



Positive about Down syndrome

Improving the lives of those with Down syndrome and their families

Positive about Down syndrome (PADS) is a national parent-led charity, proud to be actively supporting families of and professionals working with a child or young person with Down syndrome.

We work extensively in maternity care and the early years, currently providing ongoing support via closed Facebook groups to 80 expectant women with a high chance or confirmed diagnosis of their baby having Down syndrome, and have welcomed more than 300 babies via our Great Expectations group. We work with more than 950 parents of infants aged 0-18 months and 1,900 parents of children aged 18 months-4 years.

We fund independent counselling, provide online Makaton training to new parents, grandparents and nursery settings, contemporary resources to maternity units and families, Lived Experience resources on topics including heart surgery, infantile spasms, Hirschsprung's Disease and breastfeeding. PADS holds weekly online sessions around applying for DLA and advice about applying for EHCPs, as well as delivering online early development groups and physiotherapy. We employ a Breastfeeding Supporter to provide support to parents and deliver training to healthcare professionals. PADS Heart Buddies scheme has supported more than 100 families through heart surgery.

We have a team that currently works directly with all maternity units in Wales, half in Scotland, a couple in Northern Ireland, and 146 of the 231 maternity units in England. We provide resources and deliver training to medical professionals and to students – working with 22 universities that train midwives. We have recently collaborated with the RCM to create e-learning modules around sharing the news baby has/may have Down syndrome and on breastfeeding a baby with Down syndrome. We also work with the iHV to reach and support Health Visitors to provide the best care to our parents.

pants4school

Our initiative #pants4school has been a finalist at the RCN and BJN Awards, and we work with more than 4,000 families and professionals around toilet training children with Down syndrome.

Positive about Down syndrome Early Years Development Programme

Our services extend into education, providing training to early years setting via our Early Years Development Programme – being launched in April 2024. Our Director of Education and Speech and Language Therapy Dr Becky Baxter is an expert in her field, and is developing a programme to support primary schools. We provide resources to online provider Twinkl and hold monthly webinars via Twinkl's TeachMeet initiative.





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PADS has been a life-line

PADS works to improve the lives of people with Down syndrome, and their families. We primarily work in maternity care and the early and primary years, providing resources, training and support to parents and professionals to empower those with Down syndrome to thrive and flourish.

We believe every parent should receive the best possible care and support. We believe the arrival of every baby with Down syndrome should be celebrated.

To enact these beliefs, we have 4 core aims which underpin our work:

1. Raising awareness of the modern reality of living with Down syndrome in the UK today.
2. Connecting parents of children with Down syndrome to experts, best practice, and each other.
3. Ensuring all children with Down syndrome have the best start in life, and access to the support to enable them to live their lives to the full.
4. Helping parents, the public, professionals, policy makers, and politicians to celebrate and support people with Down syndrome as valued and important members of society.

PREGNANCY

BIRTH

PRE-SCHOOL

PRIMARY

SECONDARY

16+





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Our impact



550+

Expectant women supported



300+

Babies welcomed



903

New parents



325

Breastfeeding parents supported



1,900+

Preschool parents



1,200

Grandparents



4,900+

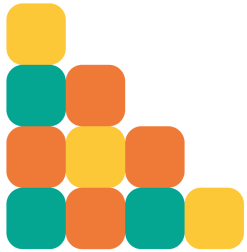
Families and professionals accessing Pants4School toilet training programme



“PADS has been an absolute lifeline. Without it, I don’t know how we would have coped. From feeling so scared and alone, we can now see an exciting positive future for our son, and know that PADS is there to hold our hands all the way.”



“Huge thanks to PADS for your eye screening session. I went into our ophthalmology appointment ready and armed. The optometrist listened to my concerns and was very impressed with my knowledge. I feel so relieved and grateful to this support group for all of the knowledge sharing.”





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Current research projects

At Positive about Down syndrome, we are committed to supporting and undertaking research to benefit our community. Aside from promoting research projects, we are currently involved with the commissioning and undertaking of the following research studies:

Warwick University

Maternity experience of expectant and new parents 2019-2022



Part 1 - The Mental Health report published in March 2024 highlights significant discrepancies in mental health support for our parents. CQC national Maternity survey published in 2023 reports that 85% of women felt they had received enough support for their mental health during pregnancy; comparative figure for mothers of a baby with Down syndrome is 38%.

Over one third of respondents (37.6%) felt that the attitude of healthcare professionals towards their baby having Down syndrome had had a negative impact on their mental wellbeing. Fewer than one third of respondents (31.4%) reported that they were given enough reassurance about the future for themselves, their baby and their family.

Parts 2 and 3 – experiences of antenatal screening and experiences of diagnosis of baby having Down syndrome to follow.





University College London

Constipation and potential use of a probiotic to alleviate symptoms



This study looks at whether taking a probiotic on a regular basis has any impact on those who are prone to suffering from constipation. The research commences end of March 2024, with findings due later this year.

University of Hertfordshire

The impact of NG tube feeding on families

At PADS we have noticed an increase in the prevalence of NG tube feeding and lack of support to wean off, so have worked with researchers to collect data.

Draft Conclusions

Importance of quality breastfeeding support that is targeted specifically for mothers of infants with Down syndrome and in particular addresses challenges faced by those whose child is fed via NG tube.

There was a lack of structured decision-making processes, including exit-planning. Mothers felt there was no consideration of how and when their child would get off the NG tube.

Mothers did not feel included or informed about decisions around their child's feeding or potential negative impacts of NG tube feeding such as the development of oral aversions and oral motor delays.

Mothers felt that their priorities were not aligned with those of healthcare professionals. Working towards oral feeding and subsequent NG tube removal was a priority for mothers and they were shocked to find that there was no structured framework to guide this process.

Mothers wanted a step by step programme they could follow to address feeding concerns and establish oral eating and drinking, to allow safe removal of the NG tube.

NG tube use profoundly hindered the development of feeding, eating and speech and language skills.

Period of NG tube use was seen to have a significant negative psychosocial impact on participants. Mothers struggled with the practical demands of NG tube feeding, which made day to day life feel complicated and impossible.

Mothers worried about whether and what their child would eat, whether they would vomit the NG feed up, constant worry about weight loss, illness, choking risks and fear that the tube may be pulled out. Mothers became hypervigilant and felt a huge emotional strain.



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Recent research we have undertaken and published

Nystagmus in children with Down syndrome 2021



Sharing the news: The maternity experience of parents of a baby with Down syndrome 2019



Breastfeeding a baby with Down syndrome: The maternity experience 2021



Breastfeeding a baby with Down syndrome: The maternity experience 2022





Feedback from our families

At PADS we are immersed in our community and through our online forums, we read the challenges and issues our families are facing. We have summarised some of the key messages that our families would appreciate paediatricians and GPs being aware of and hopefully addressing.

1. Lack of awareness and following of a Down syndrome framework/pathway

Many parents advise that they would appreciate their paediatrician having a better understanding of the routine testing and studies as recommended by the DSMIG, being proactive in organising these, and then properly reading the results with an informed view of what is usual for a child with Down syndrome (without any diagnostic overshadowing, please).



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Diagnostic Overshadowing

2. Diagnostic overshadowing

This is one of the biggest issues our parents experience and that causes much frustration and worry. Parents feedback that the health of their child is often compromised and indeed negatively impacted when doctors don't investigate health concerns but attribute them to the patient having Down syndrome.

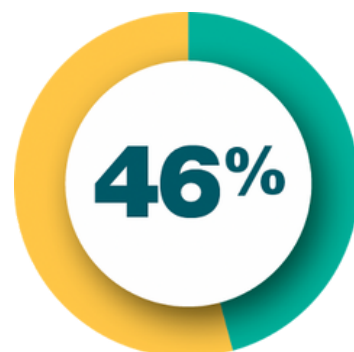
Constipation is a major issue in our community, yet parents frequently advise paediatricians and GPs either dismiss the condition as due to the child having Down syndrome, so it is to be expected or do not explain to parents about the treatment and ongoing management required to treat and manage chronic constipation.

Age of child (Number)	Percentage of instances diagnostic overshadowing experienced				Total
	Never	Once	2-3 times	4+/regularly	
18 months - 4 years (252)	18%	9%	45%	28%	100%
Primary (102)	7%	4%	28%	61%	100%
Secondary (44)	0%	11%	18%	70%	100%
16+ (44)	9%	5%	25%	61%	100%
	13%	8%	36%	43%	100%

An assumption by medical professionals that babies with Down syndrome cannot breastfeed.

46% of women were advised by a health care professional that they may not be able to breastfeed their infant purely because of baby having Down syndrome.

PADS research shows that 66% of women who breastfed were still doing so at 6 months, in contrast to UNICEF's data of 34%.





3. Views

Parents impress the importance for doctors, to see each child as an individual and not to generalise about people with Down syndrome. Many commented about their desire for doctors to listen and act on parents' views – we know our children best. Similarly, to trust what parents are telling you – we know what is normal for their child.

To be aware of the importance of early intervention and support parents to access. Please don't make judgements or tell parents about whether their child should attend mainstream or special school unless your view is sought.

Doctors to be aware that the level of speech delay does not necessarily equate to the patient's level of understanding. Be mindful that those with a dual diagnosis of autism, often fit the autistic profile better than that of having Down syndrome, reiterating the importance to treat the individual, not the diagnosis.

4. Language

We always advocate, the use of person first language – people with Down syndrome, not a Down's child/baby etc. Request for medical professionals to consider language when writing reports and letters; not to refer to having Down syndrome under a list of Problems; instead, use diagnosis or patient history.

5. Communication

Many families raise the issue of the need for improved communication between healthcare professionals and the impact poor communication has on parents who have to coordinate and follow up, particularly for those who access multiple specialist consultants. Without one person taking the lead things are missed from the big picture.

Parents appreciate those paediatricians who use Makaton to engage with Makaton users.

Parents report being unable to obtain support/prescriptions from GPs without information being shared by paediatrician.

Reports to be contextual and thus more supportive when applying for DLA. Whilst it can be hard reading the truth, it is worth asking parents if they will be submitting notes as evidence for DLA, which can be beneficial in the long run and more practically supportive than some kind words.

When age-appropriate, ask the child or young person questions, rather than the parent as many can answer some of the questions themselves.

Introduce yourself to the patient. Allow time for child or young person to process and respond .

Avoid referring to being brave to have a blood test – this suggests to children that they should be scared.

The need to always explain any examination to the person with Down syndrome and to seek their permission before carrying it out



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6. Appointments

The consistency of seeing the same paediatrician is valued and appreciated. Regular frequency and longer appointments are often mentioned – 10 minutes every six months is generally felt not to be sufficient, families appreciate the opportunity to have longer appointments.

Be realistic and honest about review dates. It is frustrating to be told a time period that's unachievable.

Worthwhile appointments in which parents and young people feel listened to, and the paediatrician is proactive in managing any potential and current issues.

Consider whether it would be beneficial to involve a member of staff from the LD team, particularly as the child becomes older.

As a young person approaches moving to adult care, provide a letter confirming all diagnoses for future health care professionals' reference and for parents to use as evidence when applying for PIP and/or Universal Credit, etc.

7. Expertise

Many parents express concern that not all paediatricians and GPs interpret results according to the child/young person having Down syndrome, as opposed to the general population – particularly around thyroid and other blood tests.

For paediatricians not to just act as a signpost, but to be proactive with managing common health issues—thyroid checks, sleep studies, eye checks, etc.

Be aware and discuss with parents preventative measures to avoid common conditions such as constipation by promoting healthy high fibre diet, drinking plenty of fluids, potty/toilet sitting, probiotics etc.

Be up to date on best practices for children with Down syndrome.



8. Sensory and behaviour issues

Be aware that some children with Down syndrome have sensory processing needs. They may have an aversion to loud noises, be scared in an unfamiliar environment, not understand what is happening to them, not react in a predictable way, and may need time to process.

Due to this, they may appear to be uncooperative or difficult when they are actually struggling and need support.

9. Reasonable adjustments

Work with families to limit stressful situations such as blood tests – arranging for cream to be applied at home, or a district nurse to take bloods at home if a child can't cope with the hospital setting.

For older children, consider providing information in an easy read format.

While making reasonable adjustments, don't condone inappropriate behaviours through your own over-accommodation. It's a fine and individual balance—follow the parent lead.

10. Context

Parents advise the importance of information being shared in context. Particularly for our new parents who can often feel overwhelmed in the first year or two.



What works well?

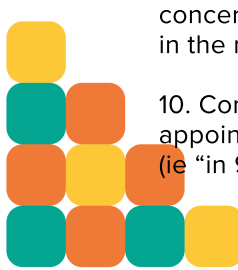
As a charity, we are always keen to celebrate and share good practice. It's too easy to focus on problems, so we share a quote from one family and examples of what good practice means to parents of 3 year old Henry.

Our community paediatrician is excellent and the good points have been:

1. As per NHS guidelines, a guaranteed sleep study at 2 years.
2. To be given the secretary's email so that contact can be made easily.
3. To be offered a blood test every year for thyroid and 2nd blood test if above 4.5 - and write a short report to parents once the results are in.
4. To be aware of local support services from the 3rd sector, especially any regular physiotherapy that may be available - the one thing that the NHS in our area is not able to offer regularly enough.
5. To make sure all standard referrals are in place - eyes, ears, S<, portage etc.
6. To be willing to be involved in writing supportive letters for DLA and EHCP applications.
7. To write a full report after each meeting and send to parents as well as copying in all other services.
8. To make parents aware of private-only services they may be interested in for our children, such as the chickenpox vaccine.
9. Be reassuring and calming when parents are overly concerned with normal activity (grinding teeth or fingers in the mouth constantly).
10. Confirm in the round-up letter after each appointment as to when the next appointment will be (ie "in 9 months time").



“The amazing difference it can make to a family when they find a good paediatrician who doesn't assume everything is due to the child having Down syndrome should never be underestimated. Our community paediatrician has backed us up and ordered tests when other (hospital) ones wouldn't and dismissed things. I feel I can contact her when I have concerns and she listens to me at our appointments. It makes a real difference to feel someone in a medical setting has your back. Please let them know how important that is! We have to fight for so much for our children, it's nice for me not to have to fight in that environment too!”





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ASK PADS

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

Monthly
Webinars for
Professionals



Expectant Parents

Website



Facebook



New Parents

Website



Facebook



Preschool Parents

Website



Facebook



Primary School Parents

Website



Facebook



Secondary School Parents

Website



Facebook



Young People & Adults (16+)

Website



Facebook



Grandparents

Website



Facebook



Dads

Website



Facebook



Breastfeeding

Website



Facebook



Guide Book



Lived Experience



Weaning

YouTube Videos



Constipation

Website



Toilet Training

Website



Facebook



Hirshsprung's Disease

Website



Facebook



Choosing a Nursery

Guide Book



Choosing a Primary School

Guide Book



Services Available

Little Orange Book



Lived Experience

Parent Stories



Pregnancy Pathway

Personalised Antenatal Care



Local Support Groups

Website



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