What shape is your child's head? It's a serious question. In the past 12 years, doctors have noticed a significant increase in a condition that makes children's heads grow in an abnormal way. It can cause pain and distress. Left untreated, some children need reconstructive surgery. You almost certainly know a child with this condition, but you've probably never heard of it.

Positional plagiocephaly – also known as flattened head syndrome, or plagio – is primarily caused by sleep position. It's not life-threatening, but it can disfigure children and worry their parents. Doctors in continental Europe and America treat thousands of children every year with 'helmet-therapy' which involves fitting a custom-made helmet or headband to a baby's skull. But treatment depends on the severity of the case, the age of the child, and where you live in the world.

Cassia Belardo was a beautiful baby when she was born almost two years ago in Oxfordshire. But when she was three months old, her mother Fiona noticed a flat bit on the back of her daughter's head. As Cassia grew, so did the flat patch, and the forehead on the opposite side of her face started to bulge outwards, so her head looked like a parallelogram from above.

"By the time she was five months old, people were saying Cassia didn't look right – her face was misshapen," says her mother. " I was frantic. I imagined other children taunting her because she looked weird, or even retarded. I couldn't let that happen."

Fiona talked to health visitors, but she "hit a brick wall – nobody had a clue what I was talking about." Her GP didn't seem interested either, but did agree to refer Cassia to a specialist. In the meantime, Fiona spent weeks on-line, searching the internet for clues. "Eventually I found a website that mentioned positional plagiocephaly. Once I had a name, I was able to trace someone to treat my baby."

Her detective work led her to Dr Chris Blecher, a craniofacial surgeon who works at the University Hospital of Giessen in Germany. He'd become an expert at fitting helmets on children with severe plagio symptoms. And he travels to London offer his services to British parents, because the NHS doesn't routinely treat positional plagiocephaly (see *The NHS View*).

Dr Blecher agreed to see Cassia at Kings College Hospital in London, and fitted her with a helmet to be worn 23 hours a day. Six months later, Cassia's face looked 'normal' and symmetrical. "There's still a tiny flat patch at the back of her head," says her mum. "But otherwise, she's perfect again."

"When I see a baby with an abnormal head shape, first, I have to rule out craniosynostosis," says Dr Blecher. (This is a rare but serious condition which stops the skull from growing properly, and can cause brain damage. Plagio does not affect development.)

Dr Blecher doesn't always fit a helmet – in some cases, simply keeping the baby off her back during the day can help things get back to normal. But with all moderate-to-severe

cases, he fits a helmet as soon as possible. "Heads grow fastest in the first year. The helmet works by suppressing the growth of the prominent parts of the skull, until the flattened parts catch up. I have treated toddlers, but the results weren't so good because growth has slowed down by this time."

The rise of plagio has coincided with the medical advice to sleep babies on their backs, on a firm mattress, with no pillow – advice we should all still follow (see *Back to Sleep*). But if all babies sleep on their backs, why don't they all get positional plagiocephaly? No-one knows for certain, but one theory is that some stress in the womb or during delivery causes trauma to the skull bones which makes them more likely to be affected by sleep positions.

Babies' heads can get flattened in the womb for lots of reasons: being a twin, or a big baby; or if the mother has a small pelvis. Plagio is three times more common in boys than girls, perhaps because boys tend to be bigger. Even fibroids can squash a foetus's head. It's possible that ventouse or forceps delivery could predispose a child to plagio. Premature babies are at risk because their bones are so soft; late babies because the bones have already started to harden. An abnormal presentation – breach, or facial or back to back – can also result in a misshapen head.

A newborn's head is three-quarters of its adult size, even though the body is only a quarter of mature size. Nature compensates for this: when a baby is born, the main bones of the skull fold inwards like petals of a flower. The frontal bones and the back bone collapse inwards, and the side bones fold over each other. When the baby takes her first breath and starts to cry, the bones open and 'pop' into place. Even if her head has been squashed in the womb, this ballooning effect should put everything back into place. That's the theory anyway. But nature wasn't allowing for the many new ways of bringing babies into the world.

Sarah Mackinnon's son Joshua was born by C-section, three weeks early. His head was quite flat at the back , perhaps because his mother is small, and he didn't complete the journey down the birth canal to 'pop' things back in to place. Josh was put on his back to sleep, and the flatness on the back of his head got worse.

"By the time he was three months old, Josh's skull was as flat as a table top," says Sarah. "And he had two lumps of bone, like horns, at the top of the flat bit."

But it wasn't only Josh's appearance that worried his mother – he cried a lot, and he would only sleep for an hour or so before he woke, screaming. "It wasn't as though he woke and then screamed," says Sarah. "He cried himself awake. Something was obviously bothering him. He'd shriek for hours on end. I remember calling the health visitor and holding the phone out, asking: is this normal?"

The health visitor and the GP offered the same advice: he'll settle down, he's just a colicky baby.

But he didn't settle down. At 18 months, he was still 'colicky' – he slept badly, he was irritable, and he had little appetite, but he did want to drink all the time. Sarah and her husband were at their wits' end. A friend suggested they take Josh to see a cranial osteopath. After his first treatment, he ate his tea and slept through the night. "It was an

astonishing transformation," says his mum. "As though he was at peace for the first time in his life." Since then he's had a lot of cranial osteopathy treatment, and according to his mother, he no longer seems 'angry at the world'. And his head is no longer flat. "It's still a slightly odd shape, but you only notice it in the bath," says Sarah. "The main thing is, he's not in distress anymore, and his head isn't completely flat. There's a bit of curve at the back, and the horn-like lumps have gone."

Cranial osteopath Amitti Sevi treats cases like Joshua every day at The Good Health Centre in Leeds. He's one of the most highly qualified osteopaths in this country, one of only two UK osteopaths to hold a Masters degree in paediatric osteopathy. He treats children of all ages, from all over the north of England, for symptoms of positional plagiocephaly. He believes that it can cause pain and distress. "Without a doubt," he says. "If you have compression of the skull it can result in headaches and a feeling of pressure in the head, which a young child cannot explain. She can only cry." Many of his plagio patients don't like their head being touched. Some head-bang – perhaps trying to counteract pain with pain.

"There are 22 bones in skull," says Sevi. "And embedded in the sutures at the junction of these bones are nerve endings whose function is to convey pain to the brain. Clinically, it makes sense that a wrong head shape can cause pain."

Dr Blecher disagrees that plagio hurts, but adds: "If left untreated, it could result in emotional distress for a child because of the way she looks. Some of the children I see are very disfigured."

Jaya Dong is co-founder of an American support group for babies with skull problems. CAPPS (Craniosynostosis And Positional Plagiocephaly Support) has its headquarters in Virginia, and members all over the United States. Jaya knows the stories behind all her members, and she agrees that most plagio babies don't have any physical pain, but some have been in obvious distress before treatment. Her own daughter, Alexi, was one: "Lexi was the devil incarnate when she was born," says Jaya. "She cried all the time. She hated everyone – she barely tolerated me. And she hated to be touched. She would sleep for short periods, then wake, screaming."

Lexi's paediatrician said there was nothing wrong – she was just a 'high-needs' baby, but as she grew, her mum noticed that her face was asymmetrical. One side was puffy, and one eye was bigger than the other. There was a flat patch just to the side of the back of her head. Jaya took Lexi to a range of doctors. Scans and X-rays were ordered. First, the specialists checked for craniosynostosis, then they suggested that Lexi might have hydrocephalus (see *Other Head Conditions*). Eventually, when Lexi was six months old, her parents were given the diagnosis: positional plagiocephaly, and Lexi was fitted with a helmet. "The first night she had the helmet on, she slept right through," says her mum. "When I woke up and she wasn't crying, I worried that something had happened to her." After five months wearing a helmet, Lexi's face was symmetrical again, her head shape had returned to normal, and she was happy to be touched and cuddled.

In Britain, there are four Craniofacial Units that will see babies with suspected plagio, but only to rule out more serious head conditions like craniosynostosis. They don't tend to

offer treatment (see *The NHS View*). Doctors at Great Ormond Street Hospital have prepared an information sheet to send out to parents and GPs. It says that most children with positional plagiocephaly have normal heads when they're born – asymmetry and flat patches don't tend to show up until the baby is a few months old.

But there is a condition to look out for that often goes hand-in-hand with plagio: torticollis, or wry-neck: when one of the main muscles at the side of the neck becomes tight and short, so the baby tilts her head to one side. Some babies are born with torticollis, and their twisted necks can cause plagio. But sometimes the plagio causes torticollis because the baby is sleeping with her head slightly askew, and this sleep position damages her neck muscles.

"It's a chicken-and-egg problem – it's hard to say which comes first," says Dr Blecher. "We need more information, but not enough people are doing research."

Suzan Robertson's baby Zara was born with torticollis, which was treated by physiotherapy. But by the time Zara was two months old, her face was becoming asymmetrical – her left eye was noticeably smaller than her right one, her ears were misaligned, and one side of her jaw was pushed forward. Her doctors said Zara was fine. Suzan warns: "Expect to hear, 'oh her hair will cover it', or 'lots of people have mismatched eyes'." Despite medical assurances, Suzan tracked down Dr Blecher on the internet. Zara was fitted into one of his London clinics – and fitted with a helmet. She was diagnosed with moderate to severe plagio, but she's now made a complete recovery.

Cranial osteopath Amitti Sevi regularly treats babies with torticollis – many of them also have flat patches to the back of their heads. Sometimes he sees older children with scoliosis (a twisting of the spine) caused by severe torticollis that's been left untreated. Amitti Sevi and Dr Blecher are unanimous on one point: you must have your child treated for plagio or torticollis by an expert.

"The internet is full of sites offering helmet therapy, but be warned, there are some quacks out there," says Dr Blecher. "Which is what happens when there's money to be made out of something." He's hoping to convince doctors in this country to take part in controlled trials to find out if most children naturally grow out of their plagio –
if not, maybe one day it might be treated on the NHS.

In the meantime, Dr Blecher travels to London regularly to treat UK babies. Amitti Sevi has new patients every month. And Josh Mackinnon is now four years old; every time he has a growth spurt, he says: "Mummy, my headache is back again." One thing is for sure: positional plagiocephaly is a condition that needs a lot more research.

In the 12 years since we started to sleep our babies on their backs, SIDS has fallen by two-thirds. The medical advice is, and always will be: Back to Sleep. Jaya Dong of CAPPS agrees, but adds: "We're all scared to put babies on their bellies, so they're on their backs all day, in bouncy seats, or strollers that convert to carriers, or car seats that convert to

strollers – second babies are particularly prone to plagio, because they spend more time getting driven around." Her message is: plagio is preventable. Carry young children in slings. Don't let them lock into one sleep position. And make sure they spend lots of supervised time on their tummies during the day. But we should still sleep our babies on their backs at night. Head shape can be treated. Cot death can't.

A rare but serious condition in which the sutures of the skull fuse prematurely: as the child's brain grows, the skull can't expand properly. Surgery is often necessary.

Most children with positional plagiocephaly present a 'parallelogram' shaped head. But in some cases, the entire back of the head is flattened, and the head becomes wide and short. This is called brachycephaly.

Produces a long, thin head – this condition often occurs if the baby was breach in late pregnancy, and her head was wedged underneath her mother's ribs.

Or 'water-on-the-brain': when an excess of fluid gathers around the brain, making the baby's head look unusually large.

According to a leaflet produced by Great Ormond Street Hospital, watch and wait is the NHS view. First, rule out other serious conditions, then try to stop the baby lying on the flattened part of the head during the day. The flattening should get better over years. But if it doesn't, and the child is so deformed that she gets teased by other children, reconstructive surgery may be considered.

Dr Blecher doesn't charge for his time, but the helmets he uses cost around £1,100. His work is funded by research.
Lexi's treatment cost several thousand dollars. Her parents' insurance company refused to pay, claiming that plagio was cosmetic, not medical. But this ruling was overturned by the New York State Insurance Department, which decided that helmet therapy should be covered, because: "This device is not used for 'cosmetic' purposes, but rather for reconstruction…This patient had a deformity of the skull caused by head position."

Article written by Susan Walls Published in Junior Magazine 2005

UK Craniofacial Units:
Birmingham Children's Hospital: 0121 333 8147
Oxford Radcliffe Hospitals, NHS Trust: 01865 224100 www.oxford-craniofacial.org
Alder Hey Children's Hospital: 0151 252 5025
Great Ormond Street Children's Hospital NHS Trust 0207 813 8444 www.gosh.nhs.uk

You can contact Dr Blecher through his web page: www.cranio-online.de (click on Union Jack for English version. Or contact him directly: blecher@transmit.de

CAPPS: www.cappskids.org

Yahoo group: http://health.groups.yahoo.com/group/Plagiocephaly

For information on torticollis: www.torticolliskids.org

The Good Health Centre: www.goodhealthcentre.co.uk Or contact Amitti Sevi directly: ami@goodhealthcentre.co.uk

How to find a cranial osteopath: www.cranial.org.uk