

# Moving Up↑

For **parents/carers** of children born with a cleft lip and/or palate

## What is this booklet about?

This booklet is for parents/carers of children born with a cleft (lip and/or palate), who are moving up to secondary school. It is written by Clinical Psychologists from Cleft Teams across the UK. We are asked lots of questions at this time, the big one being...

“What will having a cleft mean for my child at secondary school?”

The short answer to this is that **every child is different, so we can't possibly tell you what will happen with your child.** However, this booklet will address some typical things that can occur at this time, and give advice on issues parents often ask us about.


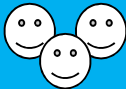

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## Moving to secondary school- what can be expected?

Moving to secondary school may feel like a big change for many children and families. It often means moving to a bigger school, with more responsibility and new challenges.

In terms of typical child and adolescent development, secondary school is a time where children go from depending on adults to being more independent. This process involves facing many important (and challenging) developmental ‘tasks’, shown here:

Tasks	Early adolescence (12-14 years)	Mid adolescence (14-16 years)	Late adolescence (16 years +)
<b>Cognitive</b> 	<ul style="list-style-type: none"> <li>• Testing rules and limits</li> <li>• Seeing multiple perspectives</li> </ul>	<ul style="list-style-type: none"> <li>• Developing ideals</li> <li>• Evidence of conscience</li> <li>• Moral reasoning</li> </ul>	<ul style="list-style-type: none"> <li>• Setting goals and following through</li> <li>• Ability to regulate impulses</li> </ul>
<b>Social</b> 	<ul style="list-style-type: none"> <li>• Girls ahead of boys</li> <li>• Awareness and interest in their body</li> <li>• Need for privacy</li> <li>• Struggles with self identity</li> <li>• Change in affection shown to parents</li> <li>• Greater peer group influences</li> </ul>	<ul style="list-style-type: none"> <li>• Concerns about sexual attractiveness, appearance and body</li> <li>• Changing relationships and romantic relationships</li> <li>• Selecting role models</li> <li>• Testing new ideas in peer group</li> <li>• Self involvement</li> </ul>	<ul style="list-style-type: none"> <li>• Concern about more serious relationships</li> <li>• Firmer identity</li> <li>• Clearer sexual identity</li> <li>• Increasing independence</li> <li>• Stable interests</li> </ul>
<b>Emotional</b> 	<ul style="list-style-type: none"> <li>• Shyness, blushing, modesty</li> <li>• Worries about being ‘normal’</li> <li>• Moodiness</li> </ul>	<ul style="list-style-type: none"> <li>• Feelings of love, passion</li> <li>• Inner reflections (e.g. may keep a diary)</li> </ul>	<ul style="list-style-type: none"> <li>• Capacity for sensual love</li> <li>• Expressing feelings in words</li> <li>• Self-reliance</li> <li>• Self-esteem</li> </ul>

If your child has developmental difficulties (e.g. a learning disability), the changes to expect may be different from the above. The team/person who supports you and your child with these needs may be able to advise what to expect over this time.

However, **if your child has a cleft and no other additional needs, we expect them to develop along a typical path.** This means by the end of secondary school, they will be an independent young person!

It is understandable to feel anxious as your child works through this challenging time, and to feel a sense of loss as they ‘need’ you less. Finding a way to navigate with your child through these stages as they become more independent can be tricky, and may feel difficult at times. Hopefully, this booklet can serve as a guide to help you through some of the specific challenges we are often asked about at this time.

# Commonly raised questions (and what you can do about them)

## 1. Making friends

One of the biggest changes during this time is that relationships with peers (i.e. friends, classmates, others their own age) become more important.

We know that solid friendships and a good social network are major factors in forming emotional resilience, helping people to cope much better with difficult life events.

Some adults worry that having a cleft will make it hard for a child to make friends. This is not necessarily the case. Most children born with a cleft go on to make good friendships both in and out of school.

Your child’s booklet suggests ideas for making friends. Looking at these together and giving gentle encouragement may be helpful. Other things you can do to help are:

What you can do	Examples
Help them stay in touch with friends (old and new)	Arranging meet ups, phoning, texts, online-agree rules (see section on mood)
Encourage contact outside school	Invite friends over; youth clubs; sports
Help with practical skills	What to say/do when you meet someone new (see children’s booklet)
Give emotional support if worried	Listen to worries; encourage them to think of solutions e.g. “What do you think you could do?”
Try to avoid being overprotective or overinvolved	Give some level of choice, independence and freedom in who they are friends with

## 2. Talking about cleft (including questions and comments)

Sometimes a cleft lip and/or palate is noticeable to others- for example if someone has a scar, or their voice sounds different. This may lead to questions or comments from others. For example...



Your child’s booklet suggests using the “**Explain, Reassure, Divert**” strategy to respond to questions/comments. Preparing and rehearsing responses together can be helpful.

It is very understandable to be afraid of possible comments and questions. Many families worry that comments/questions mean someone is judging or rejecting their child; others worry that ‘children/teenagers can be cruel’.

However, this is not always the case. Whilst we understand the worries you may have, some things we really want families and children to know at this time are...

### **Different does not mean bad- just different**

- Having something different about us- like a cleft- should not mean we should be embarrassed or scared of it. There is nothing wrong with it- it is just different!
- There is no reason having a cleft should be any different to having and/or talking about other differences between people- e.g. accent, wearing glasses, skin colour.
- Teenagers often start worrying about ‘fitting in’. However, rather than hoping they can ‘fit in’, we want them to learn to accept their difference(s)- which we *all* have.

### **Someone noticing a difference is not the same as them being nasty**

- It is normal to be curious about unfamiliar things (though it can feel annoying!).
- Just because someone notices something, doesn’t mean they think it is bad. Comments / questions/attention don’t mean someone doesn’t like you.

### **Talking about their cleft tells children/others it is okay**

- By talking to your child about their cleft, and answering any questions/comments they have, you let them know that having it (and talking about it) is okay.
- How you talk to them about it ‘models’ how they can talk about it to others i.e. that it is not a big deal, and that it isn’t something embarrassing/bad/scary.
- On the other hand, avoiding talking about cleft can suggest it is ‘bad’. It can mean they don’t understand it, making questions/comments difficult, and care confusing.

This table summarises our general advice on talking about cleft:

What you can do	Examples
Help them prepare responses	Practise explain, reassure, divert technique
Talk with them about their cleft; make it seem like any other subject (i.e. not a big deal!)	Answer questions; show them early photos, and comment on non-cleft things too: “Look how much hair you had!”; “You were a smiley baby”
Explain the difference between noticing (okay) and judging (bad)	“Have you ever noticed something different about someone?”; “We are all a bit nosy”
Provide emotional support if worries occur	Listen to worries; encourage to think of solutions e.g. “What do you think you could/should do?”

## **3. Teasing and bullying**

Firstly, this issue is not included because we are expecting children with a cleft will be bullied. In fact, lots of people with a cleft tell us this has never been a problem for them.

However, we know many families worry about bullying. We also know that if bullying does happen- whether related to cleft or not- it needs to be taken very seriously.

**Bullying is behaviour intended to distress (upset, hurt, mock) someone.** For example:

- Physically hurting someone
- Saying, doing or showing hurtful things to/about someone (including online)
- Leaving someone out (including online)

School age bullying often happens away from adults, but in front of peers. Whilst all schools should have anti-bullying policies, some rely on pupils reporting or calling out bullying. This can be a problem, as many worry this will get them in more trouble.

Bullying at any age can really harm psychological wellbeing (see section 5). It is not a normal part of growing up. Being bullied, even once, can make someone feel:

- **Helpless, Hopeless**
- **Sad, Depressed**
- **Anxious, Scared**
- **Guilty, Embarrassed**
- **Angry, Mistrustful**

Whilst bullying is different to teasing in a friendly/playful way, teasing by friends or family can still hurt (even if not intentional). The advice below may also help here.

### **What responses are most helpful?**

Importantly, there is no one thing a child can do- such as ‘ignoring it’ or ‘hitting/getting them back’ that will work for every child in every situation. For this reason, telling children what you think they ‘should’ do, though understandable, is often not helpful.

Adults can help most by making children feel they can tell them if bullying happens, then restoring power to their child by asking them what they want to do about it.

Children can find it hard to tell adults about bullying. It can feel shameful or hard to talk about. Some worry how adults will respond (e.g. get upset/angry; go into school).

Your child’s booklet tells them it is very important to tell someone if bullying happens. Let them know you will listen if they have any problems at school (not just bullying). Helpful things you can do if they tell you about bullying are:

What you can do	Examples
Listen with empathy; say their feelings are heard/understood	“I’m sorry, that sounds awful”; “You don’t deserve that”
Ask what options <u>they</u> think they have/prefer; show they have control	“What do you think you can do?”; “Is there anything you would like me to do?”
Try not to explain ‘why’ it might be happening	“They are just jealous”; “They have low self-esteem/issues at home “- you don’t know this
Try not to tell them things they or you ‘should’ do	“Why didn’t/don’t you just...” “I will go and speak to them”

## 4. Confidence and self-esteem

Although many families worry a child's confidence or self-esteem will be affected by having a cleft, there is no reason this should be the case!

### What is self-esteem?

**Self-esteem is how valuable you feel/think you are.** Developing good self-esteem (i.e. feeling positive about yourself) is a key challenge for all children at this age.

Peers, family, teachers, (social) media and others give children different messages about what they should be to be 'good enough' (e.g. fun; clever; popular; attractive...).

However, as people expect different things, and as nobody is good at everything, no child (or adult!) can always be what everyone wants them to be. If our self-esteem is based only on what others expect, we will fall short- and have low self-esteem.

Unfortunately, many people feel uncomfortable about the idea of 'liking' themselves. They mistake it for being arrogant, which it is not. Good self-esteem means you think you are valuable. It doesn't mean you think you are *more* important than others.

### What is confidence?

**Confidence is thinking/feeling you are able to do something-** whether it is making friends or completing a task.

As we all have different abilities, most people feel confident about some things but not others. Again, some people mistake confidence for arrogance- which it is not. Some also think you have to be loud or outgoing to be confident- which you do not!

Confidence and self-esteem are closely tied, and both are very important for good psychological wellbeing. You can help your child with both by:

What you can do	Examples
Notice when your child does well and give specific praise	"That was a really kind thing you did, sharing with your brother"
Praise effort as well as achievement	"You tried really hard in that work; well done"
Help them overcome disappointment; don't generalise	"It's a shame it didn't turn out how you wanted this time"
Help them notice and remember good things others say of them	"Your teacher said you're really helpful"
Help them develop positive self statements	"My friends like me because I'm kind"; "I'm great just the way I am"
Try not to generalise criticism	"You <u>never</u> tidy up"; "You're lazy" <b>Instead:</b> "Could you please tidy up"

## **5. Mood and wellbeing**

Difficulties with mood and psychological wellbeing (i.e. 'mental health') can affect anyone. As Clinical Psychologists, we are pleased that people are realising and talking about this more. We are often asked how to tell if a child (or adult) is struggling.

### **Signs of possible difficulty with mental health**

Importantly, showing one or more of these general signs does not always mean a child is struggling. For example, eating and sleeping more are normal for teenagers, as are changing interests in activities, and mood swings.

- Changes in sleeping or eating habits (less or more)
- Avoiding or not joining in with usual activities (including conversation)
- Low mood, tearfulness
- Anger, aggression
- Use of drugs or alcohol

The only way to know whether (or how) a child is struggling is to talk to them. Letting your child know they can talk to you, and that you won't judge them or 'overreact' may help, although it is common for adolescents to want privacy from familiar adults. However, you can still help by doing these general things to help with wellbeing:

### **Things you can do at home to help with your child's mood**

- Ensure they keep a good sleeping routine
- Ensure they keep a good eating routine
- Agree limits on screen time and social media
- Encourage talking about feelings
- Encourage exercising or other leisure activities
- Use relaxation and mindfulness (see *Further Support* for link to free apps)

### **Signs of serious difficulty with mental health**

If your child shows any of these issues, and is not known to mental health services, speak to their GP as soon as possible (though do let your child know you are going to do this). They will signpost to the appropriate service.

- Self harm (e.g. cutting, overdoses)
- Talking about or attempting suicide
- Delusions or hallucinations
- Withdrawing totally from necessary activities (e.g. going to school)

### **My child is struggling with their mental health. Is it because of their cleft?**

Where a difficulty is related to cleft, the link tends to be clear e.g. anger/social anxiety about speech/appearance. The Cleft Team Clinical Psychologists can offer support around these difficulties.



Sometimes it is less clear how relevant having a cleft is to a problem, e.g. eating difficulties; general anxiety with occasional cleft related worries. Here, the Cleft Team Clinical Psychologist may offer an appointment to decide which team is best placed to provide support (see *Further Support*).

Some issues, such as ADHD or ASD, are to do with physical brain differences, and never caused by cleft. Other teams support these issues.

This table summarises our advice on general psychological wellbeing for *all* children:

What you can do	Examples
Encourage the household to talk about feelings	“How was your day today?”; “Is anything bothering you at the moment?”
Respond to difficult feelings by listening, empathising	“That sounds tough”; “Is there anything I can do to help?”
If you notice any of the listed signs, ask your child about them	“I’ve noticed you are going out less. Is anything the matter?”
Call GP/current mental health team if signs of serious difficulty present; try to talk to your child first	“We need to talk to your doctor/team about this. They can help you”
Try not to react to any shared difficulties in a highly emotive way (e.g. scared, angry)- share these feelings separately, later	“I can’t believe you are doing this” “Do you know how hard this is for me/us?” <b>Instead:</b> talk to partner/friend later e.g. “It’s really worrying for me”

## 6. Additional Needs

Some children with (and without!) a cleft have additional needs requiring support at school. Importantly, a cleft itself does not cause additional needs like those below. For this reason, the Cleft Team Clinical Psychologists do not directly support these issues.

If your child has additional needs, these should be assessed and supported as they would in a child without a cleft. Examples of difficulties and where to find support are:

### Learning difficulty or disability

If you think your child struggles to do school work, speak to their teacher. They can tell you if they share these concerns, and if the school has ways to assess for/support any issues (e.g. via Educational Psychology). If the school is not worried but you still are, talk to your child’s GP (or Paediatrician).

### Attention/Concentration difficulties

Major problems with attention/concentration stop a child doing what they need to do. They affect children across all settings (i.e. both at school and home). If you think this affects your child, ask their teacher if they agree, and if the school can assess/support (e.g. via Educational Psychology). If not, talk to your child’s GP (or Paediatrician).



## **Autism Spectrum Disorder (ASD)**

People with ASD struggle to interact with others in an appropriate or expected way. They can be distressed by changes in routine, and have restricted patterns of behaviour, activities or interests. If you think your child may have ASD, talk to their GP. It can also be helpful to ask their teacher if they share concerns.

## **Additional physical/health issues**

Some children with a cleft have additional physical/health issues. Some are related to a 'syndrome' including cleft and other issues (i.e. Stickler Syndrome, which can affect the face, hearing, eyes and joints), whilst others are unrelated (i.e. a child with a cleft and diabetes). The cleft team will have told you if your child has a known syndrome.

If you feel your child's physical/health condition affects their mental health (i.e. they have anxiety around their condition/treatment), some teams can access Paediatric Clinical Psychologists, who support children with health related concerns. Ask the team providing their treatment to ask if emotional support is available. Your GP or School Nursing Service may also be able to signpost you to appropriate support.

## **22Q11 Deletion (aka DiGeorge / Velocardiofacial) Syndrome**

Some children with a cleft are also diagnosed with a genetic condition called 22Q11 Deletion Syndrome, which can affect many different systems in the body. Support varies with individual needs and local resources. Children may see relevant specialties (e.g. Cleft, Cardiology), and/or have a Paediatrician overseeing care, and/or attend a 22Q11 Clinic. Others may need or receive no specific support. If your child has (or you think they may have) this syndrome and you have any related concerns but no support, speak to your GP. The websites in the following table may also be helpful.

Whilst the syndrome affects people differently, learning and behavioural difficulties are common, so extra support in school may help. In addition to the guidance above, it may help to share school concerns specific to the syndrome with your Paediatrician, 22Q11 Clinic or GP. Some websites in the following table address 22Q11 in school.

## **A note on Pierre Robin Sequence (PRS)**

Some children with a cleft are diagnosed with PRS at birth. This is where a small lower jaw pushes the tongue into the airway affecting breathing and/or feeding. In most cases the jaw grows and/or airway issues are resolved. Once airway issues are resolved a child no longer has PRS, although their jaw may still be small (called 'micrognathia').

PRS is not a syndrome or disability, and it is rare for a school aged child to still have it. If your child was born with PRS and has difficulties at school, this should be assessed as it would be in any other child. If you are unsure if your child's PRS has resolved, talk to your cleft team. If your child still has PRS, support will be provided by an ENT team.

Concern	Where to find support
Learning difficulty/disability	School; GP / Paediatrician ; <a href="http://enquire.org.uk">enquire.org.uk</a>
Attention/Concentration	School; GP /Paediatrician ; <a href="http://adhdfoundation.org.uk">adhdfoundation.org.uk</a>

Concern	Where to find support
Autism Spectrum Disorder	GP / Paediatrician; <a href="https://www.nhs.uk/conditions/autism/support">nhs.uk/conditions/autism/support</a>
Additional physical/health	Attached Health Team; GP; School Nurse
22Q11 Deletion Syndrome	GP / Paediatrician; <a href="http://22q.org">22q.org</a> ; <a href="http://maxappeal.org.uk">maxappeal.org.uk</a> ; <a href="https://www.nhs.uk/conditions/digeorge-syndrome/">nhs.uk/conditions/digeorge-syndrome/</a>

## 7. Talking to school about cleft

### Before starting school

It may be useful to contact your child's new school before they start, to let them know about your child's cleft (and any other issues). Some staff will not know what a cleft is. As schools close over summer, it can help to contact before the holidays, or arrange a call/meeting for the start of term.

As clefts affect children differently, tell the school how **your** child's cleft does/doesn't affect them i.e. if your child struggles with hearing, tell them they may benefit from sitting at the front of class. If your child has regular appointments (e.g. dental/speech), tell them how often these are.

In this pack is a template letter from CLAPA (a UK charity supporting people with a cleft and their families) that you can complete or adapt, and give to school. It may also be useful to give them a copy of CLAPA's 'Helping Children with a Cleft Succeed at School' leaflet (also included in this pack). CLAPA also have advice on managing absences at: [www.clapa.com/wp-content/uploads/2015/11/FAQSchoolAttendance.pdf](http://www.clapa.com/wp-content/uploads/2015/11/FAQSchoolAttendance.pdf).

### During the school year

Once you have made initial contact with school, the following advice may help:

- **Ask who the best contact for the year is** and contact them throughout the year
- **Tell your contact any relevant updates about cleft/treatment** (i.e. any new issues/appointments; any treatment and recovery) and discuss how staff can help (i.e. helping catch up with work; amending work/lunchtimes during recovery)
- **If you have concerns around cleft in school:** let the contact know ASAP, and involve your child in any decisions made (i.e. how would they feel about moving seats?)
- **Decide how best to contact in each situation** (i.e. letter, email, phone, in person)
- **If talking in person:** arrange a time, and write questions/concerns beforehand
- **Keep a record of your communications with school**

If you are not satisfied with the outcome of your communications with school, raise your concerns with the Head Teacher and/or Chair of the Board of Governors.

### Moving up through school

Be aware information may not be passed automatically onto next year's teachers. Ask your contact if they will remain so for future years, and whether you need to pass information about your child onto the next year's staff (or if they will do this).

## 8. What's next in cleft care?

Once children reach secondary school, cleft care involves:

- Check-up /review appointments at key times to see if they have any issues with cleft-related function (e.g. speech, breathing, discomfort) or appearance
- Further investigation (and potentially treatment) if there are any concerns

In check-up/review appointments, they will see the members of the cleft team most relevant at that time. Don't worry if every member of the cleft team (e.g. the surgeon) is not at each appointment. The people who most need to see you will do so.

A child with no (or few) cleft concerns will be seen less often as they get older. Most Cleft Teams stop reviewing between aged 15-21 if a patient has no concerns. However, they can return at any time if needed. Your Cleft Team will explain this at the time.

### Child/young person centred care

By secondary school age, a child/young person's opinion is central to deciding what is (and what is not) an issue related to cleft, and whether to have any further treatment.

This is because cleft treatment at this age is almost always elective (non-essential). Here, potential benefits of treatment can only outweigh the risks/costs if the patient thinks so. It means that to treat a potential concern, it is important that:

- **The child/young person feels it is a concern for them, and**
- **They feel the potential benefit of treatment outweighs the risks/costs**

For example, if an adult thinks a child's speech/appearance is a problem, but the child does not, the team would not consider treatment unless the child becomes concerned.

If a child has developmental difficulties, their feelings on the above will still be sought and considered as far as possible and appropriate when making a decision.

If a child has typical development, they will be a young person in charge of their own care by the end of the 15-21 year routine pathway. You can prepare them for this by:

What you can do	Examples
Encourage your child to be more engaged/involved more in their cleft care	Ask them to think of and write down questions before appointments; ask if they would prefer to have (some of) appointment alone; encourage them to talk in the clinic room; share appropriate Cleft Team letters / records with them
Ask your child if they understand current/past care	"Do you know why it is we see (staff member)?" "Do you know what it means when they say..."

## Further Support

### Contacting your Cleft Team

If you have any concerns or questions about your child's cleft or related care, the best person to contact is your **Cleft Team Coordinator**. They can pass queries or information to the relevant team members, including:

- Cleft Surgeons
- Clinical Nurse Specialists
- Clinical Psychologists
- Speech and Language Therapists
- Dentists
- Orthodontists
- ENT Surgeons
- Audiologists

A list of cleft teams and their Cleft Team Coordinator contact details can be found on [www.clapa.com](http://www.clapa.com). You can write their contact details here:

Phone .....

Email .....

### Helpful Resources

Cleft Lip and Palate	<a href="http://www.clapa.com">www.clapa.com</a>
Mental Health	<a href="http://www.childline.org.uk">www.childline.org.uk</a> <a href="http://www.youngminds.org.uk">www.youngminds.org.uk</a> <a href="http://www.internetmatters.org/resources/wellbeing-apps-guide-for-kids/">www.internetmatters.org/resources/wellbeing-apps-guide-for-kids/</a>
Visible Difference	<a href="http://www.changingfaces.org.uk">www.changingfaces.org.uk</a>
Bullying	<a href="http://www.bullying.co.uk">www.bullying.co.uk</a> <a href="http://www.nationalbullyinghelpline.co.uk">www.nationalbullyinghelpline.co.uk</a> <a href="http://www.kidscape.org.uk">www.kidscape.org.uk</a> <a href="http://www.respectme.org.uk">www.respectme.org.uk</a>
Online safety	<a href="http://www.internetmatters.org">www.internetmatters.org</a>