



Early Development Groups

Parent Guide

September 2023

Positive about Down syndrome Early Development Group's (PEGS)

Aim

To provide parents with regular access to specialist input and support, to promote the development of a range of skills for preschool children with Down syndrome.

Background information

Positive about Down syndrome (PADS) is a large UK based charity providing information, support, and advice to more than 2,000 parents of babies and children with Down syndrome of preschool age. We also provide extensive support to more than 4,000 parents and professionals around toilet training.

PADS provides a range of services to parents of children of preschool age, including counselling, online Makaton training for parents, grandparents and nurseries, online physiotherapy sessions (POPS), ad hoc training/information sharing sessions including on applying for DLA, requesting an EHCP, early toilet training skills, constipation, early numeracy skills. We also provide boot camps for toilet training and around promoting positive behaviour in children with Down syndrome.

We have several closed Facebook groups providing support, including to expectant parents, new parents (0-18 months), preschool parents (18 months-4 years), grandparents, professionals working with preschool children with Down syndrome, primary aged and secondary students. A list of our groups and information around services can be accessed via our publication [You don't know what don't know, PADS little orange book of knowledge.](#)



PADS works with experts in their field to create recordings accessible to all, around a range of topics pertinent to people with Down Syndrome. [#PADSPods](#) are accessible via Facebook.

Following the initial lockdown in 2020 and in response to the fact that there are many areas in the UK where families do not have access to specialist early development support, in September 2020 we launched PADS early development groups (PEGs) in conjunction with LETS Go, specialists working exclusively with children with Down syndrome.

PEGs aims to equip parents with the resources, knowledge, and confidence to aid their child's development by providing research based early intervention activities to undertake with their child as part of everyday activities.

Parents access videos of c15-20 minutes, that have been created and presented by Becky Baxter, a highly specialist speech and language therapist and Sarah Holton an extremely experienced advisory teacher from LETS Go, who both have extensive experience and specialise in working with children with Down syndrome. Becky and Sarah demonstrate activities for parents/nurseries to carry out at home/in nursery to promote development, they are not designed for the child to view, but to educate the parent.

The videos are accessed through the PADS parent portal and are complimented by a follow up online session led by an Early Development Advisor who reviews the video, making suggestions as to how parents can differentiate to extend/modify to stretch/meet individual children's ability. The sessions provide a supportive forum at which parents can ask questions, share resources, and encourage peers.

Sessions run through term time only and the stage groups are in line with school start dates, commencing with members aged 6-12 months in stage A. Stage B is for children who are broadly speaking 1-2 years old, Stage C for 2-3 years (penultimate preschool year) and Stage D for 3-4 years (final preschool year).

For the youngest members we have **Stage A**, aimed at children aged 6-12 months. The family access a monthly video by Becky Baxter encouraging general development of the infant, and there is an online group zoom a fortnight later.

Since we run in line with school terms, in September we take in new cohorts into each stage. We also offer a new course in January, **Stage A2**, for those members who were too young to join in the preceding September, but we don't want them to have to wait until the following September.

Stages B, C & D are for children aged 1-2 years, 2-3 years and 3-4 years respectively. The groups consist of up to 6 families who have access to videos on a fortnightly basis.

Every 4 weeks a video with Becky Baxter provides advice and modelling of activities to promote speech, language, communication, and memory, this is followed up by a group zoom session. A fortnight later Sarah Holton's video features activities to promote early maths, early reading, and fine motor skills.

On the weeks between the videos parents are provided with the opportunity to discuss these activities with an Early Development Advisor who has specialist knowledge, training and experience in early development of children with Down syndrome.

At the beginning of the PEGS year, parents have the opportunity to speak with their Early Development Advisor to share where their child is at, discuss areas that they feel need help with and general feedback around the child's development.

Resources

PADS has produced a pack of resources that have been specifically created for PEGS. Becky & Sarah use similar resources in the videos as they demonstrate the activities to parents. We know how time consuming it can be to create resources so are delighted to be able to offer these for families to purchase to enhance our PEGS courses. Click the link to purchase a [resource pack](#)

Early Development Advisors (EDA's)

The online sessions are delivered by EDA's who each have extensive experience working with children of preschool age with Down syndrome. PADS pays for LETS Go to deliver training as required to the EDA, promoting Continuous Professional Development (CPD) to ensure they are providing appropriate information and support to our families. EDA's will ask families from time to time, if they are comfortable for a session to be recorded, which is then reviewed by LETS Go for CPD. Parents have the right to advise they do not wish for a session to be recorded.

September 2023 Schedule

Stage A

Born between 1 September 2022 - 28 February 2023
Starting school September 2027

Stage B

Born between 1 September 2021 - 31 August 2022
Starting school September 2026

Stage C

Born between 1 September 2020 - 31 August 2021
Starting school September 2025

Stage D

Born between 1 September 2019 - 31 August 2020
Starting school September 2024

January 2024

Stage A2

Born between 1 March 2023 - 31 August 2023
Starting school September 2027

Termly costs

Stage A and A2 - £25
Stages B, C & D - £40
PEGS Resource pack - £25

Parents will be provided with a link to access the videos through the PADS Parent Portal.



PADS is delighted to offer our online Early Development Groups to our families. We would always recommend you attend a local specialist service/group if available and do wonder if it may be confusing for parents to attend both local and PEGS, but ultimately that's your choice!!

Parents will access the videos through the PADS parent portal. We do expect parents to view the videos as there is not time, and it is not fair on other parents if the EDA is having to explain the content rather than focus on discussing how parents can implement activities in everyday living, ask questions and seek advice redifferentiating to their child's ability.

Videos are available for you to access per stage on an ongoing basis, assuming you continue to subscribe to PEGS. If you do not renew you will no longer be able to access videos.

It is not necessary for the child to be present during the online sessions.

Parents are asked to comply with our online safety policy, in particular ensuring folk are appropriately dressed, and background noise kept to a minimum. General courtesy is obviously expected, with folk being respectful, polite, and considerate of each other. We do ask you not to dominate sessions but ensure each parent has the chance to contribute.

It is appreciated if folk can endeavour to be punctual in attending the online sessions. If unable to attend/running late, a WhatsApp message to advise accordingly is appreciated.

It is the responsibility of parents to take any notes. A checklist for each session is available through the PADS parent portal that parents may find helpful to take notes on.

You will be a member of a WhatsApp group set up by your EDA just with members of your group. Please use this to communicate if you are running late/can't find info.



Please do not compare your child to others! Every child develops at their own pace, and we often see whilst one child may be progressing in one area of development, another is flourishing with a different skill. Just like us, our children each have their own strengths and challenges, and there's no point comparing and getting upset. Focus on what your child can do, and you will not be disappointed.

When you initially sign up, you will be asked to complete some documents online, these provide information to your EDA and to PADS around your child's development as well as some background medical information. You are not obliged to complete these forms, but they are a useful resource for EDA's to ascertain where your child is at and for PADS to identify any areas, we feel research and/or training would be beneficial, as well as providing us with data around the needs and status of our children.

