



PARENTAL FEEDBACK

FOR HEALTH VISITORS



Introduction to Positive about Down syndrome

Positive about Down syndrome (PADS) is a national parent led charity, working hard to ensure EVERY expectant and new parent of a baby with Down syndrome has access to the information and support that they deserve – the reality of what living with Down syndrome looks like in modern Britain, as well as ongoing peer support and expert advice when baby arrives.

We have welcomed over 300 babies with Down syndrome via our closed Facebook group [Great Expectations](#) and currently support over 100 women with a high chance/confirmed result of baby having Down syndrome.

Our work with medical professionals

We work with over 1,500 families of a little one with Down syndrome under the age of 3, so are completely immersed in maternity and early years care for our families.

We collaborate with maternity units and universities to provide resources and training to future and practicing midwives, and other health professionals, with our training drawing upon the real-life recent lived experiences of our members together with evidence-based research.

We are passionate about ensuring parents and professionals have access to contemporary, relevant, and accurate information as well as positive and meaningful support.

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As a proactive parent-led charity actively working with more than 3,000 families of a child with Down syndrome five years and under, Positive about Down syndrome has created this summary for health visitors to have an understanding of our families' hopes for the support and care health visitors can provide.



Attitude and Understanding

1. Please don't be sorry about a child having Down syndrome.

Whilst many parents when they receive the news baby has/may have Down syndrome are shocked and struggle, we need professionals to be understanding and supportive, but not offer condolences, be pitiful or patronising.

2. Consider your language.

How we refer to people with Down syndrome can have a subliminal and/or blatant impact on our families. At PADS we advocate the use of person first language – a baby has Down syndrome, not a Down's baby. Many parents feel referring to their baby as a Down's baby disconnects them, labels their baby as someone else's.

There is no need to continually refer to baby having Down syndrome – not that there is anything wrong with having Down syndrome, but as parents we know how much more there is to our children than them having Down syndrome. We recommend using the child's name!

3. Have a contemporary understanding.

It's really important for those working with our families to understand what it means to have Down syndrome in modern Britain – please don't fall back on outdated stereotypes or attitudes. Educate yourself and be informed.

Attitude and Understanding

4. Have high expectations.

Parents will look to you for knowledge and support. Don't assume babies and children with Down syndrome can't or won't achieve milestones. Whilst we know many are delayed, please encourage and support, don't limit and dismiss.

5. See the individual and please don't generalise.

All too often we hear of health care professionals, making sweeping generalisations, such as 'they struggle to breastfeed', 'children with Down syndrome are always so loving', or 'I've not weighed one of them before.' It is offensive to refer to people in such a way, parents say it sounds like their child is perceived as different, akin to referring to a breed of dog and its traits. Please see and consider the individual child you have the honour of working with.

6. Be aware of diagnostic overshadowing.

We often see situations where a symptom/issue is attributed to being as a result of a child having Down syndrome. Please encourage parents and fellow professionals, to think what would they be considering if the child didn't have Down syndrome?



Practical

1. Ensure the correct growth chart is being used.
2. Signpost families to their local Down syndrome support group.
3. Establish if there is a Down syndrome pathway in your area.
4. Support parents to ensure their children access the services they need. See PADS Little Orange Book - AKA You don't know what you don't know.
5. Advocate – we know from experience, that parents can often feel overwhelmed and under supported. Be the person who fights their corner, please help them to advocate for their child as they battle the systems and perhaps may be struggling emotionally.
6. Developmental checks – be very sensitive – many parents find these very upsetting. Talk this through – some parents find them helpful to determine where to focus, and/or to help with DLA application, others find them very distressing.

Enlighten, educate and empower – yourself and your families.

ASK PADS

We are here to help and support professionals as well as parents

Health Visitor
Information



Monthly
Webinars for
Professionals



Expectant Parents

Website



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Local Support Groups

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Breastfeeding

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Guide Book



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Lived Experience

Parent Stories



Services Available

Little Orange Book



Pregnancy Pathway

Personalised Antenatal Care



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