

NORFOLK'S BEAUTIFUL CHILD



Wendy Webb

NORFOLK'S BEAUTIFUL CHILD
Pathway to a Diagnosis
Wendy Webb

In memory of DAVE

Free Evaluation Edition from obooko.com

© Copyright 2012, Wendy Webb

Published by the author. Distributed worldwide by obooko

This edition is available free of charge exclusively to obooko members for evaluation purposes only. It may be amended and updated at any time by the author so please visit www.obooko.com to ensure you have the latest edition.

This book must not be copied or printed unless the author has given written permission for personal printing. It must not be sold in digital or printed form nor offered free or for sale on any website other than www.obooko.com.

For more free ebooks and to list your fiction or non-fiction book for free publication, please visit www.obooko.com

Contents

PART 1 PREPARING FOR THE BABY	3
PART 2 THE FIRST YEAR.....	9
PART 3 TROUBLE BREWING.....	17
PART 4 TERRIBLE TWOS.....	28
PART 5 WHAT'S WRONG WITH HIM?	40
PART 6 STATEMENTING AND DIAGNOSIS	62
PART 7 LIVING WITH A DISABILITY.....	102
FOOTNOTE.....	112

PART 1 PREPARING FOR THE BABY

Returning from work, something made Wendy hesitate inside her front doorway. Strange—the lights were on, the curtains drawn, yet post was lying on the front mat. Wasn't Ed home, then? She heard a noise. There was a burglary in progress. Someone was inside the house. Pregnancy made her cautious. Running out of her front door, there was a rustling sound. She knew someone was climbing over the hedge, making their getaway. It was too dark to see. Ringing a neighbour's doorbell, Wendy phoned the police. Returning home, she found Christmas presents scattered around the room, their wrappings torn. The back door was wide open, glass smashed across the floor.

It set a precedent for the pregnancy. Home no longer felt safe. Was her expected baby safe? What if Wendy had not hesitated in the doorway, but walked in on the burglars? Would there have been a struggle? Would baby have survived? Normal pregnancy tests were organised. Ed and Wendy were convinced by the doctor that Wendy should book in for the Triple Blood Test, to check for a healthy baby. The couple were adamant nothing would change their minds about having this baby. Professional advice recommended it was worth knowing potential outcome; Wendy would be 36 when baby was born. Tests were worrying. The risk of Down's syndrome was high at 1:139. Unable to face months of uncertainty, an amniocentesis test was booked at the local hospital. Was their baby normal? Ed and Wendy were convinced they would have the baby, whatever tests might prove.

Life had become very precious over the past two years. The future couple had moved to settle in Norwich,

within a month of each other. They met, then courted on the Norfolk Broads. Wendy remembered an immediate and great desire (within a week) to have Ed's children. She was in love. Romance led to marriage. Both were keen to have children. When the first pregnancy test was confirmed, both were full of hope and expectancy. They were a new couple starting a family. Nine weeks later Wendy miscarried. The future was no longer predictable. Holidaying in Greece a few months later, Wendy briefly regretted Greek cuisine. Returning through customs, she desperately wanted to throw up. Later the couple would tease each other about a 'little Greek souvenir' they brought through duty-free. Baby was due in June 1993, 18 months after their winter wedding.

Already this child was special. Whatever test results showed, baby would be carried to term. Christmas was a tense time, awaiting results of the amniocentesis. Tests proved negative. On the couple's written request, there was more news. Ed and Wendy were expecting a boy. They named him David, both parents choosing their favourite boy's name. It also helped to continue a family tradition, for David was named after Ed's dad, and baby's name was rounded off with Thomas, after Grandad Harris. They read books of names. David meant beloved. It seemed appropriate. Amusingly, Thomas meant twin.

Wendy recalled their first doctor's appointment. Nervously the couple wondered what tests would need to be carried out. They had already used two home pregnancy tests. The doctor simply added, "Congratulations". Leaving surgery, the doctor glanced at Ed. Quietly she gave her opinion, "Double buggy!"

Norfolk's Beautiful Child

They passed high risk early pregnancy and relaxed a little, looking forward to their son's birth. An undercurrent of worry persisted. Wendy grew very large with David. The doctor's joke simply indicated one healthy-sized baby. Unexpectedly, Ed's mum was rushed into hospital, following a freak accident. As Wendy stepped tentatively into the general ward, a nurse looked surprised. Surely Wendy was due in Maternity now - on the other side of the hospital?

David's due date came and went. Ed joked that baby was too comfortable and didn't want to be born. The prospect of induction loomed large. Hopes of a natural birth were shelved. Arriving in Maternity Department, precisely two weeks overdue, Wendy clutched her birth plan. Ed carried a bag for labour ward and one for baby. The father-to-be spent a day rushing between home, hospital and last-minute shopping in town. Wendy was hooked up to machines, monitoring both contractions and foetal heartbeat. The day dragged. Discussing with the midwife a possible third dose of prostaglandin gel next morning, Wendy's early excitement at baby's impending birth had fizzled into a depressing prospect of overnight stay in hospital. When would baby make an appearance?

By late afternoon, Ed arrived to find his wife begging him to connect the TENS Machine. Returning again after a snatched supper Ed was met by a wife clinging to him in desperation through waves of contractions. Ed repeated instructions from their antenatal classes. The midwife returned and sounded surprised. "Why didn't you tell me?" The couple were quickly ushered up to delivery floor and the TENS Machine was barely adequate. It was switched on

full. Wendy was attached to another monitor and the midwife recommended setting up a drip to speed up contractions. “Do you need more pain relief?” Wendy gave a resounding “Yes!”

DELIVERY

It was the middle of the night. Wendy had already faced the longest day, the Summer Solstice. She thought it was now a good time to deliver the baby. At first light she was still trying. Fully dilated, now it was time to push. Her original birth plan already appeared more like an Identikit. When the TENS Machine proved inadequate, Wendy was given a pethidine injection. She enjoyed trying gas and air; eventually an anaesthetist arrived to administer an epidural. It worked extremely well. Too well. She had no urge to push baby out. There was a long delay. The midwife watched for contractions and told her when to push. Ed watched baby's scalp clip, moving into view with each push, then disappearing again. Baby remained firmly inside.

Looking concerned, the midwife explained about assisted delivery. With a threat of Caesarean Section hanging over her, Wendy had a huge incentive to push. Already the room was crowded. Ventouse suction would be used and the epidural was topped up. Failing that a Caesarean would be necessary. The midwife mentioned 'foetal distress'. Their long-imagined natural birth, in subdued lighting, was replaced by a brightly lit room crowded out with professionals. It felt like a Monty Python sketch. A burly male doctor was ready with a medical gadget that looked remarkably like a sink plunger. Helpless in stirrups, Wendy gripped her husband's hand, staring away from the scene of action. In record time, pushing through a contraction and assisted by Ventouse suction, baby was propelled like a cork popped from a bottle. The doctor neatly caught a slippery baby and Wendy was surprised that she was still lying on the bed. Ed would

never forget delivery of a huge placenta, overflowing as it dropped into the kidney bowl and spread across the floor. It was his worst experience in a delivery room.

PART 2 THE FIRST YEAR

Professionals carried out routine checks as new parents awaited baby's first cry. At birth, 'liquor stained with meconium, needed thorough aspiration at delivery, but no problems afterwards.' The couple laughed in relief on hearing angry newborn cries, so normal in a delivery room. Apgar scores were recorded. At one minute David scored six. After five minutes this increased to seven. By 10 minutes the score was a healthy nine. All was well. Ed and Wendy had a beautiful boy. Ed held David briefly, then the midwife wrapped baby in a blanket and laid him in a cot to rest after his difficult arrival. The paediatrician picked up baby for further checks; he cried loudly. In future, the couple agreed, David would hate people in uniforms.

Some time later, Wendy held baby for the first time. A nurse assisted with latching on and baby took his first feed from the breast. A new family gazed on their beautiful, perfect baby boy. Months of uncertainty were at an end. They had delivered their firstborn, a son. David was born at 5.38 am on 22nd June 1993, weighing an extremely healthy 8 lb 3 oz (3.710 kg) and 54 cm in length. In the news headlines that day, Michael Heseltine was taken to hospital with a suspected heart attack. Wendy gazed at David, through his hospital cot, for most of the next night. It was hard to grasp that her baby had finally arrived. He was beautiful, sleeping peacefully. He seemed so perfect.

Among David's first visitors, his godmother held him in her arms. He was a picture of peace, with both hands held together, as if in prayer. She mentioned that children were only on loan from God. Wendy replied, "Well, I hope

it's a long-term loan then." Ed and Wendy had travelled a difficult journey to produce their first child. They wanted a lifetime's loan.

David left hospital on day three (weighing 7 lb 15 oz), by day seven he weighed 8 lb 14 oz. On average babies take ten days to regain their birth weight. Wendy was pleased with herself. Feeding baby had been difficult, but David settled and fed like an expert.

Returning home with baby in the car, their world felt brand new. Protecting this beautiful baby was a huge responsibility. Suddenly the world appeared a more dangerous place. Settling into a routine, Ed and Wendy learnt how to be first-time parents - changing nappies, bath-time, dressing, feeding and winding. Everything was new; by the end of the first week they both felt like experts. On day six, grandma and grandad visited baby for the first time. Precisely at the moment their Chinese takeaway was served, David cried. His dad balanced him on one shoulder, eating with chopsticks in his free hand.

David was christened on 18th July, before he was a month old. The minister had declared this was his first christening booked before baby was even born. Holidays loomed large. David was a big baby and they could not delay. He would not fit into his christening gown by September.

SAILING THROUGH MILESTONES

At six weeks he was already smiling, a big open-mouthed grin. When placed on his tummy he could push himself up with his arms, lifting his head to look around. As Ed dressed him one day, David grabbed hold of his dad's tie. He wouldn't let go. By eight weeks he was hitting objects. David was developing extremely well. Health checks showed normal progress. His growth chart was marked in a regular line a little above mid-centile. He gained weight and Wendy was proud of her perfectly average baby. He seemed to do the right things precisely on cue, according to a mounting pile of baby books. Filling in Baby's Early Years, Wendy recorded each new sign of progress. Ed and Wendy vividly recalled the screaming baby stage. Evenings were worst. Wendy read baby magazines and bought gripe water. Both assumed David had colic with a vengeance. It was par for the course, expected in stages of parenting.

At twelve weeks he was giving lovely smiles, rolling his head and sticking his tongue out. He could follow objects with his eyes, respond to sounds and hold a toy. He chortled with laughter. At the tender age of three months, David was an experienced sailor. Ed and Wendy changed his first nappy at the mooring station - David was under a month old. Baby screamed his disapproval. Men from the nearby boatyard watched in bemusement. A tale for when he grew up, joining David's list of adventures. Their small sailing boat was packed with equipment. Early in August they stayed overnight on Surlingham Broad. David was six weeks old. His car seat was strapped firmly onto the chart table as they sailed. Over the August bank holiday, they motored along the River Chet and moored at Loddon. It was a family get-together and David was dressed in one of

many sailor suits in fashion that season. Both parents envisaged a child gaining confidence and skills as he grew, familiar with open water.

Late in September the family took their main holiday together. They stayed in Ambleside, and spent the week exploring the Lake District. One family snapshot took pride of place. Wendy was resting after a long climb, beside High Sweden Bridge. David was perfectly content, strapped in his baby carrier and feeding happily. Early in October, David began weaning. He was a hungry baby. By four months he was learning to use a hang-up bouncer. At the end of the month he was bouncing along to Paul Simon music.

It was Christmas Eve. At precisely six months David sat up unaided for the first time. Wendy proudly filmed her baby, achieving his latest milestone. David held rattles and, far more interesting, wrapping paper. His first present was a baby gym/walker, designed to adapt as baby grew. David was already using both hands, picking up toys and swapping hands with them. He had discovered his feet and could also stand up, with his parents holding him. He stretched backwards for toys, rolling from tummy to back. He gurgled, screeched, blew raspberries and began to make more definite sounds. The world was full of hope, their first Christmas as a normal family.

In the New Year Wendy returned to work part time following the birth. David was over six months old. He weighed 17 lbs (7.70 kg) and began exploring the living room in his baby walker, reaching for everything in sight. Deciding together that family came before career, childcare

Norfolk's Beautiful Child

was organised for two-and-a-half days each week. Wendy looked forward to watching David's early development. They found a childminder experienced with children; she provided a happy and loving environment. Firmly and calmly they left, determined not to upset him by pausing. There were no problems leaving David with her. Congratulating themselves on encouraging a well-balanced baby, they ticked off another subject, popular in baby magazines. David was happy, left in another adult's company.

At seven months David's first tooth was clearly visible. He was dropping toys onto the floor at eight months and he also began rolling and bum-bouncing. At nine months he started crawling. Wendy proudly filmed him and Ed increased childproofing around the home. The rising toddler developed interests in pushalong toys. On 24th February David had an eight month developmental check. His length was 70 cm, his weight 19.71 lbs (8.82 kg). Hearing test reports indicated, 'A quick response to all sounds on both sides.' He had achieved all age-appropriate milestones.

David babbled and his parents were pleased to hear sounds. As first-time parents they assumed he was developing normally. They waited for more complex sounds and mimicking of normal speech. He didn't seem to fit the description terribly well. Yet he was making a variety of noises and they assumed the rest would follow. At ten-and-a-half months, his early sounds included "Ngg, ngg, ngg", "Mamamamam", "Dadada", "B-b-b". He blew raspberries, bubbles, sucking, blowing, and smacking his

lips. He could also pull himself up to standing. By eleven-and-a-half months he was cruising.

His parents eagerly awaited his first word and wondered what much-repeated phrase would take pride of place. It was "Oh dear!" More precisely, the phrase was "Oh der." Wendy waited for an expanding language. Soon it would be two-word sentences and the normal mis-sayings of a young child's vocabulary. Wouldn't it? Yet that didn't happen.

David was bald for a long time. He lost all his newborn hair. Both parents waited for new hair to grow. By 12 months his head was covered with fine blond locks, difficult to see from a distance. Yet they admired their baby with big blue eyes and a beaming smile. Posing for his picture in a baby competition, David's photo appeared in advertising for the local paper. He progressed as expected, dribbling his way through teething. Carpets in the lounge-diner grew muddy-coloured. Weaning was a messy business, but Ed and Wendy looked forward to baby's next stage of development. They hoped mealtimes would get less messy as he learnt to feed himself.

ACTION BABY

With a wide range of normal development at this age, David appeared to fit very neatly in the middle. He crawled and climbed into everything. His favourite place was inside the TV stand. He posted videos underneath, emptied a cupboard full of saucepans and crawled inside. Every other cupboard was childproof. They called David an action baby; he was far too busy crawling around to concentrate much on speech. His parents were convinced that speech would catch up. They tried not to worry as overprotective parents. Filming him on video, David crawled around downstairs, stopping to swing doors open and closed. Reaching the stairgate, his mum waited on red-alert. He would climb upstairs fast - the gate was open. But he didn't. He played with the stairgate. He opened it. He closed it. He watched it swing.

Both parents talked to him. They hoped to interest him in books. They bought every toy for his stage of development. Sometimes he played with toys. Other times he didn't seem interested. Wendy assumed he didn't like some toys. Could he build a tower of bricks? They thought so. He could knock them down. Some toys were ignored. Sometimes he responded to sounds, or his parents' words, but not always. Perhaps he didn't understand or wasn't ready to answer? They knew he could hear. Riding in his pushchair, David sat forwards, as if he was on a magic carpet.

Two weeks before David's first birthday, the family returned to the Lake District, staying at Coniston. David travelled happily in his baby sling, as the couple went on

long walks and boat trips. Their holiday cottage was memorable. David stood up, pushing his baby walker the full length of the living room. It was another first.

PART 3 TROUBLE BREWING

It was a special occasion. David celebrated his first birthday. Mum dressed him in a smart two-piece outfit, with a bright red waistcoat and gold buttons. He wore the same outfit for his professional photo, blond-haired, blue-eyed, with a beaming smile. It took pride of place in their living room. He was too young to invite guests, but everyone played Pass The Parcel, admiring mum's special cake, the Seven Dwarves from Snow White. David sat briefly on his plastic rocking horse and tried to grab his birthday candle. He opened birthday presents, far more interested in boxes and wrapping paper. Turning his huge box into a house, with window and door, David happily crawled in and out of his house, closing the door behind him. Mum and dad stored up a future anecdote, when he had more fun with wrappings than present. It was so normal, wasn't it?

Next month, as the family prepared for a short break, Ed loaded David into his car seat. Baby vomited everywhere. In the morning Wendy threw up. Their carefully planned trip was cancelled. It set another precedent, of regular minor illnesses catching each family member in turn. At 13 months David could climb upstairs. On 22nd August, at precisely 14 months, David was given his MMR Immunisation. He was grumpy and poorly for a couple of days. For a while he had been cruising around the furniture; a few days later David reached a new milestone. It was August Bank Holiday and the family were sailing on the Norfolk Broads. Both grandparents visited for the afternoon. In true sailing style, David was having his bath in a washing up bowl. Everyone chatted on the riverbank

at Reedham, while David splashed around. Suddenly he stood up in the water, squealing with delight. Standing on his own for the first time, he looked extremely pleased with himself. He always gave big smiles and his parents photographed the occasion. Wendy recorded it under Achievements in his Baby's Early Years book. At 14 months he stood up unaided, taking his first steps on 1st September. He seemed perfectly within the normal range. He was not an early walker, but he wasn't late either. Boys took longer than girls, didn't they?

The childminder expressed some concerns about David. "He's not talking", she said. Ed and Wendy considered his small collection of words and decided he would get there, given time. After all, he was their action baby. She said, "He just sits there." Considering his antics at home, David was enormously energetic. Normal. He rarely stayed still. He would not look at a book. It was difficult to get his attention. No-one else seemed to have any concerns about his development, so his mum and dad shelved these concerns. Perhaps he behaved differently away from home?

At 15 months he tried to brush his own hair and eat the toothpaste. His mum told him "Flush, flush" and David would flush the toilet. Whenever mum said "Finished," he would follow. He responded to "Come here". His mum said "Go to daddy," and he would toddle off to find him. A few words had emerged. He could say "Mama" and "Dada" and "Ber" for bear. His words tended to be one-syllable and he always dropped off the endings. His family assumed word sounds would improve with practice, along with an increased vocabulary. David passed his early checks. Both

Norfolk's Beautiful Child

parents knew perfectly well their toddler could hear. There was no reason to be concerned. David's latest word was "Baby". Ed and Wendy wondered where he got it from. More precisely, his word was "Bay". They laughed that he had some insider knowledge. The latest pregnancy test proved positive. Wendy was expecting another baby. It was due four days after David's second birthday. Daunted by the prospect of a toddler reaching the terrible twos as a new baby arrived at home, they reassured each other that it was a good spacing for siblings. They looked forward to completing their family, providing David with a brother or sister. They had hoped he wouldn't be an only child. By 16 months he was toddling confidently round the house, sweeping up with mum's brush and dustpan. According to her diary, David could wave and say "Bye, bye". His grandparents visited and David toddled to the door. Seeing them, he squealed with delight.

Planning carefully for an expanding family, the thought of weaning another baby in a carpeted dining room was too much to face. Their kitchen was tiny. The children would need to play in a proper garden. Soon their house was on the market. Double glazing was installed, to ensure an easy sell. David's favourite game was posting things. On the night before payment was due, Ed couldn't find the building society book. Workmen needed their cheque, the book had to be found. It was almost midnight when they found it, in the last place they chose to look - the kitchen rubbish bin.

With a buyer, and Christmas fast approaching, the couple looked for a perfect family home. They made an offer on a new house, with completion date some way off,

their home as yet unfinished. Full of hope for the New Year, they waited for the birth of their baby that summer. They couldn't take any pregnancy for granted, due to earlier experiences of miscarriage. Tests carried out during David's pregnancy had left a degree of caution. Yet they had passed the dangerous stages of early pregnancy. Wendy teased Ed that baby would arrive on David's birthday, or his own eleven days earlier. Second babies were always early, weren't they?

David had a collection of words at 18 months: "Mam!", "Dor" for door, "Baa" for bye. His most amusing was "Tikka, tikka" as he tickled his own tummy. Other words included "Yess", "Gon", "Ba" for biscuit, "No", "Ber" for bear, "Choo" for train and "Tho" for Thomas. He could say "Ti" for Tigger, "Tr" for tractor and "Carr" for car.

Discussing arrangements for after the birth, Wendy decided it was a good time to give up work and concentrate on her growing family. It seemed the best step for their own family circumstances. Wendy would be 38 when baby was born.

David had his 18 month developmental check a few days before Christmas. His length was 79 cm, his weight 25 lbs 10 oz (11.60 Kg). He achieved all developmental milestones. His mum and dad gave him his first trike for Christmas. He didn't know what to do with it, but both parents were happy the bike was well-designed for several stages. Ed used the tow bar to push him along. But his red pushalong car was an instant success. He showed little interest in new Duplo bricks. His parents longed for the challenge of a toddler pedalling unaided on his first trike.

FAMILY PRESSURES

In the New Year their careful plans fell through. On 4th January, news reached them that their housing chain had collapsed. They needed another buyer to proceed with purchasing their new home. On 24th January, following months of stress, departmental reorganisation culminated in redundancy for Wendy. A week later, Ed's office underwent major reorganisation and downsizing. Ed still had a job. Many didn't. Stress levels were enormous and Wendy's pregnancy was progressing rapidly. The house move became urgent as baby's expected date approached.

David became more difficult to manage. The terrible twos had struck with a vengeance. David was 18 months old. Expecting tantrums and embarrassing moments in supermarkets, both parents watched David enter this new stage with vigour. Wasn't it early for terrible twos? They had hoped for a few months of relative calm. For Wendy, resting during pregnancy became impossible. By 19 months David could run. He was on the move all the time. His parents looked forward to his language developing. There would be less frustration, fewer tantrums, when he could talk.

At 22 months David was playing with a toy telephone. He chatted into the receiver. "Phone grandma," mum encouraged him. David gave a fair impression of his mum nattering on the phone. Every word was unintelligible. He gave the final "Bye" and put down the receiver. Perhaps he was making progress. It sounded like conversation. There were no Bye Byes when relatives or friends visited. His parents were no longer sure whether

he had ever said Bye Bye. There were no little waves. No response. It was easier to stop expecting phrases. Repeating them drew attention to his inability. He would say Bye Bye when he was ready.

“Say Hello,” his parents told him, as visitors arrived. There was no response. They thought of variations. Hello seemed a difficult word. Perhaps another phrase would be easier for him. Hi, Hiya, nothing worked. They considered it unfortunate that all ‘Hello’ words began with H. It was embarrassing, continuing with difficult phrases. David was unable to respond. They waited for language to progress. He was slow, yet so were other children. He was just a late talker.

From the moment David could crawl, he collected bangs and bumps. On countless occasions his parents were unnerved as their toddler collided with furniture. All toddlers were clumsy and into everything, weren’t they? Expecting him to learn by practice and find his own limitations, David continued to bang his head. He repeated the same things, time after time. He didn’t remember what he should not do. Ed had childproofed furniture around the entire house, well ahead of each stage of development. It was never enough. David tore off protective corners. He smashed the video cover, again and again. He couldn’t suck with a straw. Both parents wondered how to help him. Didn’t children learn some things naturally, or must everything be taught?

He fell over and his parents waited for a cry. David picked himself up. He didn’t seem hurt. They had tried not bringing him up as a cry-baby, but David didn’t even cry

Norfolk's Beautiful Child

when he was hurt. Wendy wondered if she had overdone advice from baby magazines. It was embarrassing taking him out, displaying a collection of bruises down his shins, or bumps to his head. At 16 months David sat on a footstool, a radiator behind him, and bounced his head backwards. Apparently, he was experimenting with noise. The radiator clanged. He banged his head and kept on banging. He didn't learn that it hurt. He crawled into everything and underneath the TV. When he finally decided something hurt, next day he would try again. He didn't learn from mistakes.

Finally they arranged a new house purchase, under a part exchange scheme. They said farewell to a house they had watched as it was built, the house they thought would be their home. Completion date was arranged; six weeks before Wendy's due date. Time to unpack and await baby's arrival. David was difficult to manage, but the family were back on track. It was a family-sized house, with space for children to play. Wendy organised a change of doctor's surgery, so antenatal care could continue.

Ed and Wendy explained to David about baby. They bought a book and pointed at pictures. David was oblivious. It was difficult reading books with him. They repeated words but he turned pages without pausing. He wasn't interested in naming familiar objects. He chewed books, tore pages and posted them in every nook and cranny. Books were familiar at home. David wasn't interested in them. Wendy read books on sibling rivalry, and getting used to a new baby in the family. She bought David a present for first meeting, a present from baby. David settled into his new home. He had a new bedroom.

Soon he would need to move from a cot into a bed. His parents tried not to organise too many changes close together. David continued with his childminder, a familiar face through a time of change. It would also help during the difficult early days with a new baby.

DISASTER STRIKES

The family were struck by tragedy, eight days after moving house. Wendy was exactly eight months pregnant with her second child. Ed worked late at the office that evening. Wendy began to bleed. She had to get to hospital quickly. David was tucked up in his cot for the night. He had been difficult to settle. Wendy phoned Ed urgently. He came home and drove Wendy to hospital. They bundled David into the car, dressed in pyjamas. Taken straight to delivery floor, Wendy remembered David's arrival there two years earlier. Now she was hooked up to monitors and the midwife checked foetal heartbeat. There was a heartbeat, wasn't there? Ed held David in his arms. "Wave Bye Bye," he said. David gave a beaming smile, charming the nurses. Wendy waved back, keeping calm. She didn't want David upset by the strangeness of everything around him. It was a Bank Holiday weekend. Friends and neighbours were away. Ed arranged for David to stay at his childminder's overnight.

Returning to hospital, Ed stood frozen in the doorway. Medical staff switched on the foetal scanner and stared at the image on screen. Had they detected a heartbeat on arrival? They no longer seemed sure. A doctor gave the fateful words, "No foetal heartbeat. No foetal movement." Their second son would be stillborn. Wendy laboured through the night. It was lunchtime when they finally met their son for the first, and last, time. Wendy had previously laboured through the night with David, delivering him at 5.38 am. Now Andrew was born at 1.08 pm, following long labour through the night. It was a poignant reminder. David weighed 8 lb 3 oz at birth. Andrew weighed 3 lb 7 oz (1.57 Kg). The weights were

almost in reverse numbers. David had been two weeks overdue, while Andrew was delivered early at eight months. Andrew's cause of death was later diagnosed as placental abruption and pre-eclampsia.

David stayed with his childminder all night and the following day. At the end of that day Ed collected David from his childminder's. He was taken to visit Wendy in hospital. Both parents were keeping everything as normal as possible. David needed to see his mum. Wheeled back to Maternity floor, Wendy cuddled a tiny baby, wrapped to protect him from casual gazes of passers-by. David ran into the room. He was no longer a baby, but an energetic toddler. David climbed up onto his mum's lap and sucked his thumb. He was unaware of the tiny baby next to him. "Meet baby Andrew," both parents told him. They knew David needed including in their personal tragedy. One day he would recognise his family background; the couple hoped to explain about his brother. They took photos as memories for later. David had no idea what was happening. He didn't understand. He didn't begin to understand.

Ed took him home. Wendy remained in hospital overnight. Both parents understood it must seem strange to David. Within days of moving house, his mum was in hospital. Next morning David came to hospital with dad, to fetch mum home. Ed bought two cuddly rabbits. One was for David and one for Andrew. David took home a fawn rabbit. They buried Andrew with rusty rabbit. His parents were painfully aware it would be the last present for both sons. Six days after delivery, David went to the funeral accompanied by his grandparents. "What a good boy,"

Norfolk's Beautiful Child

everyone commented. He remained quiet throughout the service. How much did he understand? His parents had no idea. He had too little language for much to be explained. They included him so one day he would know he had been part of it. Later that day, David played at pushing around and humming in the pitch of a vacuum cleaner. A month later, the family celebrated his second birthday.

PART 4 TERRIBLE TWOS

David wore a new jumper covered with bright balloons and a stuffed teddy bear, a present from grandma along with his favourite new toy - a Hoover. It was his second birthday and parents bought him a Cozy Coupé car. His older cousins pushed him around the garden at high speed. David was enjoying himself. New to the area, Wendy tried to join in local Mother and Toddler groups. It was a difficult time for her to meet people. "Is this your only child?" they asked. She tried several groups. Too soon the focus was on David's behaviour. Other mums sat down and chatted. Wendy was jumping, continually checking on David. With one prize pushalong toy, a train, David wanted it. No other toy would do. He had to play with that toy. Other parents could persuade their children to share, to take turns. Nothing distracted David. He could not share, or play with a different toy. Time was fraught. What would David do next? Every new scene held conflict. He was a terrible two with a vengeance. David was more terrible than all the other twos put together.

In the playground, Wendy hovered between 'fight or flight'. Confrontations with other children were inevitable. It was a huge effort to defend David. He was oblivious to the effects he had on everyone around him. In the back of their minds, both parents knew David wasn't being naughty or malicious. He didn't understand. He played happily. Always he had a big smile. He was unaware of glares from defensive parents. Wendy started telling him off simply to pacify other people. It went over David's head. He was unaware of doing anything wrong. David was rarely upset.

Norfolk's Beautiful Child

He was exactly the same next time around. His difficult behaviour continued.

Reading baby magazines, his parents tried each method as recommended. It never worked with David. Each article focused on one difficult toddler behaviour, of biting, hair-pulling, spitting or kicking. David tried each of them, one after another. A new behaviour started before the earlier one stopped. Sometimes there was a collection of toddler vices at once. Wendy talked, but listening was impossible for him. Each time Ed and Wendy congratulated themselves on riding a difficult storm, the behaviour returned with a vengeance. He didn't learn nicer ways of behaving.

Soon after Andrew's birth, a long-distance friend visited Wendy. Sitting down to lunch, Wendy watched her well-behaved little girl. She did what mum told her. She ate nicely. David behaved and ate in his usual manner. Food landed on the floor. Every time his parents attempted a direct approach, David screeched and would not cooperate. Wendy had read magazines that recommended not making an issue over food. Keep calm, clear up and don't let the child turn mealtimes into a battleground. Soon the friend spoke up about David's behaviour and table manners. "You're not doing anything," she said. There seemed little point in explaining. David ate well some days and very badly at other times. He ate almost anything. Wendy was pleased he ate his vegetables and virtually everything else on his plate. Nothing reduced the amount of food ending up on the floor, the walls, in his hair. Wendy had kept calm. Getting a message through to David was difficult. Trying too hard made David impossible. The

remainder of her friend's visit was fraught. She left thinking Wendy was experiencing longterm grief, from loss of Andrew three months earlier. Wendy was screaming inside. Whatever she tried with David failed to work. To an outsider, David appeared as a badly behaved little boy.

Early in the Autumn a new health visitor came to see David at home. He was now two-and-a-quarter, with a small collection of words. Wendy had tried to simplify words, giving him an easy choice. "Orange or blackcurrant?" "Drink?" "Come here." Tentatively she raised the question of David's lack of speech development. Thinking he was late developing language, Wendy wondered whether he had hearing problems. Did he have glue ear? Perhaps this caused his other problems? The health visitor raised concerns about his lack of language. Wendy thought two was an early age to refer him for tests. Lots of late speakers exploded with new words at age three, didn't they? David was late talking, perhaps he was within the wide range of normal?

It was a difficult time to hear that her beautiful, perfect little boy might have problems. David was their firstborn. As a couple they had recently lost their second son. David was the only child they had. He looked perfect, normal. Wendy asked for checks to be carried out at Christmas, three months later. Both parents were convinced his language would improve. Soon David would join Two Plus playgroup. They were settling into a new area. It was only a matter of time, wasn't it? He was a beautiful child, with blond hair, bleached fairer through the summer months, big blue eyes and a lovely smile. He enjoyed cuddles with his mum and rough-and-tumble with

Norfolk's Beautiful Child

dad. Frequently his parents commented how happy he was. Whatever happened in relation to other children, there was nothing deliberate or malicious. He was unaware when other children were upset. David couldn't say sorry. It was difficult encouraging him to say Bye. If he could have used words, the problem remained. He did not understand he had caused upset.

In mid-September the family went on holiday to Pickering in North Yorkshire. It was chosen as a best timing following the birth of their second son. They were painfully aware that they were a family of three, not four. David had a lovely time. He went on the North Yorkshire Steam Railway, on a special Thomas Day. It was too crowded, but David had fun. He watched the steam engines turning round on turntables. The family went on long walks. It was relatively quiet and David didn't need containing in the same way as a crowded town centre. He had always been a water baby, taught firstly in the bath at home and very early in the toddler pools. Now he could tread water, supported only by water wings. He bounced a beach ball in and out of the pool, giggling with delight.

David joined the local Two Plus group. Parents supervised their own children as they enjoyed playgroup facilities. It was a good opportunity to encourage David's socialising. He spent hours playing with trains on their tracks. Then he played with a circus train without a track. Occasionally he played with sand or water. More water ended up on the floor. Wendy tried not to intervene too quickly. She wanted to encourage him to play alongside other children. It was a tense time. David had no interest in dressing up, reading books, engaging in tabletop

activities. Wendy spent a long time kneeling on the floor, discouraging confrontations as another child wanted to share the trains. She wondered if David was benefiting from his time with other children. He lined up engines and carriages, made steam train sound effects and trailed carriages round and round the track. He was completely absorbed. He had no concept of sharing trains or track, or of listening to mum. He played happily on his own. At least his parents knew what present to buy him for Christmas.

Wendy joined an informal coffee group, but it was difficult spending time with expectant mothers, and mums with newborn babies. David needed to belong to a social group, yet many times she returned home in tears. Other people's children were younger, or girls, or listened to their mum. They shared pushalong toys. They took one biscuit at a time. Not David. Everything needed to be out of reach, out of sight. If David wanted a toy, he took it. His mum talked to him, distracted him, brought him back into the play area. He did not respond. He needed Thomas The Tank Engine. It was impossible encouraging him to play with anything else. Other children did not exist. Trains belonged to David.

On 8th October Ed's parents celebrated their 40th Wedding Anniversary. It was a big family occasion and eight adults and three children gathered together in a restaurant for Sunday lunch. It was a slow meal. David sat in his high chair, completely happy. His parents fed him with starters and bread rolls. Eventually his children's meal arrived. David was calm for a remarkable length of time. He was having a good day.

Since moving into their new home, David could open all the doors himself. He opened and closed them; frequently. Parents were concerned about trapped fingers. At home door stops were used to prevent doors slamming shut. David became upset if he couldn't close doors. He screeched. Later he would fix on light switches, then curtains. His need for doors was as strong as his urge to play with trains. Arriving at a coffee morning, David ignored all toys and moved to his favourite activity, opening and closing doors. David slammed the door several times. Then he emptied the pile of toys with a crash. He narrowly missed the household plants. Finally he attempted crawling across the coffee table. The hostess had had enough. "You vandal!" she told him. "You're a vandal, aren't you?" Aware of textbooks disapproving of labels for young children, Wendy tried to tone down the insult. Children lived up to labels, didn't they? By the time the same phrase was repeated, she decided it was time to defend David. "He's not a vandal. He's just a terrible two," she explained.

It made no difference and Wendy would not hear her son named a vandal yet again. It was the last straw. She had tried to belong to a group, for David's sake. The stress of joining in social situations was too much. David was different from other children. He didn't fit in. Would she ever be able to socialise with David around?

Wendy was pregnant again. As a couple they had dared to risk having another baby. They wanted David to have a brother or sister. It was a stressful time, carrying another baby after losing one through stillbirth. Each day Wendy felt she was treading on ice. She willed each day to

pass. Three months would be an important milestone. Christmas approached, apparently full of hope for their family. It would soon be New Year, and there would be a baby born next summer. Wendy always delivered summer babies. They told fewer people about this pregnancy. The risk was too great.

Three days before Christmas, she miscarried. They put on a brave face, for David's sake. On Christmas Eve, Andrew's memorial rose budded; next morning snow settled on the ground. Aged two-and-a-half, David had a wooden Brio train set. His parents watched him playing with it for hours. Their hopes had vanished. Wendy began to think David would never have a baby brother or sister.

Early in the New Year the health visitor arranged a referral for David. He could not talk properly. The words he used were difficult to understand. They were almost impossible for anyone except his mum and dad. They waited for an appointment with the paediatrician, testing hearing and making developmental checks. Did he have glue ear? Were his tantrums due to frustration and inability to communicate? Sometimes he understood well and did precisely what his parents asked. Faced with family tragedies, it was ironic that worries revolved around David. Their beautiful little boy was less than perfect. Each hope was shattered. They waited until they could try again for a baby. The couple knew it would be their last attempt. For David's sake, and for their family unit, the next baby would be their last.

Due to slow speech development, on 8th February David attended a hearing test with a paediatrician. The

report said, 'Very difficult to understand when he speaks in sentences... Comprehension seems OK.' He was two years and eight months. His hearing test confirmed David did not have glue ear. Written comments stated that there were 'no significant hearing problems'. Tests came back negative. David's hearing was fine. He was referred to the speech therapy team.

David played trains at home. He played trains at playgroup. Wendy wondered what he gained from his weekly trips to Two Plus. David needed to play with trains, every single one. Distraction didn't work. He knew what he wanted. He was a boy. Boys played with trains, didn't they? At least he was playing. His Brio kept him absorbed for hours. David was easier to manage when trains were around him. He screeched when they did not do what he expected. He learned to turn trains round, to use magnets to connect each carriage. It was difficult showing David how to do anything. He became upset when his parents explained how anything worked. He had to do it for himself, whether he understood or not. His parents were frustrated. They listened to him screech, yet he refused all offers of assistance.

SPEECH THERAPY

David attended a speech and language skills assessment at his local surgery on 11th March and 24th April 1996, following referral by the community paediatrician. Diagnosis and recommendations were then given: 'David has a developmental expressive language disorder associated with a short attention span. He is keen to communicate, however, and there are signs of progress.'

Wendy had tried every conceivable activity for his age group. They had visited places of interest for young children. They'd been to the zoo, ridden on steam trains, explored adventure playgrounds. They rode tractors, carts, visited the farm, climbed to the top of the castle, named all they saw. Speech therapists gave her simple activities to carry out at home. It was all too familiar. Relatives said they couldn't understand a word David said. They told him off for misdemeanours. "He doesn't understand. He doesn't even realise you're talking to him," Wendy fumed quietly. He had no idea people got angry with him.

Before Easter they said goodbye to David's childminder. She had provided continuity for David and a break for Wendy at a time of trauma.

The family took an early break, staying in a holiday village in Dorset. Steam trains and boat trips featured strongly in all their holidays. They provided a David-friendly mix of energetic activities, limiting time spent in crowds. Ed carried David up the hillside in his backpack. Halfway up it was too much; he was too heavy to be carried. His dad regained breath and David climbed his first mountain, jollied along by mum. The view from the top, overlooking Lulworth Cove, was breathtaking.

STARTING AT NURSERY

Booking David into a local nursery for one half day per week, by late June he had one full day weekly. Nursery had excellent indoor equipment, extensive grounds, a good adult ratio and organised activities. Wendy thought it would help David mature, learning in a new environment with lots of other children. It was a short distance by car. Soon David also began at local playgroup, a chance to mix with local children.

About the same time, David joined a speech therapy group. It had seemed a slow process. Other children had a variety of speech problems. Wendy dreaded each appointment, aiming to time his arrival precisely, to avoid waiting outside the therapy room. Other children sat, or read a book. David wandered. He scattered leaflets across the floor. Sometimes he showed interest in wall pictures, so Wendy talked about them. He would tear them down if mum was not a step ahead of him. It was difficult talking to professionals after each session. There were other children, other parents. He scattered toys before she could reach him. It was a tense time if David was out of reach. His decision to leave a room was instantaneous. Unless he was ready to go, it was difficult removing him. The room became an obstacle race course. The therapist told Wendy David 'wandered' around the room during sessions. He didn't benefit from group therapy. David was assessed regularly. Yet it was difficult for speech therapists to complete structured tests. David would not co-operate. He could have achieved a higher score. He failed to name animals and familiar everyday objects. Wendy wondered what they were doing wrong. He didn't seem to know even basic words.

That summer, Wendy booked an appointment at her doctor's. She arrived with two subjects on her mind. Would counselling help her cope with the next planned pregnancy? More importantly, what was the matter with David? At surgery, she explained about David. It was difficult to give a clear picture. He had good days and he had bad days. Sometimes he was hyperactive, other times he appeared perfectly normal. Wendy wondered how they could imagine anything was wrong with him. Other days they tore their hair in frustration. Living with David felt as if his parents were banging their heads against a brick wall — every day.

The doctor listened sympathetically, then sat observing David. He discarded toys. Nothing was safe from David. Files were within reach, computer paper piled on the floor. David began a round of destruction. Wendy found it hard to continue the conversation. After a while, the doctor decided he was attention-seeking. Wendy left surgery with her counselling sessions booked. She was no further forward with David. 'Attention-seeking,' Wendy fumed. David prevented her from joining in any social activity. She had to concentrate on David. It didn't solve the problem.

Wendy went to her local minister in desperation. Again she explained about David. The doctor called him attention-seeking. It was not that simple. David played on the floor, absorbed in a game. It was difficult explaining what he was like. He had major speech problems. The minister watched him play and she saw a normal child. He was perfectly happy as mum sat nearby chatting. They

Norfolk's Beautiful Child

moved outdoors and David was fascinated by the sandpit. He enjoyed shifting sand with a tipper truck. "He's a lovely little boy," she told his mum. Wendy could not disagree. "Enjoy him while you can. They grow so quickly."

Wendy left feeling the same as the day she left the doctor's surgery. The minister had given her a panacea for all ills. Everyone generalised about a normal child. Wendy believed they had not heard what she was really trying to say. How could she explain about David? They didn't live with him all day, every day. She felt she was treated as an overly-protective mother. Enjoy her little boy? Of course he was a lovely child. Both parents knew that. His babyhood had slipped away as they tried to complete their family. Yet they gave him all the attention in the world. They couldn't enjoy his early years, he was different. He was not a normal, average child, but he was still beautiful.

PART 5 WHAT'S WRONG WITH HIM?

David had a garage with a set of cars. It wasn't long before he chewed the cars to pieces and pulled the garage apart too many times for repair. His parents hoped a new trampoline would help burn up his excess energy. His cousins encouraged him to bounce, but he went round in circles. He learnt to jump when he was five. His preferred activity was running around, hitting balloons in the air. "Gon!" he squealed. "Up!" he pointed as balloons hit the ceiling. David giggled with delight. He had learnt a new game.

On the morning of David's third birthday, the family organised a brief party. One other child came to his party, Emily aged four, his former neighbour. Emily always enjoyed videos of her and David, on a shared outing. With presents, balloons and a cake, David was happy. "Trai!" he declared, as he unwrapped a car. Everything was a train. If his parents could understand general words, David never mentioned names of other children. Except Emily. David also enjoyed mum's home videos.

That lunchtime, Ed and Wendy took David on his latest boating holiday. It was difficult sailing with a toddler aboard. It would be impossible once their second son was born. They hired a traditional sailing craft for the week and set sail from Martham Ferry. They both struggled to lower the mast and Ed negotiated the notorious Potter Heigham Bridge without a navigator. David spent much of his trip trailing ropes in water. Jib ropes were soggy, and Ed looked worried as he tried to control the boat. Towards the end of their trip, Wendy begged Ed for chips with curry

sauce. She recognised a craving; Ed realised when they returned home. The pregnancy test was positive.

Wendy took David on train rides. They had been on every steam train in the county, several road trains, nursery rides and miniature railways. On a family outing, one phrase from David was clear as a bell. "Going for a ride on the train, David?" "Yes, ride train," he beamed, full of enthusiasm. "Good. Yes, ride train," mum confirmed. David spent the rest of the journey in a little carriage, sitting and sucking his thumb. He was completely absorbed. Wendy vividly remembered one such outing on the Wells to Walsingham steam railway. David was straining to stand as close to the train as possible. He watched manoeuvres as the engine was uncoupled and shunted in front of coaches for the return journey. An older boy was next to him, positively flapping with excitement. There didn't look much difference between them; where trains were concerned. Both were hooked. Wendy shared a brief comment with the other boy's mum. She dismissed, but never forgot, her reply. "He's autistic," the mum explained.

David was referred for a second opinion from speech and language therapy services on 19th June 1996. His therapist visited David at speech therapy and nursery. She organised home visits throughout the summer holidays, then prepared an assessment report, 'David presented as an active three year old with a lively interest in all going on around him but with short attention span except to activities of his own choosing. He has excellent eye contact and is quite sociable... much of his vocalisation consisted of jargon.'

She recommended specific action, in his speech therapy group and at nursery. His parents hoped that, as his speech developed, his behaviour would improve. They were told that tantrums were caused by inability to communicate. When he could talk there would be less frustration.

September arrived. Stress levels increased throughout Wendy's pregnancy. After experiencing miscarriage and stillbirth she now counted every day, without certainty. One day David wore fancy dress. Every child arrived at nursery as a favourite character. Wendy made a tunic, a hat that jangled, a belt and a white beard. She expected the beard to melt before he reached the entrance. He was one of the Seven Dwarves. Next morning Wendy returned with David to nursery. She was called aside into an office, with two members of staff present. They said David had held his side the previous day. They mentioned bruising, something they had noticed for a while. They had phoned Social Services asking for advice. Wendy could hardly believe they were having this conversation. She explained an earlier-remembered incident. David had fallen off a picnic table in the local playground. Somehow he had become wedged in sideways. She saw him disappear on the far side of the table and waited for the cry. Why hadn't he hit the floor? He was firmly wedged between table and ground. Wendy described to staff what had happened.

She left the premises as waves of emotion overwhelmed her. What were they thinking? Wendy was pregnant with another baby. It was a last attempt to complete their family, providing David with a longed-for sibling. He had displayed bruises since the moment he

could crawl. No-one had questioned them before. Wendy could not believe anyone would think they might harm their own child. Didn't people realise how precious their only son was? Called out of his office, Ed spoke calmly. He returned at the end of the day, to collect David from nursery. He explained the stressful pregnancy they now faced. Nursery staff were happy with the explanation. Ed was matter-of-fact. "They're just doing their job," he explained. Wendy was terrified by every bruise as it appeared, at regular intervals. Wendy had a son who failed to learn from his mistakes. He produced new bumps and bruises almost daily. Now she felt each one had to be justified. She visited her local doctor, who provided support through a stressful pregnancy. The doctor confirmed and recorded her examination of David. Each bruise was a normal impact bruise.

Later, Wendy realised why David had clutched his side at nursery. It had nothing to do with bruises. He had worn a belt, as one of the Seven Dwarves. Undressing him for his bath that evening, she had noticed the belt had ridden up over his ribs. He had worn it all day. The belt had hurt him. Wendy had expected a bruise to appear; much later it emerged. It was tiny and appeared after the talk at nursery. David's ribs hurt because of the belt; not his fall from a picnic table.

INCREASING ISOLATION

Since the start of the Summer Term, David had visited playgroup every Friday afternoon. In the autumn this increased to two mornings each week. Soon his mum received feedback about his behaviour. "He's a different child," the playgroup supervisor advised. He had behaved much better in the summer. Wendy thought about all the improvements his speech therapist had noticed in the holidays. What could she believe, was he better or worse?

Wendy ceased taking David to local coffee groups and toddler groups. It was attempting the impossible as each time they returned home stressed. It was more important to keep calm and enjoy a quiet time without pressure. His parents wondered whether something deeper was happening with David. Perhaps there was a label? Did he have a condition that tests might identify? Their child was not normal. Wendy had long conversations with their health visitor. She listened. It made a difference, explaining the way he behaved. They had tried everything. Wendy thought his label could be hyperactive. She had read about Attention Deficit Hyperactivity Disorder (ADHD) and sometimes David fitted the definition. He was very active and found it difficult settling to anything. Yet other times he was absorbed for hours. He pushed trains round and round their track. Was he learning anything? Was he playing? However, David slept at night. Hyperactive children didn't sleep. Ed and Wendy couldn't imagine coping with David 24 hours a day. There was relative peace at night-time.

Since David was a tiny baby, his parents had put him in his cot and he slept through the night. At three months

Norfolk's Beautiful Child

the family enjoyed their first holiday away from home. David slept in his own room for the first time. Wendy tossed and turned all night, but David slept until seven o'clock the next morning. Both parents congratulated themselves on reaching another milestone. They were keen for David's sleeping pattern to continue at home. It worked. They heard of other parents facing long evenings with baby in charge. They decided that recommended techniques in baby magazines were possible. Apparently.

David took a long time before he could open doors. Moving into a new home David, aged two, was able to open them for the first time. Door handles were now easily within his reach, so he spent a lot of time opening doors. Yet he always stayed inside his bedroom at night. His parents considered they had trained him well. He knew his bedtime routine. He stayed in his room. Now aged three, he had discovered how to open his own door. His play extended to the landing, then the stairs. Games with trains took him everywhere. It was difficult keeping him inside his bedroom. He played for hours. How long should it take him to switch off at night? Many evenings his parents found him balanced at the top of the stairs, fast asleep, trains lined up nearby.

They gave him books, but these were lined up in neat rows too, like trains. Wendy found him curled in a corner, halfway up the stairs. Frequently one or other parent would settle him back in his bedroom. One day, the playgroup supervisor had a chat with his mum. David was pushing other children. "Do staff have your permission to deal with him?" she asked. "Could you have a word with him?" Wendy wondered how to control his environment,

when she was not physically in the room. She was happy that playgroup dealt with him appropriately. Wendy attempted talking to him. She was convinced he didn't understand a word. She couldn't talk to David away from the scene. He showed no signs of recognition, of place or subject. Another social situation held an air of tension for Wendy. Public places were a nightmare with David. Wendy needed to rest when David was out. She had to give her new baby a chance. "We will see how things go," the staff member told her. Wendy wondered how long he would continue with the group.

It was another pressure-point. Collecting him at the end of each session, other children sat neatly in a row, awaiting their parents. If any child was difficult to settle, mostly it was David. Sitting on a chair, he was liable to pull name labels down. Although he was in a social situation, he was not learning how to socialise. Finally, David's parents agreed to increase his time at nursery and remove him from local playgroup. Perhaps two groups were confusing for him. There would be plenty of opportunities to mix with local children later on. He was already in another speech therapy group.

A NORMAL PREGNANCY?

As Christmas approached, Wendy was not convinced how long her pregnancy would last. Every day felt like treading on ice. She hoped to reach the New Year, giving baby a better chance of survival. She told David there was a baby in her tummy. She wanted to prepare him for a new sibling. Yet she had no confidence that she would return home from hospital with baby. She couldn't sleep, she couldn't settle. Her baby was almost seven months.

Both parents hoped to give David a normal Christmas, but everyone had streaming colds. David sniffed his way through present-opening, had fun with his musical keyboard and enjoyed the Thomas chocolates even more. Snow fell and they helped David make a snowman. Ed took him out on a new sledge. He wouldn't sit on it. Other children allowed dad to pull them along, not David. Soon Ed was pulling along a heavily pregnant wife, with a three-and-a-half year old on her lap.

Two days into the New Year Wendy had an antenatal appointment. Monitored closely, her pregnancy was high risk. She persuaded David into the doctor's surgery and then the consulting area. She paused for his trains to stop at the station. Wendy's blood pressure was high. There was protein in her urine. Both were classic symptoms of pre-eclampsia. David was returned to the waiting area, as Wendy's doctor phoned hospital, checking admission procedure. Calmly she returned, "It's probably nothing to worry about, but go to the delivery floor—now." David was extracted from his game. He was strapped into the car seat.

On his first day back in the office, after the Christmas break, Wendy phoned Ed. "Meet me on delivery floor in half an hour." Wendy was attached to monitors. Her blood was taken for analysis and steroid injections administered. They would help mature baby's lungs. Wendy found it difficult to believe baby would be born nine weeks early. This was an emergency. Hours dragged by. Wendy's blood pressure was high. Ed phoned his brother-in-law, arranging care for David. His auntie and uncle were recent and familiar faces. David was happily settled with them overnight.

Could he remember the last time mum was in hospital? Did he realise she had a baby then too? He had no words to tell his parents. Wendy waved Bye Bye. At 31 weeks' gestation, both parents knew baby had an excellent chance of survival. Wendy was glad to have reached hospital with a live baby. He would be monitored intensively.

Peter was finally born next morning in Ipswich Hospital, over forty miles away, on 3rd January 1997. He was delivered by emergency Caesarean, while Wendy was under a general anaesthetic. Peter's story was recorded in 'Rocky Start - Diary Of A Special Care Baby' and more recently in 'Rocky Start—Home At Last, Baby's First Year'. He weighed in at 3 lb 5 oz (1.495 kg) and had a head of dark hair. He didn't look like David, who had been born covered with meconium, making his hair look orange. By the time he was bathed and cleaned up, he had a fine down of blond hair. He was a well-rounded baby-shape, weighing in at 8 lb 3 oz. Peter weighed about the same as Andrew. He was

tiny. Ed and Wendy now had a blond-haired child and a baby with dark hair.

Ed travelled back and forth between Ipswich and Norwich. David came home the second night. He needed routine. The couple wanted David to see his mum as soon as possible, so he would know she was coming home soon. David needed to see his new baby brother. Ed explained that baby Peter was in hospital and poorly. They hoped he would come home soon, when he was better.

MEETING BABY BROTHER

David bounced into the hospital ward. Wendy was recovering well and monitored less intensively. Another mother shared the room. Her baby was born by Caesarean, under local anaesthetic. David ran across to her, seeing a baby in her arms. It must be his baby, David knew he had a baby brother. He was ushered back to mum. His parents explained he would meet baby another day. His brother needed to recover first. Grandparents looked after David, giving Ed and Wendy time with Peter. Together as a couple, they visited their new son in special care, alone for the first time. Over the next few days, relatives and friends spent hours accompanying David as he climbed up and down flights of stairs, attempting to contain him in a large hospital. A bag of toys was not enough to amuse David. He was constantly on the move.

Seeing David for the first time since delivery, his language had improved in a few short days. Perhaps a new baby was good for David. His mum hoped it was what he needed. She thought it would help his development. She

understood more of his words. He talked in complete sentences. Much of it sounded like gobbledegook. Yet there were stray intelligible word. She felt it was more than meaningless chatter. He understood far more than he could say. He responded to whole sentences, sometimes with two instructions. At other times, both parents knew, the simplest word or phrase was beyond his recognition.

Over the next few weeks and months, David's speech gradually improved. It was difficult for anyone to understand a word. Wendy tuned in to an increasing range of words among his usual phrases. He knew what he intended to say. Responding to a simple question was another matter. Wendy spoke loudly, she spoke slowly, she used one or two-word sentences. She began each phrase with, "David!" It was painfully difficult. "Drink?", "Biscuit?" He had no real urge to communicate.

They introduced David to his brother for the first time. "Meet baby Peter," his parents told him firmly. He was directed to their incubator. David was fascinated. There were bright lights, rhythmic patterns, loud bleeps. He wanted to press the buttons. Ed firmly gripped both hands. David couldn't understand why he wasn't allowed to open the box. Why could mum touch baby inside, when he was discouraged? His parents were tense, aware of nursing staff dealing with a more fragile baby in the same room. David was ushered out quickly. "Say Bye Bye, baby Peter." Wendy persuaded him towards the exit. "See you another day." After the third set of Bye Byes, Ed and Wendy succeeded in removing him from Nursery One. The room contained many tiny, fragile babies in incubators. It was difficult showing their son his new brother. They

wanted David to understand that mum would come home soon. They hoped Peter would come home one day.

David was booked into extra nursery sessions. Ed provided continuity in his world. On David's first day in nursery since the birth, he sat quietly in the corner and cried. He had never cried at nursery before. Everything was strange for him. On day nine, Wendy asked to be discharged. She had to spend time with David. He needed to see his mum back home. David's second godmother, Auntie Jo, looked after him while Ed drove to Ipswich to bring Wendy home. David drew mum a Welcome Home card. He beamed as she walked slowly through the door. He cuddled up on her lap and Wendy tried to ignore her stitches. His world was complete again. Baby remained in special care in Ipswich. Wendy found it painful to part from her new baby. But David needed her home.

ACCIDENT PRONE

Next morning the family packed up for a daytrip to Ipswich Hospital. They would visit Peter alternate days, working around David's days at nursery. He was his usual, energetic self, bounding around the room. It was difficult getting him into shoes and coat. In a split second he crashed into the patio door. Wendy recognised the cry. David rolled around on the floor. He had hurt himself; she saw blood on his forehead. The door was toughened glass, and childproof. She tried to examine him, as David crawled under the TV. He would not let anyone help him. He tried to copy what had happened, as Wendy restrained him. Bandages were fetched. They took David to Accident and Emergency, Norwich.

Instead of a car journey to Ipswich Hospital, visiting a special care baby, they had to face another hospital experience first. David was now the patient. Wendy began to feel like she lived in hospital. David pulled off his mum's bandaging. A vertical split ran down the middle of his forehead. Wendy restrained him in the car seat, calming him and preventing him grabbing his head. Ed drove fast. They were pleasantly surprised by the speed and efficiency of A&E and the way they dealt with children. Calm staff dealt with the injured child, in a separate play area. David left sporting butterfly clips. His parents were relieved that stitches were not necessary. How long would David leave the clips in place?

By the time they reached Ipswich, they were fraught. At hospital, Peter had faced a bad night. He needed to rest. Worries about their children were endless. It was a round of tragedies and trauma. They began laughing, recalling David's attempts to fly backwards through the air, repeating his impact with the patio door. If they had not laughed, they would have cried. How many injuries would they have to patch up; how many scars on his once-perfect face? He was accident-prone and clumsy. When would he learn to match his behaviour to the environment? Why couldn't he learn what was impossible, silly, or dangerous?

PROTECTING BABY

On 12th February, six weeks after delivery, baby Peter came home. His parents carefully arranged his arrival while David was at nursery. When David was carried home for the first time, he appeared tiny and fragile. Peter was half that size, he had to remain indoors with few visitors. Friends' children were unable to visit; risk of infection was too great. David arrived home. Ed and Wendy introduced him gently to the new baby, no longer in the strange environment of special care. David was a model brother. He kissed baby Peter, completely unaware of sibling rivalry. He kissed Peter exuberantly, again and again. His parents watched nervously, toning down his less than gentle approaches. They didn't want to give David the unspoken message to Keep Away. They hoped he would have no reason to dislike this new arrival.

Wendy dreaded taking David to nursery, carrying a fragile baby who must be kept apart from other children. On non-nursery days, Wendy spent hours talking and involving David in everything. He thought he had mum's undivided attention. Peter needed cuddles and reassurance. Yet he was a small baby and babies slept much of the time. Ed and Wendy helped David to complete lots of complex jigsaw puzzles, he was extremely good at them. He worked the hard way, refusing assistance and ignoring the picture. They praised him every time he completed a puzzle, yet it never lessened his negative behaviour, or increased his positive behaviour. When he achieved something, Ed and Wendy tried to let him know how pleased they were. David wouldn't let his parents help. He painted many pictures and then cardboard boxes, blue for Thomas the Tank Engine and red for James.

Mostly, David painted James. Wendy helped him join boxes together, making long trains. She tried to interest him in houses, or farms. Trains won every time. Each train had a funnel, wheels and a face. Wendy drew lots of train faces. Happy trains, sad trains, fast asleep trains. Eventually David could label the faces in his Thomas books: happy, sad, asleep.

THREE-AND-A-HALF CHECK

On 18th March a paediatrician gave David his three-and-a-half year old developmental check. He was three years and nine months. Wendy hoped David would have a good day. On a bad day it was impossible to get him inside the surgery. Questions were asked, forms filled in. Would the appointment last long? Wendy hoped Peter would remain quiet in his car seat. David co-operated, fascinated by an array of small objects in a box; Wendy breathed a sigh of relief. Perhaps the tests would be completed without incident. David didn't open and close doors. There was a sink in the corner. He was fascinated by water and loved pouring games. The paediatrician needed him weighed and measured; he had to stand in position. Facts and figures were recorded. David refused to stand for his height chart. His mum persuaded him onto the scales, as digits were rapidly read out. His height was 96.5 cm, his weight 16 Kg. David had to follow his routine first, like playing a game of badminton with a bird instead of a shuttlecock.

A second appointment was booked; tests were unfinished. One hour-long session was not enough for David's assessment. Wendy extracted him from the consulting room. He had fixed on the sink for a third time. He wanted to play pouring games. The record from this meeting indicates, 'Not very co-operative... difficult to understand...I think he should be put forward for Statementing.'

The speech therapist had already made the same recommendation.

Meanwhile, the health visitor came at regular intervals. She checked progress of their special care baby. Peter was developing well. He followed the mid-centile curve on his growth chart (adjusted for his prematurity). Wendy continued talking to professionals about David's latest exploits. Sometimes David seemed hyperactive, sometimes autistic. He was neither all of the time. He had good days and bad days. Sometimes he switched over, with no apparent reason for change—he was unpredictable. She couldn't think of any trigger factors. David slept at night. He couldn't be hyperactive. David made beautiful eye contact. He couldn't be autistic. Above all, David was intelligent, neither parent doubted that.

David happily painted most days. One moment he was completely absorbed. Then he painted table, floor and anything else within reach. Without warning he ran from the kitchen, hands covered in paint and brush held aloft. Wendy manoeuvred him to the sink hurriedly and wiped him clean. David preferred red, occasionally he tried orange. His mum painted outlines of trains, a house, a tree. He covered it in red paint. She wondered when he would experiment with different colours. When would he scribble, draw lines, dots, circles? She looked forward to his first picture of a house. Did anything else exist for David, except red trains?

Between February and April, David was assessed again and placed in a different speech therapy session, one-to-one. The group structure didn't work for him, so they used an experimental approach. "David," his speech therapist told him. "This is your time." David was allowed to play with any toy in the room. His only boundary was

end-of-session. Then play must stop. David always had difficulty managing beginnings and endings. During his first session, the array of toys around the floor did not engage him. He ran directly to the shelves and unpacked neatly filed boxes of flash cards. David enjoyed posting them. It was his favourite activity. He spent the whole session rearranging each carefully ordered box. Next week the therapist had removed all the boxes, placing them out of his reach.

The therapist saw it as an opportunity for David to enjoy his own space. She restricted adult input to naming objects. Words accompanied everything he did. "David's picking up the box", "David's pushing a train". It was designed to extend his vocabulary and his own space. Every week he had a special time. Peter was carried into each meeting in his car seat. His mum hoped baby would remain quiet for best part of an hour. He slept. He fed. Wendy tried to follow the thread of each session and to concentrate on David. At home she helped him complete his homework. She named aloud every item and activity, as if reading from a book. David's parents were willing to try anything the professionals thought might work.

The family visited steam railways, admiring James on his turntable. Most of David's words consisted simply of their first syllable, he could not manage word endings. His mum was always "Maa". Trains were "Tho" (Thomas), "Per" (Percy), "Jay" (James), "Toe" (Toby). Drink was "Bla" (Blackcurrant). Wendy translated words she understood. She repeated them back to him correctly. She put his words into short sentences. It was difficult understanding him; impossible for those who knew him less. David learnt

his primary colours. He learnt colour mixing, oranges, greens, purples, pinks and browns. Ed noticed him lining up trains by colours. He lined up books by colours too. Wendy named every part of a train she knew. David soon knew them all. There were engines, carriages, funnels, bumpers, track, trucks, crash and landslides. Wendy named each train's colour. She learnt which was Thomas, Percy, Henry, Edward, Gordon. In fact, David knew precisely which green or blue train he was talking about. A red train was always James.

STATEMENT OF SPECIAL EDUCATIONAL NEEDS

It was a long time since the speech therapist had asked Wendy, "Do you mind if David is Statemented?" "Why should I mind?" Wendy had wanted to know. She wondered how she could mind about him receiving a Statement. David was now due to start school in six month's time. With an Educational Statement the school would receive funding, providing David with the support he needed. He would require extra help in Reception Class. However, the question had to be raised. Parents sometimes found it difficult accepting a Statementing label for their child. The Statementing process would be carried out by the local authority and normally took six months. There was just enough time. Some weeks later the process had not begun. The local authority was informed. David's Statementing process was placed in the fast track. It was urgent. Would it be ready in time for him starting school?

In April 1997 the community paediatrician gave a Health Service notification of Special Educational Needs. The report stated, 'Developmental disorder affecting communication and behaviour... David's difficulties with communication, social interaction and behaviour will cause significant problems in a classroom setting without considerable extra support.'

The speech therapy report at the same time included, 'David presents with a developmental receptive and expressive language and phonological disorder. His progress is slow in all areas of play and communication... his progress appears to be hampered by his limited co-operation.'

Ed and Wendy thought they had handled the introduction of a new brother well. There was no sibling rivalry, for David received most of the attention. Peter obligingly slept like a baby. Apart from sleepless nights, life was quite civilised. Peter woke up regularly through the night. He needed lots of extra feeds. Coping with sleepless nights and no evenings, plus an energetic child in the daytime, was difficult. David needed constant attention. He was kept busy with activity after activity, it was the only way of containing him. His mum watched him closely; he needed moving quickly to each new task. He didn't play houses, play in the garden, choose his own toy. He needed constant adult input.

He didn't realise that climbing onto mum's lap would squash baby Peter and it was difficult persuading him to sit beside her. He had no idea that Peter might object to being sat on. David seemed to have more than his fair share of elbows, knees and feet. His head impacted like a rugby tackle. He was oblivious to other people's shins and feet. He never understood, "Gently, David!" Wendy tried to protect Peter and she concentrated on keeping them apart. On 22nd May David was assessed at a different speech therapy unit. A series of one-to-one sessions was booked through July. Wendy felt there was real progress.

The family took their first holiday together since Peter's birth. Nervous travelling with a small baby, they filled days with David-friendly activities. It was the best way of ensuring the whole family had a peaceful time. Taking a picnic, they travelled on the Lakeside to Haverthwaite Steam Railway in the Lake District. The day

Norfolk's Beautiful Child

after their return home, David celebrated his fourth birthday.

PART 6 STATEMENTING AND DIAGNOSIS

That summer he had an outdoor climbing frame; to burn his excess energy. Wendy hoped to enjoy summer in the garden, looking after her small baby and watching David play. Indoors, he was making elaborate towers of bricks, always with red roofs. He lined up tracks of bricks. Sometimes the bricks were houses, and sometimes railway tracks. Peter was put in his hang-up bouncer intermittently. It was never safe for him when David was home.

An appointment was booked with the educational psychologist for 11th July. She visited David in nursery, spending an hour assessing his behaviour, play and the way he interacted with other children. She followed up the appointment with a home visit, discussing her impressions with mum. David was interacting with other children at nursery, in a primitive way. He was oblivious to approaches made by other children. His reactions were boisterous. They tried to make contact, but quickly grew wary. He didn't know how to make contact, he used physical rough and tumble. He couldn't ride a trike. His parents had encouraged him to ride, time after time. He was never able to pedal. How did a child learn to push pedals for the first time? He didn't do things other children tried quite naturally. David was happy with pushalong toys. Wendy thought he wasn't interested in his trike. The educational psychologist was recording this as a stage of development. He had reached the pushalong stage. He hadn't achieved the pedalling stage, more normal for his age. David's movements were immature. He ran like a younger child, without a maturer straight run. David

appeared cute. Now his parents realised he was displaying characteristics of a younger child. He had not reached his expected developmental age. Nursery staff mentioned he did not use the climbing frame. Ed and Wendy felt confused, for many times in the playground he made a beeline for the climbing frame. They encountered problems when other children used the equipment. David was unaware of other children and his parents watched him like a hawk. Was he finally learning caution? Perhaps climbing was more difficult than they realised. They couldn't compare him with other children of similar age, for any social encounter was difficult. The couple noticed his developing physical skills, they saw improvements, but they could not compare him with other children. Professionals referred to age-appropriate play. The interview with the educational psychologist was an eye-opener. A written report was prepared for the local authority.

'David is an attractive little boy... unable to use the pedals (of a pedal toy) and used his feet to scoot along... although he runs around quite confidently he still seems to run around a broad base as a younger child does...

David... is beginning to attend to an activity of the adult's choice but is difficult to control... David's comprehension is better than his expressive language.'

David now had two working definitions; they were basic labels. Although they did not explain why David was different, phrases from professionals gave his parents something they could quote to friends and family. David had an 'expressive language disorder'. He also had 'developmental delay'. At least they had a label for the type

of problem they were dealing with. Ed and Wendy thought it was just a matter of time before problems gradually disappeared. David had regular speech therapy sessions. His language improved slowly. Soon he would start school. It would not be long before he learnt to communicate. Increased social and educational support would ensure their beautiful little boy developed normally, his differences would become less noticeable. Frustrations would disappear as communication skills improved.

ASSESSMENT PROCESS

The Department for Education had issued a Code of Practice on how they could meet special educational needs. Stages 1, 2 and 3 were met within each school. Stages 4 and 5 were arranged by the local educational authority, through assessment and possible Statementing. One in five children are likely to have special educational needs at some point during their time at school. One in fifty will have more complex learning difficulties, needing specialist help over a longer period. This group requires detailed assessments and may need a Statement of Special Educational Needs.

Each professional wrote a report on David. They had a deadline for returning their forms to the local authority. Everything was finally compiled into a Statement of Special Educational Needs, with particular recommendations for David. His parents were informed at each stage. They received copies of each report, and given opportunity to query or add to what professionals had written. These comments were included in the final Statement. The name of school, or recommendation for schooling, was left blank. This was added at the end of the

process. Nursery gave a progress report at the end of their year, when David was just over age four. Comments included, 'David prefers to play alone... can become boisterous with other children... has difficulty holding a pencil... loses interest quickly... prefers to play with a train.' The only tick he received under the 'very good' column was for 'plays alone'.

A medical examination was carried out on 25th July 1997. The report prepared for David's assessment, during the Statementing process, indicated, 'He has great difficulty in expressing himself, and although he makes lots of attempts at talking, his speech is often unintelligible. His language difficulties lead to frustration which result in disruptive behaviour and defiance in following instructions.'

A speech therapy report was prepared, as part of the formal assessment procedure for the Educational Statement, 'David fails to observe word boundaries so that his words tend to run together. This frequently gives the impression of jargon, i.e. meaningless words and phrases. However, it is likely that unintelligible utterances do actually have meaning.'

Wendy had visited local schools, applying for a place for David in Reception Class. Wendy thought it better to explain to the Headteacher about David, before he arrived for the new term. The health visitor volunteered to accompany her on the visit. Between them they could give a fair description of David's difficulties. His mum was relieved to have a familiar face in the room. It gave her confidence. Wendy wrote a list of key issues. The

Headteacher was extremely positive. She was happy to see something in writing, giving a better picture of David. Wendy asked about the school's policy on special needs. Each school had this document. It explained their approach to special needs and how they aimed to fulfil their targets. Parents could ask to read it.

His mum found it difficult imagining David in a large Reception Class. He would be four-and-a-quarter when he started school. Was he ready? Would he cope in a First School? She tried to prepare David for transition from private nursery to Reception Class of a mainstream school. She looked forward to the day David would arrive at school in his new uniform. She would be one parent among many, collecting her child at the school gates. They extended David's time at nursery through the long summer holiday. "Big boys go to school," mum told him. She said he would move up to big school and wear a uniform. Big boys went to school, not nursery.

POTTY-TRAINING

David was not potty-trained. It made a huge difference, from a school's perspective, if he arrived wearing nappies. Wendy had tried potty-training twice already. The first time, she was determined to have David out of nappies before the new baby arrived. David had no problem sitting on his potty, producing anything was a different matter. She read baby magazines and other books. He wore pants. There were stains on the carpets every time. She tried pullups, he treated them like nappies. His poo was not regular. Both parents grew fed up scraping pants clean. They gave up and waited until after baby was born. Now aged almost four, David was far from ready for toilet-training.

Before end of term, professionals discussed David's schooling. His Educational Statement would not be ready for start of term. They needed funding to provide David with one-to-one assistance in the classroom. David would need a great deal of attention, enabling him to cope with everything in Reception Class. Wendy hoped to toilet-train him during the school holidays.

Wendy met the school nurse. A series of home visits were arranged, helping David with his toilet-training. He sat happily on the toilet, as instructed. She encouraged him to produce, explaining the technique with a few grunts. His mum found it impossible to reproduce the grunting noises in later practise sessions. David was oblivious to their purpose. By the end of school holidays, they were no further forward. David could happily sit on a toilet or potty. He sat at all the correct times of day, around mealtimes. Any indication of performance led to

congratulations and treats. Wendy gave him drawings to colour in, as instructed. He wanted to complete each drawing at once. He covered the entire picture in his favourite colour, red. His mum tried wall charts. He liked sticking on shapes. He wanted red shapes. He thought he could pull them off and re-stick them and was very upset when stickers lost their adhesive. If anything wouldn't work, that was the way David had to try it. Simple things caused him huge frustration. Wendy felt she was talking to a brick wall. He could not understand when something was impossible. He had to make things work his way. Rewards made no difference to his performance. Wendy got fed up with piles of washing. Both parents could no longer face wet and stained carpets, David was not ready for toilet-training.

STARTING NURSERY SCHOOL

September arrived. Wendy tried to smooth the transition between nursery and big school. She had talked to him about leaving nursery and, as a big boy, moving to school. She hoped the message would filter through. David would begin, not in Reception Class, but in nursery. During the holidays, his mum pointed out the new building within the grounds of the First School. David talked about big school. Wendy pointed out the red roof, David loved red roofs. He loved anything red. The family took David for a daytrip on the London train. Over a year later he was still talking about London trains with ten carriages. He again wanted to "See the Queen". The family's visit had coincided with the tragic death of Princess Diana. In London they visited Buckingham Palace and David stepped around huge

crowds and an ocean of flowers in front of the palace gates. Next day the pavement was impassable.

School opened for the Autumn Term. Later, Reception children began their first day at school. David's last day at nursery was on 12th September. Wendy counted the days until he could move to little school. Time dragged. His mum wanted to spend more time with Peter, now aged eight months. David took all her attention at home. Wendy breathed a sigh of relief when nursery staff arrived to see David. They visited each child in their own home first. He was talking much better since Peter's birth, but he was extremely difficult to understand. Sometimes it was impossible getting messages through to him. Wendy explained to staff about David, she wanted them to be prepared. David made a beeline towards his new support worker.

David's Statementing process was completed at the end of September 1997. It's objectives were, 'To extend his phonological, receptive and expressive language skills; to develop his fine and gross motor skills; to extend his listening skills and attention to task; and to extend his interactive play and develop his social skills.'

He was given a Statement of Special Educational Needs. There was opportunity for both parents to read through the draft report and add amendments. A Statement meant finances were available, so David would have the classroom support he needed and regular review meetings. He wasn't ready to move to Reception Class. Nursery was the best place for him. He could play happily in an informal environment, learning skills for when he

moved to school. Mum told David he would move to big school later, "When you're a big boy." David wanted to move up to school straight away, but his parents had no idea when that would be. When would he be ready? It was always over the next horizon. He was happy in nursery and enjoying himself. There was no hurry. Nursery was the best place.

On 3rd October he arrived, dressed in his optional school uniform. The jumper was his favourite colour, red. It was his first day of term. He was a new boy, in his new school uniform. However, mum was not a new parent at the school gate. David was in nursery school, with children up to a year younger. How long before other parents realised he was different?

BEGINNINGS AND ENDINGS

David's new series of speech therapy sessions continued through the Autumn Term. He was in a mixed group he enjoyed, but getting him into the room was another matter. In the play area he opened and closed cooker doors and washing machine doors. He tucked dolls into bed. He never used the blackboard at home, but now he was fascinated. There was one tiny piece of chalk. Ignoring other children playing alongside him, David had to finish his game. Start of session proved difficult. He sat on the red chair, it was always a red chair. Speech therapists persuaded David onto another chair. "David. I need that chair. Larger bums need larger chairs!" The new approach worked. David gave up his favourite red chair. He grew less rigid about a particular chair. Given a choice, he would always prefer red.

Norfolk's Beautiful Child

All too soon, half term arrived. Shared time with David and Peter was a nightmare. As Peter grew mobile, it was difficult keeping them apart. Peter was learning to crawl. He could reach David's toys, David's games, David's arrangements of bricks and houses. Mum wondered whether he had finally gained a strong dose of sibling rivalry. She now realised lack of earlier problems was simply because Peter didn't encroach on his world. Now he reacted against his small brother with a vengeance.

Parents booked David into his former nursery to cover the holiday period. Did he remember his time there, half a term earlier? It was difficult to have a conversation with David. He gave no clues he understood what mum told him. On the first day, his beaming smile said it all. Extracting him at the end of the day was hard work, if David wasn't ready, it was impossible to remove him. Facing other parents was difficult. Their children would happily leave with mum or dad. David needed advanced warning, change was hard for him.

During half term week a volunteer was organised through Norwich Family Friends, providing support for mums with young children. Kate was a retired headteacher, with experience of special needs children. Soon she was a regular visitor, playing with the boys as they squealed in delight. Wendy watched, exhausted. Before long, her support proved invaluable.

David returned to school nursery after the holidays. It was embarrassing, arriving or leaving with him. One day he crawled underneath the bookcase and refused to come out. He didn't want to go home. That same morning, his

mum had talked him through his early routine, encouraging him to attend nursery in the first place. Other children sat in a circle, waiting for parents to collect them. David was last to leave. Nursery staff needed their lunch break. Professionals and parents agreed David had a problem with beginnings and endings. It was the same story at his speech therapy groups. Nursery staff said David could arrive before other children and they settled him into his first activity. Wendy collected David last. Life gradually became easier. Soon David happily hung up his coat and bag on a chosen peg. He selected his own name from a large collection arranged in front of him. He chose his first activity. One morning, he chose a tabletop activity, neat portions of playdough were set before each place. David collected together his favourite red stuff, piling it onto his own place; he sat down and began work. Sharing was meaningless to him. Later he would need to learn that playdough came in other colours and that other children wanted to join in.

There were regular meetings with nursery staff. They explained the latest plan of action, encouraging David to acquire nursery skills. David could play happily on his own. He was oblivious to approaches from peers. He did not learn from shared activities. There were times David reacted strongly, making other children wary of approaching him. Staff observed him, trying to find a trigger for his challenging behaviour. David remained unpredictable. There were no obvious triggers. He would not join in storytime. He wasn't part of the group. Encouraged to sit down, or join in, he wouldn't stay. He had a quiet time looking at a book. He sat near to the group, but wouldn't join in singing.

Norfolk's Beautiful Child

SIBLINGS

Arriving a few minutes late for his speech therapy one morning, David moved quickly into the play area. The group had already adjourned into the therapy room. David continued arranging dolls, furniture, doors and books. He refused to budge. With great difficulty, mum picked him up. David was heavy. Wendy picked Peter up in his car seat and staggered through the childproof gate. David was dumped in his seat in the therapy room. Winded, his mum caught her breath. She was shaking. "What a knowing look," exclaimed the speech therapist, noticing Peter's expression. "If he could talk!" Wendy wondered how much Peter would have to put up with, as sibling of a special needs child. Managing two children was difficult. With a four-year-old acting as a two-year-old, sometimes it was impossible.

The couple cleared away baby equipment. Mobile toys filled the house. Every toy had to be more than babyproof. It had to survive rough-handling from a four-year-old. Peter's travel cot/playpen was in constant use - to protect Peter from his older brother. Peter stood up in his playpen. He wanted to chat. Toys were less interesting than opportunities to socialise. He didn't want to stay in his playpen. He wanted to reach every toy in sight. David had been happy in his playpen as a baby. His parents recognised this new budding toddler was behaving very differently from his older brother at the same age.

David discovered a new game. Tearing apart his night-time nappy, he dropped flakes of snow downstairs. A drift of super-absorbent crystals gathered in the hallway. Snowdrifts continued night after night. His parents

discovered how sodden those crystals could be, they crunched on them everywhere. Eventually he stopped. His parents thought David had learnt his lesson. Months later they realised their mistake. David had simply forgotten and moved onto another game. It would repeat without warning, months later. Ed and Wendy were fed up with disposable nappies - David had his own way of disposing with them. His mum regretted the snow storms in 101 Dalmatians.

Coping with a special needs child was hard. Wendy could see no answers. She didn't know whether a condition existed which matched David's behaviour. Some days he appeared hyperactive, other days autistic. Nothing was consistent. Were there hereditary factors? Was it her fault? Were his language delays due to major family tragedy in the run-up to his second birthday? They had done everything they could to protect him. He didn't seem anxious or insecure, he was an extremely happy boy. No-one gave him a label. Wendy found it difficult recalling his toddlerhood; why was he different?

Wendy talked to the speech therapist. She listened sympathetically. She was reassuring, professional. She emphasised that his parents were doing everything they could. Wendy felt encouraged; briefly. She had expected David's behaviour to improve as his language developed. She remembered times David's behaviour was explained as frustration. Why was his behaviour worse, not better? They had another child to consider. What would happen if they couldn't contain David?

David's speech was improving. Speech therapists noticed David refusing to answer questions he knew; he didn't want to fail. Group leaders ensured easy questions so children were rewarded with success. Did David fear failure? He never gave the impression of being afraid of anything. Slowly, his language improved. Newer words didn't have endings dropped off. Earlier words remained firmly fixed in single syllables, with endings missed off.

EXTRA HELP NEEDED

Further assessments were necessary, because David was receiving maximum care available at his age. Funding provided an assistant four nursery mornings per week. It would not cover longer mornings in Reception Class. David was out for two-and-a-half hours at a time. It didn't seem very long, when he was back home with Peter for the rest of the day. School sent reports to the local authority. It would ensure funding for a fifth morning at nursery from the New Year. David was not yet of statutory school age. School had to present a strong written case to receive extra funding. Wendy found it difficult having to act as a pushy parent. David needed more time in an educational setting. His peers had now been in Reception Class for a full term.

Wendy thought wistfully about the fast-approaching New Year. Other children were moving to full-time at school. David should have been among them. Starting school was a distant dream. Goal posts kept moving. David was better placed in nursery, yet routine revolved around David, not Peter. David's speech therapy report at the end of the year indicated, 'Greatly increased listening and attention skills and ability to respond to adult direction...

expressively he is using more complex language structures...'

Particular areas of concern included difficulty understanding him (he reduced words to one syllable, with endings dropped off) and periods of non-compliance and aggression to other children.

Sometimes both boys played together and there was relative calm. David began to line up every toy box he could find behind his pushalong Thomas, while the red car became James. Everything had to be a train. He lined up boxes as carriages and Peter happily sat in one. Every sentence David uttered was intelligible, "Bay Pee's in the truck", "Daav's got James", "Pee's got Thon's". David was excited by his neat arrangement of trucks and trains. On this occasion, Peter was happy to fit in with David's game. Peter liked climbing into boxes. Problems began when Peter was bored or decided another game would be more fun.

Ed put up a stairgate in the living room doorway. It would better contain Peter. His parents showed David how to open and close the door as a big boy, he was encouraged to use it. David extended his game of houses, the stairgate became his door. He needed the door open and would not let it shut. The stairgate naturally swung closed, David squealed in frustration. He needed the doorway open. It was easier showing him how to put a cushion in the doorway, so it would not swing closed. The gate stayed firmly open. David stopped screeching, he would not allow the gate to close. When his parents locked the gate in place, so Peter could explore safely, David shook it forcefully. It fell to pieces. As a constant source of frustration, the couple

removed it permanently. David could not cope with it closed. Peter was returned to his playpen. David leaned into it and Peter pulled his hair. David giggled with delight, he wanted his hair pulled. Every time David was at nursery, Peter was able to explore. It was always too short.

The family enjoyed a quiet Christmas and admired Peter, who was learning to cruise around the furniture. David spent hours trying to decorate and clear the Christmas tree. On 3rd January they had a small party for Peter's first birthday. His pushalong trolley of bricks was soon used by David to line up with his trucks and trains. Peter's sturdy pushalong car had to be David-proof. David's own tractor and trailer were ignored. Peter rarely got an opportunity to play with his toddler car.

A new series of speech therapy sessions continued with one-to-one therapy. His latest speech therapist was surprised. She had met him when he was three years old. "He was improving then," she declared. Wendy could no longer remember earlier improvements. It was a long time ago, and much had happened since then. She had seen David over a period of several weeks, during the Summer holidays in 1996. Now he was four-and-a-half. As his mum, Wendy felt she was to blame. She told the speech therapist how David learnt and unlearnt. His parents were no longer convinced when David learnt something new, for it did not last long. They remembered nappies torn to shreds, taps left on, insistence on David entering a door first. Always. Difficulties in protecting Peter from his elder brother escalated. Behaviour regressed to previous patterns, time after time. His parents felt they were banging their heads against a brick wall—frequently.

TOILET-TRAINING

On 21st January Wendy met the nursery headteacher. David now had five nursery mornings each week. Nursery targets for David in the New Year included: working towards toilet-training, helping David play alongside other children, helping him to listen and join in storytime, and encouraging him to join in planned activities. He made some progress in each area. He was also 'beginning to take part in more of the planned activities, but still in his own time.' At the meeting the teacher told his mum, "Tell David he must come to nursery in pants now." At home, David was informed "Nursery wants you to wear big boy pants." Next morning, David arrived without his usual nappy. There was no reaction from him at all. As a big boy, nursery wanted him to wear pants. David was ready. He also had excellent bladder control. In his nursery report at that time it was recorded that he arrived at nursery without a nappy, 'however he has never used or asked for the toilet'.

It was many months later before David would use the toilet away from home. On holiday he would dance around on the spot before his mum could persuade him to use a public convenience. At his former nursery, during school holidays, he lasted all day without asking for the toilet. He was taken at strategic times of day, but never performed. The second he was out of his car seat at home, he ran indoors to the toilet. Fast. David was less interested in trains. He returned to them at regular intervals, but everything now became a house. All Peter's pushalong toys were walls or doors. Piles of bricks were never towers,

they were walls or chimneys or roofs. Peter grabbed interesting toys and David screeched as his walls were destroyed. He pushed or pulled Peter out of the way.

David's speech therapist suggested Wendy apply for Disability Living Allowance (DLA). She explained it could help pay for extra help during school holidays, or for respite care. Wendy thought it was strange applying for DLA. They had a perfectly healthy child, hadn't they? Getting him from A-B was difficult, but he wasn't in a wheelchair, he didn't look handicapped. Other people never treated him as a special needs child. Sometimes Wendy thought it would be easier if they did. The advice was useful and some time later they applied. It was hard to think of David as disabled.

REFERRALS

The speech therapist referred David to the consultant community paediatrician at the Norfolk & Norwich Hospital. The referral summarised a variety of David's behaviour, 'David now presents... extremely erratic behaviour during therapy sessions, at nursery and at home... His behaviour becomes disruptive and obsessive... During therapy sessions David may be extremely inattentive, difficult to focus, strongly resisting adult intervention... Formal assessment is unreliable because of David's unpredictability.'

David grew increasingly difficult to handle, he grabbed handfuls of Peter's hair. He also leaned into the playpen and encouraged Peter to grab his own hair. David loved his hair to be pulled, he enjoyed it and it never hurt him. Was David trying to communicate with Peter, was hair-pulling the only way he knew? His parents found it hard to see it that way. David pushed Peter over in his playpen as he stood up, cruising around for toys. Peter chatted to everyone yet he was no longer out of David's range, or safe in his playpen. His parents packed it away. When cooking dinner, mum took Peter into the kitchen. David ran in and left the door open. "Let bay Pee out," he squealed with delight. Wendy strapped Peter into his high chair. It was the last safe place for him downstairs. Childproof now meant Peter had to stay in mum's sight at all times. He was not safe near his brother, David had no sense of what he should or shouldn't do. He had no sense.

Nursery encouraged him to join in tabletop activities, work with playdough and construction toys, play with one other child and improve his fine motor skills

(scissors, drawing, painting). Although he took part in his own time 'he is choosing these activities more frequently... (he) can be encouraged to make a particular model.' He allowed other children to play near him but he 'rarely plays co-operatively'. Using scissors was more difficult.

After half term, David was poorly and needed two more days off nursery. On his return, Peter was ill. David's first morning back in nursery was also the day the educational psychologist was observing him. He was far from well and a lot calmer than his usual self.

SCHOOL REVIEW MEETING

A review meeting was held at nursery on 25th February, involving all professionals concerned with David. Each provided their own reports and insights. Present were the headteacher, class teacher, learning support assistant, speech and language therapist, statement and assessment officer and the educational psychologist. Both parents were also there for the lunchtime meeting, aware that nursery staff had a tight schedule with a morning and afternoon nursery class plus the hour-long meeting. Wendy found it nerve-racking. However, it was an eye-opener, listening to each specialist presenting their perspective on David's development. A member of nursery staff played with David. Ed watched over Peter, who was now mobile and fascinated by everything in sight and within reach. Wendy began to wonder whether David had a condition like dyspraxia. He was certainly clumsy.

The nursery teacher explained David's varied progress. She spoke of difficulties relating to other

children. She listed activities that encouraged him to integrate. It was a familiar picture. They had informed Wendy of what they wanted to achieve with David. The report from his time at nursery was typical of David's behaviour and fixations, 'David frequently displays obsessive behaviour... he becomes aggressive when other children move his 'door' This obsession with lining things up extends to chairs and other toys.'

He had particular speech difficulties, dropping endings off words. His main problems were no longer a speech therapy issue. He learnt new words more accurately than early words. These continued in the primitive way he had first learned them. David could complete exercises when he chose to, his language would continue to progress.

For the first time his parents heard professionals using a new preliminary label. Autism was mentioned; they discussed Asperger's syndrome. The couple were not surprised. Ed had brought home book after book from the local library. They had read about the condition in detail. David fitted a lot of the descriptions for autism, particularly for Asperger's syndrome. He did not fit the whole picture. He was untypical. David had beautiful eye contact. He could relate quite well to adults, one-to-one. He had enormous problems relating to peers. His parents knew David was intelligent. Perhaps he fitted the label of Asperger's syndrome? Reports they had read suggested children with this condition learned to talk early. David didn't. Delayed language development could be an early indicator of autism. David was clumsy. Did he have high functioning autism? The mixture of labels was confusing.

The couple knew he had all the social problems that accompanied autism, they were less sure whether he was lacking imagination. He was intelligent, yet he didn't play as other children. He lined up bricks and trains and had a fixation on building houses.

The educational psychologist, who chaired the meeting, seemed confident that David probably had Asperger's syndrome. She spoke clearly and with sensitivity. It was a label the parents expected; it was still a huge shock. At last a professional was confident about giving a label; for Ed and Wendy, it was a familiar term. She wasn't using standard labels, because she knew of untypical cases of autism. David had beautiful eye contact—that was possible with autism. David didn't withdraw from physical contact—that was possible too. David could relate well to adults—but they gave him more individual attention.

The educational psychologist's report indicated, '(David) plays alongside other pupils, but shows little awareness of them... (He) does everything on his own terms and it is impossible to persuade him to join in an activity not of his choosing.' She felt that aspects of David's behaviour fell within the autistic spectrum, which would need further investigation by a paediatrician before an official diagnosis could be given. David's appointment with the paediatrician was already booked. A follow-up meeting was arranged at school, when they knew results of the hospital appointment. It was clear David's diagnosis almost certainly fell within the autistic spectrum, probably labelled as Asperger's syndrome.

It was recommended that David's nursery place should be increased to fulltime in the summer term and Social Services could provide respite care for the family. The educational psychologist recommended other activities to help David's development: structured tasks, increased tabletop work and introducing new skills, developing fine motor skills (pencils, playdough, etc.) and encouraging co-operative play. The couple were glad to have a probable label for David, a professionally recognised condition.

RESPITE CARE

Wendy thought there would be a sense of relief now a diagnosis was so close. Instead, she reeled under the shock. She glanced at David's beautiful picture as a blond-haired one-year-old with a beaming smile. She couldn't bear to look at it. She began to wonder whether his smile had been a specific smile or was he smiling generally at the world? Did his smile not focus on people? It was an impossible question. She wondered how many of their precious memories, of a beautiful baby wearing his sailor outfit, would remain now David faced this diagnosis. Ed remained calm and down-to-earth. He brought home books from the library. Wendy read everything she could about the condition. She read until she could read no more. It was an enormous shock to consider their beautiful child had a major lifelong condition.

Wendy had another chat with David's speech therapist, who suggested, "Have you considered respite care?" Social Services could provide respite care, following a referral. What sort of respite was on offer? His parents didn't want David away from home for long. They wanted

to continue as a family. Perhaps after a break, it would help them cope. It might be good for David. They agreed to referral and waited for another professional to contact them. Every meeting was a waiting game.

They waited for the hospital appointment. They needed an official diagnosis. They were no longer in any doubt about the label's accuracy, yet without a label there was hope David might get better. The couple knew something major was happening with him. Nothing less than a diagnosis could help them face the future. They needed to learn to cope with the child they actually had; every social situation was difficult, now it began to make sense. David had a medical condition.

Wendy cancelled Peter's planned MMR Immunisation. She needed to find out more about risks before she could face taking Peter to surgery for his 13 month jab. Newspaper headlines at the time raised questions about the Measles, Mumps and Rubella vaccine and whether there were links with autism. Wendy needed to be certain. Peter was a beautiful, normal little boy. He had survived a difficult early delivery and weeks in special care. His mum couldn't imagine living with two autistic children.

MEETING A PAEDIATRICIAN

Both parents took David to a day clinic to meet the consultant community paediatrician, following referral by the speech therapist. After the meeting (on 20th March 1998) the paediatrician reported back to David's GP: 'His language has improved quite considerably with help from speech therapy although it is still rather stilted and mechanical. In other areas he has quite good skills. He appears to be an intelligent boy and is good at jigsaws, at working out problems which do not involve social interaction or use of language and his motor development, although a little clumsy, is basically all right... David's parents feel that he may have an autistic type of disorder. I agree with them although there are many positive signs... More importantly he is an intelligent boy and is able to learn how to react to unusual social situations.'

Further tests were arranged for two months ahead, checking for Fragile X syndrome through chromosome analysis. He would also be given an EEG under sedation. Fragile X syndrome and epilepsy are sometimes present in association with autism, above the averages for the general population. The paediatrician recommended behavioural management within the school environment. He also arranged a referral to the clinical psychologist, to help with David's management at home.

Talking with other mums from a voluntary support group proved informative. One had already applied for Disability Living Allowance. It encouraged Wendy to try. Local agencies could provide assistance with form-filling. Wendy filled in pages and pages of information, relating to the nature of David's condition and how this affected 1) personal care and 2) mobility. Comparison had to be made

with an average child of similar age. The mobility component applied to children over age five. All young children needed lots of parental attention; David needed much more. Dressing was difficult, mealtimes were hard and David was not safe on the streets or in any public place. Some time later, the family heard that their application had been successful.

At Easter the family holidayed in Dorset. They visited the on-site swimming complex once. Until now, David had been a water baby, now he sank like a stone. He was panicky. Peter had little chance to relax and enjoy the water. He clung tightly to mum. Coaxing David back into the water proved difficult. A small girl walked past the edge of the pool, a detour to the changing rooms. Instantly, David ran, grabbed her bag and hurled it into the pool, screeching with delight. He was grounded and marched back to the changing rooms, before he had time to consider the neat row of chairs, bags and shoes within reach. All future swimming trips, David's second favourite activity, became an endurance test for the family. However, David had fun at Beaulieu, a nostalgic theme park. They travelled through time in revolving cars, climbed aboard a topless double-decker bus and spun around the track on a monorail train. Staying in a self-contained holiday chalet, the only problem was a gap between carpet and floor in David's room. He discovered floorboards. He was fascinated by the threadbare carpet. At the end of the week, floorboards were clearly visible. Puppies in the film 101 Dalmatians had escaped through a gap between floor and skirting board. David had learnt a new fixation.

At David's former nursery, they noticed changes. He could settle down and enjoy tabletop activities. Late in May his Statementing Review Meeting was held. Nursery targets were extended to encourage him to work alongside other children through sand and water play and learn to throw a ball. His targets also included pedalling a tricycle, joining in rhymes and songtime. After the Review Meeting extra targets included: gross motor skills (jumping, throwing, kicking), teaching David to write numbers up to ten and extending co-operation through joining in rhymes and songs. They would also encourage playing with one other child and taking part in one tabletop activity as directed (before choosing his own). The main aim was addressing David's behaviour, the difficulty of pre-empting an outburst and the concerns over restraint methods and protecting other children—problems for both home and nursery. Further speech therapy was arranged in April and May and observation at nursery. A new speech therapist would visit him regularly when he moved up to First School.

Wendy walked to nursery with David whenever she could. It was difficult, encouraging David to keep moving. Peter was secure in his pushchair, but David stopped to inspect every drain along the route. He wanted to pick up twigs and post them through gratings. They were Pooh Sticks from Winnie The Pooh. He was oblivious to roads and traffic. The best way of keeping him moving was by shared commentary. David read house numbers. Soon he could count and recognise numbers up to a hundred. He read ahead odd or even numbers. He always got them right. Wendy knew it was a bad day when David counted every square on each cover. It took fifty, instead of the

usual twenty, minutes to get home. One day, David remembered a phrase he had heard recently. Quite unexpectedly, he stated, "Cats have sharp teeth." Wendy wondered what he had been learning at nursery. A moment later he repeated, "Dogs have sharp teeth." Now he had developed his theme. "David has sharp teeth," he declared, with complete enthusiasm. Wendy tried not to laugh. She could vouch for the latter comment. He had sharp teeth, as both parents had found out to their cost. He had sharp elbows, sharp knees and feet and a hard head. Happy with his theme, David continued. "Auntie Jo has sharp teeth." Her name would do as well as any other on the subject, since they were visiting her next weekend. David was extremely happy with his conversation. He had received lots of praise and attention as he talked. Without another word from mum, David concluded, "Auntie Jo has very sharp teeth." Wendy wondered whether she too would see the funny side. Chats with David always followed unexpected routes. David was learning how to have a conversation; it was logical, but far from accurate.

David returned to his game of snow storms with a vengeance. Every night he scattered sodden nappy crystals around his bedroom floor, or down the staircase. Soon he had extended his game to include books. Instead of posting them, he began to tear them to shreds. One evening there was a trail of destruction. His mum recognised a new game. He tore paper into tiny pieces across his wooden track. The trains were facing a landslide at the mine. Thomas The Tank Engine had nightly landslides, rain and snow. When David had the chance, he also used beakers of water to create floods.

Norfolk's Beautiful Child

On 29th April 1998 David received his first visit from a social worker. The speech therapist had referred him as an urgent case. Some weeks later, his parents were told their social worker was on longterm sick leave. A new social worker received referral details for David and two days later an initial meeting was held. His mum expected her to stay an hour; she was there two hours later. "He's not having a bad day," Wendy told her. David spent the next hour disproving that comment. He was indoors. He was outdoors. Nothing contained him. As his mum left the room, David lunged at Peter. If this was a good day, the social worker was concerned. He wasn't having a bad day, but then David's good days were like an average child's bad days.

Wendy found it difficult being observed, although professionals had to assess David in his home environment. Faced with another assessment, she found it hard to think straight. How could she act as normal? Next day, she received three phone calls from the social worker. Her calm, professional manner had left Wendy feeling that her child wasn't too bad after all. Perhaps he was mild, compared to others the social worker dealt with? "I was shell-shocked," she told mum. She had been told that this was not one of David's bad days. This was a family under severe stress, they needed support—and urgently.

At last, Wendy felt they had moved into fast track. Their case was treated seriously. Professionals had to consider ways of supporting the family, providing help and respite care. They also had to consider Peter's protection—from David. Follow-up visits were arranged monthly, organising short-term respite care. Meetings were held

when David was out at nursery, so both of them could think.

HOSPITAL DAY CASE

David's hospital appointment finally arrived. Food and drink were restricted. Wendy tried to explain to David about hospital. Kate arrived to help, geared up for a day in hospital with David sedated. Calmly David lay on the bed while a doctor talked with him and administered a sedative. Soon he wanted to explore. He wandered around like a drunken man and Wendy and Kate spent hours wheeling him around the ward in a pushalong car. How long did a sedative take? When would David be unconscious? They were both comatose long before David admitted defeat and staggered onto the bed. A peacefully sleeping David had missed his appointment slot. Despair turned to elation as they rushed David into a cancellation slot. He was wheeled through long corridors; then a small cap covered with electrodes was attached, by the paediatrician, to David's head. It looked remarkably like a swimming cap. As Wendy sat down to watch the EEG scan, David raised his head and looked around with bleary eyes. It was like a film with a zombie theme. Wendy balanced on the edge of his bed, "Go back to sleep, David. It's not time. Not yet..." He was wide awake and ready to leave on foot, as his bed was wheeled back through long corridors. Kate cuddled him on the bed, as Wendy breathed a sigh of relief. Nurses had to carry out blood tests on a fully conscious child. They used every distraction method they knew, but Wendy and Kate had to physically restrain him. He was very strong. "Please don't. Please don't do that," David pleaded. They were glad when they could take him back home and feed him. It was a very long day.

Ed and Wendy awaited hospital test results. Meanwhile, they had a label for David's condition. Wendy

noticed a pattern to other people's reactions. "It must be a relief," they said. "At least you have a diagnosis." Wendy began to realise some people wanted to be reassured. They believed what they wanted to believe. Yet the diagnosis was not good news. It could never be good news. Their son had a lifelong handicap. First, they had to face shock. Their son was not normal. He would never be normal. The implications were enormous.

Respite care was provided through weekly trips to a childminder, organised through Social Services. David met Ann on 9th May and was fascinated by dolls' houses, train sets, puzzles and a large garden. Peter would have liked to stay too. Every Monday afternoon, David enjoyed his favourite dinner, such as fish cake and chips with jelly for pudding. Ann always knew what food children liked. On car journeys he developed a new fixation. "That way! Not that way!" he screeched. At traffic lights it was always, "Go now!" If Wendy varied her usual route, David panicked and screeched. Loudly. Wendy learnt to talk constantly to him as she drove. She talked about traffic lights, main roads, other cars. She warned David before she turned right or left, or went straight on at the roundabout. "It's the wrong way. Go back!" Weekends were fraught. David needed constant attention, even on a car journey. "Stop talking!" he screeched. Soon music and conversation became impossible. Protecting Peter in his car seat was a new issue. On a good day, intense concentration on David's needs worked. Soon David knew all about red, amber and green. He told mum when to stop at the lights. If he was forewarned, he would also tell her whether to turn left or right. David had to feel in control.

STATEMENTING REVIEW MEETING

A review and planning meeting was held on 20th May 1998 at school nursery. A review is carried out every year for any child with an Educational Statement. Attending the meeting were both parents, class teacher, speech and language therapist, educational psychologist, headteacher and a representative from Social Services under-fives team. The speech therapist reported that David could manage everything they asked, if he chose. Main problems were no longer speech, but behavioural.

A detailed report was provided by the class teacher. Many comments sounded extremely familiar to David's parents, 'He frequently displays obsessive behaviour... he sings 'Happy Birthday' every day at inappropriate times... David shows a keen interest in the weather and how it changes. He knows the days of the week... David has poor gross motor co-ordination, he is unable to pedal a bicycle and runs awkwardly... David is unable to use scissors and refuses help with this.'

All professionals agreed David would not be able to cope in a Reception Class. The educational psychologist explained to both parents what alternatives were available. Schools coped with children according to their level of special needs, from mild to moderate, or with severe learning difficulties. The educational psychologist recommended that his parents visit the local Special School, which had a separate autism unit. They all agreed that the best place for David was in an Assessment Unit of a local mainstream school. The school's placement meeting was less than a month away. Written reports had to be sent to the school urgently. Both parents needed to visit schools and agree to

the placement. They booked appointments immediately following half term. New phrases were added to David's Educational Statement: 'Diagnosis of autistic spectrum', 'Recognition of the need for a high level of support', 'Development of appropriate behaviour and raising David's awareness of danger.'

Two days after the school review meeting, David's mum attended a follow-up appointment with the paediatrician. Kate came too, looking after David in the play area. Wendy tried to think of the best questions to ask the consultant and watched Peter as he crawled around the consulting room floor. EEG tests came back negative, which meant David had no significant epilepsy problems at that time. The consultant confirmed David's diagnosis fell within the autistic spectrum. He said that if they wanted a more specific label, they could use either 'Asperger's syndrome' or 'high functioning autism'. He felt it was more important to assess David's strengths and weaknesses and provide the educational background and behavioural management to help him with his development. In the play area, Kate watched with some amusement as an older girl tried to play with the same toys as David. Neither child backed down. The little girl was taken aback that David reacted exactly the same as she did in a social situation. The other child had Down's syndrome. A few days after this appointment, David's chromosome tests also came back negative. He did not have Fragile X syndrome, a condition causing retardation.

CHALLENGING BEHAVIOUR

David's difficult behaviour escalated. Utterly frustrated, his parents reacted against a newly acquired swear word. Soon David was repeating it. Frequently. At the breakfast table he used an ear-piercing screech that echoed around the kitchen. Noticing his dad's response, David soon had a repertory guaranteed to provoke a reaction. Mealtimes with David had always been exhausting, keeping him in his place impossible. Now he had learned how to get his parents' undivided attention. Peter joined in screeching, beaming at everyone as he shared this new family interaction. When he wasn't screeching, David was pushing Peter, or bouncing on top of him. He chewed his own cuffs, his T-shirts, his jumpers. Soon they were soggy with puncture marks. His mum gave David a Teletubbies outfit. He was Po and wore his bright red outfit to pieces - it took him one week. Mum no longer took him on supermarket trips. It was easier shopping late at night. How much more could his parents face? Negative behaviour was multiplying daily.

Returning to school nursery on 1st June, he had an extra three afternoon sessions booked until the end of the school year. Professionals thought it would make a difference, now that David was in a nursery for five mornings and three afternoons. David met two different sets of children, one in the morning and another in the afternoon. For the first time he named another child—George. He had noticed not one child but identical twins; he saw a lot of "George".

Also on 1st June, David's first day back at nursery after half term, the the family received their first visit from

a clinical psychologist in the afternoon. Wendy had been keenly waiting this appointment. David's behaviour had grown particularly difficult by June 1998. He had a list of half a dozen difficult behaviours, each causing major headaches for both parents. They could see no improvement. David learned a new challenging behaviour almost daily. He did not drop one behaviour before the next arrived. They didn't know how the family could continue under such continuous onslaught. Life was a nightmare.

Wendy began to feel life was a constant round of meetings. Each professional had their own specialism, asked questions, filled out reports and recommended levels of support. They could not provide all the answers. At the end of the day, parents had to grasp the overall picture, ask for help and make a huge effort to understand what was best for their child. Professionals helped, but parents had to live daily with a handicapped child.

The clinical psychologist provided a summary of recommendations to deal with David's difficult behaviour. She loaned Wendy an invaluable book, Parent Survival Manual. It provided a wealth of personal experience from parents, covering every type of difficult behaviour that Ed and Wendy had already faced. Some caused particular amusement. The book explained how parents found their own solutions to problems. Wendy avidly read the book and learned that, at the end of the day, they needed to work out WHY David was doing something. Then they could find their own solution that worked. If it didn't work, they could try something else. In her report the clinical psychologist included a summary of recommendations.

'Planning a structured day, so that things are predictable, can be helpful. Sometimes, children with problems like David, even if language is good, find it helpful to be given visual support for their thinking. A visual calendar was recommended, with photos of common everyday activities. It would help to give a shape to David's day, to reinforce his thinking. David doesn't yet seem to understand that other people think and feel for themselves. This can lead to difficulty in predicting the behaviour of others, in understanding emotions, in developing a sense of guilt and a motivation to please.'

She advised that instructions should be clear and simple, avoiding explanations and telling David precisely what they expected of him. She also recommended they kept David and Peter apart, that they should not be left alone together. Simple locks or barriers should be used in the short-term, designed to give David his own space. David wasn't ready to learn how to relate to his young brother. There was plenty of time for him to learn about sharing—after he started school. A follow-up meeting was arranged at the end of a month, when David was out at nursery.

It was a great relief for Wendy. She didn't need to attempt the impossible. If David wasn't ready to learn how to relate with Peter, she just had to concentrate on keeping them apart. She remembered the huge difficulty of teaching David potty-training. Other children may have been ready earlier, but David wasn't. Switching over from nappies to pants was easy, once he was ready. Everything was a waiting game. Soon David would start school fulltime. It would provide a settling influence and a new

range of social situations and educational input. His parents had to simply survive for the next three months. It felt like an eternity.

SCHOOL PLACEMENT

On 2nd June both parents visited the school recommended by professionals. Reading the school report, which gave criteria for a child admitted to the unit, the description fitted David perfectly. Next day, Wendy visited a Special School, accompanied by Kate. It was good to compare, but Wendy couldn't imagine David there. He was intelligent and quick to learn new behaviours. What would he learn in a Special School? For David, mainstream was best for him. They hoped that one day he would move into a normal class. They would have to wait and see.

Following a chat with the paediatrician, Wendy decided it would be fine having Peter immunised. Peter, aged 16 months, finally had his MMR vaccination. As a special care baby he was more susceptible to illness and he constantly had coughs and colds that David brought back from nursery. Risk of illness was greater for Peter than more uncertain risks surrounding the combined vaccine.

David was accepted at his recommended school. In September he would join an Assessment and Learning Support Centre within a mainstream First School. Class size was low, with around eight to twelve special needs children. Ed and Wendy breathed a sigh of relief. They waited for the new school year, when David would be able to attend fulltime.

PART 7 LIVING WITH A DISABILITY

David had a traditional children's party to celebrate his fifth birthday. All afternoon he practised Statues and Pass The Parcel, wrapping his own parcels and then unwrapping them in time to music. By teatime his guests arrived: Laura (aged three), her brother Matthew (who spent the afternoon asleep in his baby car seat) and Peter (aged 18 months). Mum, Kate and Auntie Jo supervised. Three children sat around the table, eating tea from red car party boxes. They finished with a Teletubbies birthday cake, eating marzipan numbers from a clock face. David enjoyed his party. For mum, it was the happiest and most normal party they had ever had with David.

Since David was a baby, the family had taken him to church. It became a fraught occasion, as he grew mobile. When Peter developed, it was easier taking David on his own on a good day, if the family felt able to cope. Wendy talked him through a service, as David commented loudly: "Why's that man still talking? Man, stop talking." It was prayer time. On one occasion, Ed took David into Sunday School. All the children were preparing display posters on the theme of Journeys. Every child drew around their own footprints. Without a moment's thought, the teacher announced, "David, stick your feet onto the picture." David was already taking off his shoes and socks, until Ed stopped him. He was trying to do precisely what he had been told.

It was almost end of term. David visited his new school and spent some time with a complex red train jigsaw puzzle in his future classroom. He completed one model,

then another. "Finished, David!" David was looking forward to his new school.

David was invited to a birthday party. The full nursery class visited an indoor ball pool and play area. Would David cope? Would the food arrive on time? Children squealed with delight through tunnels, down slides, crashing into a huge ball pool. Rows of children sat down to a party tea. Wendy ensured that David sat at the end of a row. She stood, piling favourite food onto his plate. Other children politely passed him more cakes. Oblivious to everything else, he wasn't upset until they sang Happy Birthday To You. He knew the words. He sang them every day at nursery. Why didn't they cut the cake? He had stayed in his place, watching as another child blew out the candles. Wendy tried to explain that cake would arrive in a goody bag at the end of the party. Finally, he accepted a different party cake instead. As every child returned to the ball pool, David sat happily and continued eating. He had managed a good hour at the party before reaching his social limit. Mum asked for David's goody bag. He had to leave; happily unwrapping sweeties and cake on the way.

End of term arrived and David beamed for his school photo, wearing his bright red jumper. At home he spent hours on his new electronic alphabet, pressing letters and numbers and spelling out his name. He asked mum to spell out new words, including Pingu and Thomas The Tank Engine. David jumped from the breakfast table, keen to spell out a new word on his keyboard. He could say the entire alphabet, count numbers up to a hundred and spell his full name. Mum spent hours with a face painting kit as David became a clown, a tiger, or a seashore. Reading that

educational computer games could help him, Ed and Wendy bought a selection of pre-school CD-ROMs. His favourite was Reader Rabbit's Toddler CD. Soon David had learnt excellent mouse control. He could play with letters, numbers, colours and shapes. Soon David began singing nursery rhymes. He watched rabbit and copied the actions. He learnt to sing Twinkle, Twinkle, Little Star and Baa, Baa, Black Sheep. He sang out of time, but he was learning.

Wendy booked David into a holiday club for children with special needs. A clown arrived to entertain the children. David knew all about clowns; he walked straight up to him. "I want balloons and hats and cake..." he declared. "What's your name?" "D, A, V, I, D," David pronounced carefully. He enjoyed spelling words out in full. "He's lively!" the helper told mum at the end of the day.

WHEN YOU CANNOT HIDE

The family arrived at a motorway service area in the Midlands and ordered a meal in a restaurant. They sat in front of the open doorway. The manageress frowned, but David was behaving impeccably—for David. At the end of the meal, Ed picked up the bill and went to pay at the far side of the restaurant. Wendy began unstrapping Peter from his high chair. In a split second, David ran to the door, grabbed the menu board and hurled it through the doorway, screeching with delight. As Wendy tried to pick up scattered leaflets, David whooped and hurled menu cards outside. Silence transfixed everyone in the restaurant. Wendy sat down in the middle of the floor and held David tightly. He sat there, chatting happily to mum. Every member of staff arrived at once, loudly discussing the shattered menu board. No-one moved towards the family. On the next table, one couple stared and kept on staring. Quickly, Ed returned from paying the bill and both parents ushered David away from the scene. Returning a few minutes later, Ed spoke to the manageress. "Our son is handicapped," he explained. "We had to leave the restaurant before there was a more upsetting scene - for your staff and your customers." The manageress was satisfied. She walked away with a smile on her face.

Social Services provided Peter with an occasional childminder. One afternoon each week, Wendy was able to take David out alone. He went swimming, rode on steam trains and crawled through indoor play areas. On 13th August, Peter had his 18 month developmental check.

David visited his favourite local theme park, a place he could enjoy, with plenty of open space and room to

explore. He could play energetically on climbing equipment. More importantly, other people were kept at a distance. He ran happily to his favourite tree house as mum waited cautiously. Nothing was ever certain with David. Other children climbed the walkway through the trees and squealed as they descended the slide. David did not emerge. There was a No Adults sign on the kiddies walkway. A tidy row of children queued patiently as an older child paused to help. David was out of sight, but mum knew precisely where he was. Climbing along the walkway, brushing past tree trunks, she heard worried-sounding children, speaking of the hole in the floorboards. David was crouched on the floor. He had a fascination with loose floorboards; they were for crawling through, he had seen it on 101 Dalmatians. Wendy's heart sank as she saw the gap in the floorboards. In five minutes, their day's outing had become unmanageable. Nothing could persuade him down the slide. A huge selection of play equipment and woodland explorations meant nothing. David knew there was a hole. His fixation on loose floorboards led to his attempt at climbing through them. They were at adult height, the ground a fair drop below. She persuaded David back to ground level. Nothing would distract him from the walkway.

Wendy made a quick decision. Calling a passing attendant, she told him they needed to leave the park, although they had only just arrived. She would like a refund. He said he would need to call the manager. Wendy remained, calming and containing a strong five-year-old who had discovered his autistic heaven. The manager was professional, as David's mum spoke about problems with their play equipment. "My son is handicapped," she

explained, describing the fixation that could only be resolved by leaving the park. "You know your child," the manager responded. A refund was organised and, handing Wendy a replacement discount voucher, she concluded with "Come again." Wendy wasn't sure whether she would dare. Could anything have diverted him from the floorboards? How loose were the floorboards before David discovered them? One day she would return to the theme park, for it contained everything David enjoyed.

Racking her brains, Wendy thought quickly of another local trip. "David, would you like lunch at Burger King?" He had asked several times recently. Gradually, with a lot of repetition, his mum was able to distract David. He enjoyed fast food restaurants. Wendy had handled a difficult encounter with David in public and was happy with the outcome. Her child had an official diagnosis. She did not need to explain David's condition in detail. She knew he was autistic and had used a term to describe David, one that seemed to work. David didn't look handicapped and the general public were unaware of hidden handicaps. Perhaps she could learn ways of facing the public with her handicapped child.

DISASTER RECOVERY

His parents would never forget one disaster. David had gone to bed relatively easily that evening. He was terribly quiet. Too quiet. As mum went to investigate, she gazed around his room for the latest pile of debris. She stared in silence, for his room was a work of art. David had beautifully coloured in every wall with elaborate pictures of trains, tracks, engine sheds, houses, clocks, water and

slides. Suddenly David was inconsolable, thinking mum and dad would wipe clean his beautiful picture. Mum remembered the day he had smothered himself in squeezey paints, like a scene from *You've Been Framed*. If Jeremy Beadle had walked through the door, she would not have been more surprised. Remembering David's messy birth, it seemed typical. Now David had produced a beautiful work of art. His parents would need to find a longterm solution for his bedroom walls. Meanwhile, Wendy confiscated the coloured chalks.

Before start of term, David climbed hills in the Lake District, fascinated by waterfalls. "When do they switch off?" he enquired. Soon he was discussing wooden floorboards, then fences. Everything needed a hammer and nails. He would make them. Always, the conversation ended with his hammer and nails. On his next trip to the swimming pool David discussed Incey Wincey Spider. Suddenly mum saw the connection, for he 'climbed up the water spout'. David was convinced that occasional water spouts and whirlpools were the sole responsibility of Incey Wincey Spider. Swimming was never the same again. Soon he would learn about power cuts and ask his parents another impossible question, "When will the lights go out?"

On 7th September David started school, in an Assessment Unit of a mainstream First School. He travelled by taxi, provided by the local authority, with other special needs children. At the end of his first day at school, mum heard how David had objected strongly when staff insisted he pick up a tray of tiles deliberately tipped onto the floor. By his fourth day there was a real achievement—David had managed to stay in the whole school assembly that

morning. Why was this so remarkable? David had sat quietly for twenty minutes, with two hundred First School children. Very different from the start of the week, when he had walked into assembly and begun singing Baa, Baa, Black Sheep. Knowing David, mum and dad could easily picture the scene. The previous term he had arrived at nursery school every morning and begun singing Happy Birthday To You, regardless of whether or not a child had a birthday that day. David's singing was generally loud, fairly tuneless and sung with great enthusiasm. He would only stop when he had finished the whole song, oblivious to its effect on anyone present. A week later, Wendy received her first visit from a member of the Children with Disabilities Team. It was the first step towards providing longterm respite care for the family. Would a respite carer be found for David? The family joined a waiting list.

Wendy attended a course about Asperger's syndrome. One image stayed in her mind. The tutor, with a great deal of experience with autism, compared the problems to a graphics equaliser on a home music centre. Think of three knobs, each can be adjusted up or down, changing the treble or bass, etc. Each knob that is too high or too low will make a great difference to sound quality. On average, keeping all three knobs around the middle position gives a fair sound. Imagine each knob can be tuned to hundred positions on the scale. That means there could be a combination of 100 x 100 x 100 positions that would create a different sound. Autism is identified by the Triad of Impairments: social relationships, social imagination and communication. Each impairment, like knobs on the amplifier, could be higher or lower on the scale. Every person with autism is an individual; there is a

staggering range of impairments that makes each one unique—one in a million.

For the first time, Wendy began to understand a phrase she had read about, a Theory of Mind. Every young child learns that other people think. The child bites, the parent hurts and the child learns to control his impulse. Eventually they learn to negotiate, to persuade, because they know that other people think and feel. Soon after the course, Wendy was at home with David. Walking into the hallway, she recognised a glint in David's eyes, he had done something and was extremely pleased with himself. Following her instincts, she headed into the cloakroom. David had a fixation on water, it was not uncommon to find sinks full to the brim, or taps left on full with the plug in. Sure enough, the sink was full of water. No harm had been done, but David was bubbling with excitement. With a sinking feeling, Wendy lifted the lid of the large box in the hallway, usually full of shoes and his school bag. A puddle was dripping down through six layers of hats, scarves, bags and shoes. David was delighted. He had absolutely no sense that mum would be angry, or that he had done wrong. Wendy suddenly remembered the course she had attended. David wasn't being naughty, but his actions were obvious to no-one but himself. If his school bag was soaking wet, he couldn't take it to school with him next day. He would have to take his favourite broken bag from the playroom instead—it was bright red. David had taken his Power Rangers bag to school for over half a term, he had never had a problem with it until that day. Suddenly he had found his own solution to an immediate problem. He did not bother to mention to mum that he would like a red bag instead. A mum is always expected to be a mind-reader

Norfolk's Beautiful Child

with her own children, especially so when her child has no Theory of Mind. Yet.

Let's finish with David's own words, "What will I do when I'm grown up?" "What will you do, David?" "Then I'll build a house... and there will be walls, and FLOORBOARDS... and there will be two upstairs." "Two upstairs?" "And a roof.... and tiles... and a chimney." "What colour roof?" "RED!" "Will there be windows?" "Oh, YES!" he giggles, waving his arms. "And then I will make the curtains, and then I will put them up... and carpets, on the floor." "Will there be doors, David?" "YES!" he beams, with an expression of pure delight. "What a lovely house."

THE END

FOOTNOTE

DAVID WEBB (19) died tragically recently, having achieved his dream to go to University (Computer Science). He achieved much in his short life, including a clutch of GCSEs, ASDANs, and a BTEC(Triple Distinction) in Computer Games Design. David was buried on 9th November (died 17th October) and had a good send-off, and people travelled far. We have supported David's needs for 19 years, how can it all end! Now we want a star named after DAVE, so please spread the word to family, friends, companies, and lets see how high we can shoot this star, for charity.

TREASURED MEMORIES

If you would like to help other people, children and adults on the autistic spectrum, and their carers, then please visit this website, where pics of David are regularly updated. You may donate there to autistic charities:

<http://www.justgiving.com/Wendy-Webb>

Main Treasured Memories page for David

<http://www.justgiving.com/DavesAStar1>

Christmas fund-raiser for The National Autistic Society, in memory of David

MOBILE GIVING:

You can use a simple mobile text to give to Treasured Memories. Just text 70070 to DAVD99, or to DAVD98, add an amount, like £1.

Thanks.