

Meet Ben

Ben is 2 and has been coming to Child and Family sessions at Pace since April 2019. Ben lives at home with his mum, dad and older brother. He was born at term following an uneventful pregnancy. Ben was found to have a heart defect and required surgery when he was 4 months old.

When Ben was around 12 months old, his parents became concerned that he was not achieving his developmental milestones and he was referred to a paediatrician and NHS paediatric therapists. Ben was found to have hypotonia (low muscle tone which presents



as floppiness) and delayed development. Ben was referred to the genetics team to investigate the cause of his hypotonia.

Ben had a series of non-febrile seizures in May 2019, and he underwent investigations including a brain MRI scan and an EEG and continues under the care of a neurologist and a paediatrician.

Child and Family assessment

Ben was 16 months old when he came to Pace for an assessment. His parents' main concerns were Ben's delayed development, particularly his physical skills, communication and learning. They had recently had an NHS speech and language assessment and were worried that the assessment had highlighted severe delay in his communication.

Ben's parents were looking for more consistent and frequent therapy input. They were looking for a place to support their own activities at home to help Ben develop.

Ben was assessed by several members of the Child and Family team at Pace including a physiotherapist, speech and language therapist and occupational therapist. The family were given time to fully discuss their concerns.

On assessment, Ben was a happy boy who was keen to engage with new people and the environment. Ben was able to roll and moved around the room using commando crawling (moving himself forward whilst on his tummy). Ben was able to sit but could not keep his balance when reaching for toys. Ben used eye contact and body movement to indicate he wanted more of an activity.

What were Ben's challenges?

Ben had delayed physical skills; the hypotonia and hypermobility (increased joint movement) meant that moving up against gravity into positions such as crawling and standing was very effortful. Ben had difficulties moving between positions, e.g. lying to sitting, and this limited his ability to play and explore his environment.

Ben had delayed play skills – shown by his tendency to bring his head down to explore toys with his mouth rather than use his hands. Ben had limited ability to hold and manipulate toys and showed immature hand grips.

Ben had limited abilities to communicate with his family, he was able to use eye gaze to direct his parents to something that he wanted but was not using any words or signs consistently.

The findings of the assessment were discussed with the family and initial goals were set with the family which included:

- Learning to crawl
- Developing understanding of cause and effect e.g. pressing a switch to activate a toy
- Developing his communication i.e. asking for 'more' of something motivating

Child and Family intervention – how did Pace help Ben and his family?

The Child & Family team supported Ben and his family in a variety of ways, as we outline below. The headings in bold correspond to the characteristics of our E13 early intervention programme, outlined in our [summary Theory of Change](#).

Early, intensive direct sessions: Ben was able to immediately start attending twice weekly transdisciplinary therapy sessions at Pace. This immediacy and intensity is always absolutely critical to make the most of each child's window of early neuroplasticity. The opportunities for changes in brain development are greatest at a younger age when neuroplasticity (the brain's ability to reorganise itself by forming new neural connections) is at its highest.

These regular sessions mean that the therapists could be highly responsive to Ben's small steps of progress and could optimise the therapy sessions and advice to the family. This accelerated his skill development. Based on the developing neuroscientific evidence, this early motor experience is important in providing a solid grounding for cognitive development.

The frequency of the sessions meant that Ben was able to develop strong, trusting relationships with the therapists. This allows him to be more confident to attempt new challenges such as moving up into standing and taking steps.

Specialist and expert: The therapists involved with Ben have a significant amount of experience spanning physiotherapy, occupational therapy and speech & language therapy and have a range of further paediatric specialisms, including Bobath, Sensory Integration, Makaton signing and augmented alternative communication (AAC).

Ben was able to trial a Bugzi chair which is an early powered wheelchair. Independent upright mobility is important in developing spatial awareness and concepts. Pace is a regional hub for training young children on Bugzi chairs.

Ben attended an appointment at the Pace hand clinic, run by a specialist paediatric occupational therapist, to assess Ben's abilities to use his hands and provide splints to improve his hand function.

Play-based transdisciplinary practice: Ben's sessions kept 'play' at the centre of his therapy using a child-led approach. A child's learning will always be greatest when he/she is most engaged and self-motivated. Pace has a large selection of toys, activities and equipment which were used to make Ben's sessions exciting and provide varied opportunities for learning. These play-based techniques are ideal for parents to carry on at home, creating an intensity of intervention that would be hard to achieve in any other way.



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Ben's sessions focused on his goals, regardless of which professional was leading the session. For example, he would be practising his communication whilst working on standing with the physiotherapist. This transdisciplinary approach allows greater repetition of skills and again provides a model for the family to apply at home.

Parent coaching: Pace's therapists modelled ways of facilitating Ben's movements and play for his parents to learn. Sessions allow time for practise and problem solving so the family could confidently use these skills at home, becoming 'experts' in their own child's care and support.

Family focused: The therapy team worked with multiple members of the family including family friends and grandparents. This meant that Ben's whole support network understood how they could best help and support his development. For example, the team were able to support the family to adapt a bike trailer to meet Ben's postural needs, so they were able to go on family bikes rides on their holiday.

Reliable point of contact: During this period, Ben and his family were attending multiple medical and therapy appointments e.g. paediatrician, neurologist and genetics. Pace therapists were seeing the family on the most regular basis and were able to help to interpret the findings and to try to answer any questions the family had.

Community support and liaison: Ben and his family attended coffee mornings at Pace to meet other families with children with additional needs to begin to develop a peer support group.

Ben's family were supported as they navigated the complex system of Special Educational Needs funding. For example, the team provided evidence to support Ben receiving Higher Needs funding at nursery and for his Disabled Living Allowance. They provided direct input into his nursery to support his inclusion with his peers and training and advice for his nursery staff.

How has Ben progressed?

Ben has made significant progress in all areas of his development. Ben and his family have developed strong relationships with the therapy team and Ben is visibly excited when he greets the therapist with a wave and comes into the room to start his session.

Physically, he has moved on from commando crawling (moving forward on his tummy) and started crawling on his hands and knees in August 2019. As Ben's trunk strength increased, he was able to move between floor positions more efficiently and was less reliant on using his arms for support in sitting. Ben began pulling up into standing and achieved his goal of taking three side steps in January 2020. Ben's standing balance is improving on a weekly basis and he is able to stand using only one hand for support. Ben has achieved his goal of walking along the length of the parallel bars (2m) much to the delight of his family.

Ben's interest and exploration of his environment has grown, and he is able to focus on an activity and share his interest with his family. Ben can manipulate toys, passing and

rotating them and use his index finger to press buttons and switches. He has recently been enjoying playdoh activities, using bimanual skills to remove the lid and roll out the dough to cut shapes. He enjoys games with his brother such as rolling a ball or pushing a car. In nursery, Ben is developing his turn-taking skills with his peers. Ben's imaginary play is developing and he is using his favourite toy to go for a ride in a toy bus.

Ben has been supported to use a total communication approach, he is able to communicate with his family and in his nursery setting using several words, signs, gestures and using his new trial PODD 9 (Pragmatic Organisation Dynamic Display) communication book. Ben is able to say words, including 'bubbles' to ask for his favourite activity, and sign 'more' to request a repeat. He is also developing his skills in using his PODD book to direct the play, including pointing to the 'something different' symbol to request to change the activity, or to sing a different song that was not on the choice list.



Wider outcomes for Ben and his family

The interventions that Ben has received has led to progression in the skills he needs to engage in the occupations of early childhood including physical abilities, play and communication. The improvements in his strength have reduced his atypical movement patterns, which means he is less at risk of developing musculoskeletal issues in the future

Ben's family have a much better understanding of his abilities and difficulties and celebrate with the therapists as he achieves each new step. Ben has a strong attachment with his family and they use the learning from Pace session to creatively enrich his home environment. His parents are able to successfully advocate for him, meaning he is receiving the support he requires at nursery.

The Pace support Ben has received directly at nursery, is supporting his transition to his age appropriate nursery group. Ben's increased communication skills will allow him to engage with his peers as he moves through his early years education.



What is next for Ben?

Ben will continue with sessions at Pace with input into his nursery as needed. He will also be invited to attend our Play and Learn sessions, a playgroup for children with physical difficulties including song time, messy play and soft play alongside his peers and therapists.

The family are attending communication training lead by our Lead Speech and Language therapist. Looking forward, we expect Ben to be able to stand independently and take steps with a walker.