

# CLAPA Spring Survey 2014 – Parents/Carers

## OVERVIEW

444 Parents and/or carers of at least one child with cleft lip and/or palate were surveyed.

85% of these parents had a child with a cleft born after 2000

## DIAGNOSIS

### Antenatal

#### **71.6% of parents of a child with a cleft lip were diagnosed at their 20 week scan**

- **34%** were told about associated syndromes such as DiGeorge or Patau's
- **50%** were offered an amniocentesis procedure for further diagnosis
- **77.5%** of parents felt like they had enough support and/or information at this time to make informed decisions and/or prepare for their child's birth.
- **51%** felt all of their diagnosis and what followed was handled sensitively and professionally, while 38% agreed that parts of it were.
- **73%** were offered the opportunity to speak to a cleft specialist and/or CLAPA Parent Contact
- **25%** were offered a termination without asking about it first (2.5% asked and were then told).

#### **How did parents feel about being offered a termination?**

**13.9% - Category 1** – These parents considered a termination due to the possibility of further syndromes or due to outside pressure, but changed their minds after receiving further information. Generally, these parents were glad to know it was available in case of further complications or particular test results and that they would be supported in their decision.

**10.8% - Category 2** – These parents understood why they were given the option but said they would not personally consider a termination. Some said they were reassured by their doctor and/or nurse that the condition was not serious, which helped with their decision.

**24.6% - Category 3** – These parents do not believe this question should be asked unless another diagnosis is involved or if a patient asks about it first. While they understand that this choice should be available, being asked made them feel panicked and afraid because it suggested to them that their child had a more serious condition. Parents also reported feeling pressured to make a quick decision, with some saying that they were offered termination procedures that would take place that same day or very shortly after. One parent commented that while they were sure this was something they did not want, they were 'made to feel' as though it would be a reasonable decision which they do not now believe it is.

**50.77% - Category 4** – These parents were greatly upset by being asked this question. Many report feeling 'horrible', 'sick', 'upset', 'disgusted', 'most horrendous thing anyone has ever asked me', 'it scared me so much that I spent days crying and not sleeping'. One parent commented that as her husband was born with a cleft lip she thought it was particularly insensitive to ask, though she admitted that it would have been something she'd consider if she had had to pay for all her child's treatment. While these are all personal reactions, it's possible that the insensitivity of particular sonographers may have been a factor, as several parents reported feeling almost 'bullied' into agreeing to a termination which was very upsetting.

## General comments about antenatal diagnosis

Most problems reported point to a lack of information available and/or training of generic health professionals. In several instances, sonographers and other health professionals used outdated terminology like 'harelip' or delivered the news in a way that parents felt was very insensitive.

Parents who had to wait for several days for a second scan to confirm the diagnosis said that this was very difficult for them and that they would have liked immediate support or information available, even before confirming the diagnosis, as instead they were left to google the condition which they said made them feel much worse.

Several comments were made about the lack of support available for extended family members such as grandparents or uncles/aunts who may have opinions on the diagnosis.

All parents that mentioned the cleft teams reported that they felt immediately at ease once they were put in touch with them, but that this could often take far too long.

## Diagnosis At Birth

**41% of parents received a diagnosis after the birth of their child.** Of these children, 42% had a cleft palate.

**39%** received their diagnosis from a midwife and **35%** from a doctor or nurse.

**14%** said they were the first to notice their child's cleft, and **8%** said it was their partner.

**20%** said their diagnosis and what followed was **not** handled sensitively and professionally, **38%** said all of it was and **42%** said parts of it was.

**53%** said they felt they were offered enough support and/or information at this time, but **37%** said they were not.

## General comments on diagnosis at or after birth

A wide range of comments were received, and the issues reported were again largely about a lack of knowledge and sensitivity from generic health professionals involved in the birth of their baby. In some cases, babies were taken out of the room straight after birth which was very distressing to parents, and in others parents felt as though the health professional delivering their diagnosis did so inappropriately or insensitively. Some were given inaccurate information, others felt overwhelmed by too much medical information which they could not take in straight away. Several mothers reported feeling like they were 'blamed' for not being able to breastfeed their child, or that their distress at not being able to breastfeed was not handled appropriately.

The main thing that could have improved their experiences would have been an antenatal diagnosis, and many parents praised the improvements in scanning techniques and technology which could make this available for future parents.

## Diagnosis of Cleft Palate

**60%** of parents were diagnosed within 24 hours of their child's birth

**20%** were diagnosed within 72 hours, **7%** within one week and **14%** more than one week after their child's birth.

**43%** were diagnosed by a midwife or nurse immediately following birth, **40%** by a paediatrician, **5%** by a GP and **1%** by a health visitor.

**6%** found their child's cleft palate themselves, in **1%** of cases it was their partner and in **3%** a friend or family member.

**32%** thought their diagnosis and what followed was handled sensitively and professionally, while **51%** thought only some of it was. **16%** said it was not.

**65%** agreed that they had enough support and/or information at this time, but **33%** disagreed.

### **General comments on diagnosis of a cleft palate**

A big issue for mothers was being told they would not be able to breastfeed. Many said this was not handled sensitively, especially as in some cases they had been trying unsuccessfully for some time with their newborn child before the cleft was diagnosed. Parents who received a later diagnosis also reported feeling as though their concerns about their child were dismissed by health professionals and said they often felt blamed for being unable to feed their child.

## **POSTNATAL SUPPORT AND CARE**

### **Local Groups**

Only **44%** of parents attended an **antenatal** group or class (not including CLAPA or cleft-related groups). Of those that did, **31%** only attended a group after receiving an antenatal diagnosis of cleft.

**32%** regularly attended a parent/carer and baby group (not including CLAPA or cleft-related groups) once their child was born, and **19%** attended these groups sporadically. **16%** said they did not attend a group like this but would have liked to.

When asked if their child's diagnosis changed whether or not they wanted to attend these groups, **54%** said there was no change in their opinion. **9%** said they wanted to attend these groups MORE, and **23%** said they wanted to attend these groups LESS.

Only **18%** of parents said they attended a CLAPA group such as Happy Faces or a group run by their local cleft team. **33%** said they did not because there were none nearby, **41%** said they did not know about these and **8%** said they did not want to. There was no significant change in answers for those with children born before 2000.

### **Postnatal Depression**

**54%** reported a change in their mood after the birth of their baby, with **28%** saying this was significant and **26%** saying it was moderate.

**21%** of respondents had received a diagnosis of postnatal depression. National statistics claim around 10-15% of new mothers experience this, but some estimates put the number as high as 30% experiencing at least some symptoms.

### **Feeding**

**10%** of mothers wanted to and were able to breastfeed following the birth of their child, and 5% breastfeed exclusively while 5% supplement with expressed milk and/or formula milk as necessary.

**37%** wanted to breastfeed but were unable to, and now express breast milk.

**29%** wanted to breastfeed but were unable to, and now use formula milk.

**1%** stated they did not want to breastfeed and express milk instead, while **23%** said they did not want to breastfeed and use formula instead.

**67%** said they felt they received enough specialist report to make an informed decision about feeding their baby, while **23%** said they did not.

**51%** said they were very (28%) or somewhat (23%) supported in this decision by others including other parents and health professionals. **19%** said they were 'not really' well supported and **11%** said they were not at all supported.

While **56%** of parents had never used a dummy/comforter, **21%** did before and after surgery, **19%** did before surgery only, and **2%** did after surgery only.

### **Other Support**

When asked about CLAPA's **Parent Contacts**, **56%** said they had never contacted one and **24%** said they did not know about this service. Of those that had used this service (**20%**), **54%** said they found it 'very helpful', **25%** said it was fairly helpful, and **11%** said it was not very or unhelpful.

When asked about CLAPA's **Happy Faces Groups**, **34%** had never attended one due to geographical reasons, **10%** had never attended because they did not want to, and **38%** had never attended because they did not know about these groups. Of those that had attended a group (**19%**), **64%** had found it very helpful and **23%** fairly helpful. Only **5%** found these groups unhelpful.

### **General Comments on Postnatal Support**

Parents reported a lack of support with expressing at home or with feeding in general outside of that offered by their cleft nurse specialist. Some wished they had been able to try to breastfeed again instead of allowing hospital staff to tube feed their baby in what seemed to them to be unnecessary. There was often confusion about whose responsibility it was to support the parent in situations like this.

Some parents reported feeling isolated after their child's birth, especially if they were spending a lot of time expressing milk. They were also unhappy at having to explain their child's condition to every health professional they came across, and occasionally received conflicting advice.

Many parents commenting on a general lack of support were quick to point out that things have clearly improved a great deal since their child was born.

### **Welcome Packs**

**56%** of parents received a Welcome Pack, **36%** did not.

Of those that received one, **23%** rated it perfect, **50%** good, **14%** said they had no strong feelings, **12%** said it wasn't bad, and **1%** said it needed serious improvement.

### **When asked what it should include, parents agreed with the following:**

- 91% - Bottles and teats as needed
- 90% - Information about local Happy Faces Groups or other support groups
- 84% - Catalogue of bottles/teats
- 80% - Local Branch contact details
- 78% - Letter of welcome to the CLAPA Community

- 75% - List of Parent Contacts
- 77% - Information about and/or samples of other bottles (e.g. Vital bottles)
- 72% - Information about all of CLAPA's services
- 69% - Medical information
- 55% - Information about cleft research
- 48% - Non-medical information such as case studies and signposting
- 38% - Information about fundraising
- 35% - Information about volunteering

### Information Packs

CLAPA is considering providing information-only Welcome Packs to parents who do not require free specialist feeding equipment. **63%** of parents agreed that this would be a good idea, with **6%** disagreeing.

When asked what should be in those packs, parents agreed with the following:

- 92% - Information about local Happy Faces Groups or other support groups
- 84% - Local Branch contact details
- 84% - Information about all of CLAPA's services
- 82% - Medical information
- 82% - Letter of welcome to the CLAPA Community
- 81% - List of Parent Contacts
- 64% - Information about cleft research
- 55% - Non-medical information such as case studies and signposting
- 40% - Information about fundraising
- 38% - Information about volunteering

### HOSPITAL APPOINTMENTS

**7.5%** of respondents indicated that they had missed a hospital appointment for any reason without it being cancelled or rescheduled (known as a Did Not Attend or DNA). National statistics estimate that around 10% of appointments are missed like this, and anecdotal evidence tells us this is a serious issue within the cleft service, but our survey does not reflect this.

Of those that did miss an appointment, **36%** simply forgot, **7%** said they were concerned about their child missing school, and **14%** could not get time off work. **43%** said their clinic was difficult or expensive to get to.

To help with this, the majority of parents suggested a text reminder service before their appointments. Others said it would help if patients who had to travel long distances could have appointments later in the day.

Of those parents whose children were in school or nursery (**76%** of respondents), **84%** have had to remove their child from school/nursery for appointments. Of this group, **7%** said they had had these absences marked down as unauthorised, while **59%** said they were authorised.

**38%** of parents whose child(ren) missed school for appointments said they were worried their child was missing out on their education. **42%** had similar concerns about them missing out on the reward or merit system for full attendance, and **21%** said they were worried about their child missing out on socialising.

Only **28%** said they felt there was enough support available at their child's school for children who will have frequent absences for things like surgery, with **31%** saying there was not enough. **17%** said that they wanted to challenge this or take things further but were unsure how to go about this.

**61%** said they believed it cost more to have a child with a cleft. Of these, **43%** named travelling to and from hospital as the biggest expense, followed by other costs associated with hospital stays (**26%**), lost earnings from time off work (**18%**), specialist feeding equipment (**11%**) and other specialist equipment such as car seats (**3%**). **52%** estimated they had spent between £100-500 extra within their child's first 12 months, with **26%** estimating over £1000. Of these parents that had applied for DLA (**25%**), **83%** were successful.

Generally, parents were happy with the treatment they were receiving. When asked about their last experience with their cleft team, **90%** reported that they were 'happy' (27%) or 'very happy' (63%), with only 4% saying they were unhappy or very unhappy.

## **POSITIVES**

When asked whether or not they believed there were positives to having a child with a cleft, **58%** of parents agreed and **15%** disagreed.

Of those that thought there were positives, we which positives they would agree with:

- 80% - Has made me stronger as a person
- 71% - Has given me a new or different perspective on physical appearance
- 69% - Has given me a new or different perspective on congenital abnormalities in general
- 62% - Feel closer to my child and/or my family as a result
- 42% - Has 'broadened my horizons'
- 37% - Feel good about opportunities to help others
- 24% - Feel part of a community

## **Comments on positive aspects of having a child with a cleft:**

Most parents stated that having a child with a cleft taught them to be more compassionate and open and not to judge people straight away. Some said they were grateful for finding a supportive community and others said the wonderful treatment their child received made them feel very lucky.