HISTORY

In order to support the investigation, it is important to collect the following information on the child's history:

- **Ethnicity** – as height varies between different ethnic populations
- **Birth weight and gestation** - postnatal growth problems can be associated with a history of intrauterine growth restriction or being born small for gestational age
- **Neurocognitive development and behavioural problems** - these could be related to other underlying disorders which are also associated with poor growth
- **A family history of short stature** - this could highlight simple familial short stature or a more serious genetic problem
- **Delayed puberty** - have they had a growth spurt at the same time as their peers or are they physically immature in comparison?
- **Features of chronic illness** – for example, weight loss, poor appetite, gastrointestinal symptoms, fatigue, tiredness, recurrent infections, headaches, visual problems, nausea, vomiting. These could indicate a chronic, serious illness that needs further investigation
- **Medications** – particularly drugs used for ADHD and long term steroid use
- **Psychosocial or safeguarding concerns** - these can significantly impact a child's well-being and their growth

INVESTIGATIONS

The following panel of tests aims to detect the signs of common primary and secondary growth disorders. Identifying the underlying conditions could help direct referrals or indicate that management can be undertaken within primary care, thereby avoiding unnecessary referrals. Tests should include:

- **Full blood count and ESR** - which are identifiers of chronic anaemia and inflammatory conditions
- **Kidney and liver function** - to detect renal problems and chronic liver disease
- **Calcium phosphate and alkaline phosphates** - which can indicate kidney and calcium disorders
- **Coeliac disease screening and other problems that cause malabsorption** - these lead to nutrition problems and poor growth
- **Thyroid function** – to identify undiagnosed hypothyroidism
- **Specialised tests** e.g. for Turner Syndrome - this could include a karyotype (chromosome testing) in girls or, if this is not available, FSH levels are an alternative. High levels can indicate signs of ovarian failure which is also a predominant feature of Turner syndrome. Note: FSH can only be interpreted if the child is under the age of 2 years or over the age of 9 years
- **Serum IGF-1 or insulin like growth factor 1 - as a marker of growth hormone secretion. Note: this can be difficult to obtain and sometimes difficult to interpret because a normal IGF1 doesn't necessarily rule out growth hormone deficiency**

WHEN TO REFER

UK guidance recommends referral for children with a height below the 0.4th centile. However, you should also consider referral if:

- The height centile is more than 3 centile spaces below the mid parental height centile
- There's a poor growth rate defined as a drop in height of 1 to 2 centile spaces
- If there are any red flags, including - weight loss (usually tracks within 1 centile of height), gastrointestinal symptoms, constipation, diarrhoea, headaches, vomiting, abnormal fat stores, disproportionate short stature (e.g. short arms and legs), dysmorphic features which might indicate a short stature syndrome, anaemia, delayed puberty or clinical features of hypothyroidism or any other chronic illnesses

FURTHER READING AND REFERENCES

- Freer, J., Orr, J., Morris, J.K., Walton, R., Dunkel, L., Storr, H.L. and Prendergast, A.J. (2022) 'Short stature and language development in the United Kingdom: a longitudinal analysis of children from the Millennium Cohort Study', *BMC Medicine*, 20(1), p. 468

- National Childhood Measurement Programme https://digital.nhs.uk/services/national-child-measurement-programme/

- Orr, J., Freer, J., Morris, J.K., Hancock, C., Walton, R., Dunkel, L., Storr, H.L. and Prendergast, A.J. (2021) 'Regional differences in short stature in England between 2006 and 2019: A cross-sectional analysis from the National Child Measurement Programme', *PLoS Medicine,* 18(9)

- Stalman et al. (2015) 'Application of the Dutch, Finnish and British Screening Guidelines in a Cohort of Children with Growth Failure' *Hormone Research in Paediatrics* 2015;84:376–382

- UK WHO growth charts https://www.rcpch.ac.uk/resources/uk-who-growth-charts-2-18-years

- Link to the webinars in full: https://childgrowthfoundation.org/hcp-education/ or scan the QR code right:

Resources and information

The CGF support a number of growth conditions, further information can be found at the website below. The CGF also connect families and individuals through peer support programmes, virtual and in person events/meetings which can all be vital in helping those living with rare conditions.

https://childgrowthfoundation.org/conditions/

If you have any questions regarding the information contained in this booklet, or any other queries, please get in touch with our friendly team.

How to contact our nurse led Support Line:

-Call our dedicated Support Line number: 020 8995 0257
-Complete our Support Line online contact form:
childgrowthfoundation.org/supportline
-Email us at: support@childgrowthfoundation.org
-Book a slot at: childgrowthfoundation.org/bookings
-Scan the QR code:

By contacting the Child Growth Foundation Support Line, you are providing consent for us to collect, process and store your data to provide you with the information or services you are contacting us about, in line with our Support Line Privacy Statement childgrowthfoundation.org/supportlineprivacy and our charity's Privacy Policy at: childgrowthfoundation.org/privacy

CGF RESOURCES FOR HEALTHCARE PROFESSIONALS

The CGF have a dedicated area for healthcare professionals on our website

https://childgrowthfoundation.org/healthcare-professionals/

There you will find a number of digital resources available to download. If you would prefer printed copies there is an order form available at:

https://childgrowthfoundation.org/hcp-order-form/

Information for parents / carers who have concerns about their child's growth is available, please scan the QR codes below:

Childhood growth

SCAN ME

Growth concerns

SCAN ME

Concerned my child is too small

SCAN ME

Concerned my child is too tall

SCAN ME

FURTHER SUPPORT FROM THE CGF

"The CGF are unique as they support people with a wide range of growth-affecting conditions. Their team, supported by Medical Advisors, encompass extensive expertise and importantly includes those with lived experience. The CGF is a very friendly and approachable charity that provides numerous opportunities for patients and families to connect with each other and Medical Advisors."

-Professor Helen Storr,
Professor and Honorary Consultant in Paediatric Endocrinology

Our charity supports hundreds of children, young people, adults and families each year through our in-person and virtual events, and we help thousands of people in the UK and beyond with our online information, guidance and support.

We provide peer support including our Virtual Cuppa & Chats run by our nurses and involving parents and carers, alongside closed Facebook groups, and also opportunities to meet other families in the child growth community through our in person Meet Ups and convention - and much more! See our full range of support at: childgrowthfoundation.org

"I just wanted to say a big thank you. The information was so helpful. It was a comfort to talk to you and the other parents, I feel less alone with what we are going through."

-Virtual Cuppa & Chat attendee feedback

GET INVOLVED

The CGF is an independent charity that depends entirely on your support to continue it's work. If this resource has helped you, we'd be grateful if you'd consider becoming a member or making a donation via the QR codes below.

Make a donation

Become a member

Fundraise

Volunteer

Help us continue making a difference wherever growth is a concern. Find out more on how to get involved at:
childgrowthfoundation.org/get-involved

Acknowledgements

With thanks to:

- Professor Helen Storr and Professor Justin Davies for their support and guidance with the production of this booklet

Disclaimer

We have taken every care to ensure the accuracy of the information contained in this booklet. The information enclosed should not be used as a substitute for the advice from a clinician, GP or other healthcare professional.

Feedback

Your feedback helps us to ensure we are delivering information to the highest standard. If you have any comments or suggestions, please contact us at info@childgrowthfoundation.org or on 020 8798 2139.

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