For the UK
cleft community

# Returning to cleft care

## A guide for adults

## About CLAPA

Cleft Lip and Palate Action (CLAPA) is the UK charity supporting, connecting and championing the cleft community. We offer free services to adults in the UK who were born with a cleft.

You can learn more about our services on Page 45 or by visiting clapa.com/adults

## Contact CLAPA

Email adults@clapa.com to contact CLAPA's Adult Services Coordinator.

Call 0207 833 4883 to leave a message with your name, phone number and enquiry for a call back.

Within this booklet you will find answers to some of the most common questions about cleft treatment as an adult.

For further information visit **clapa.com/adults**

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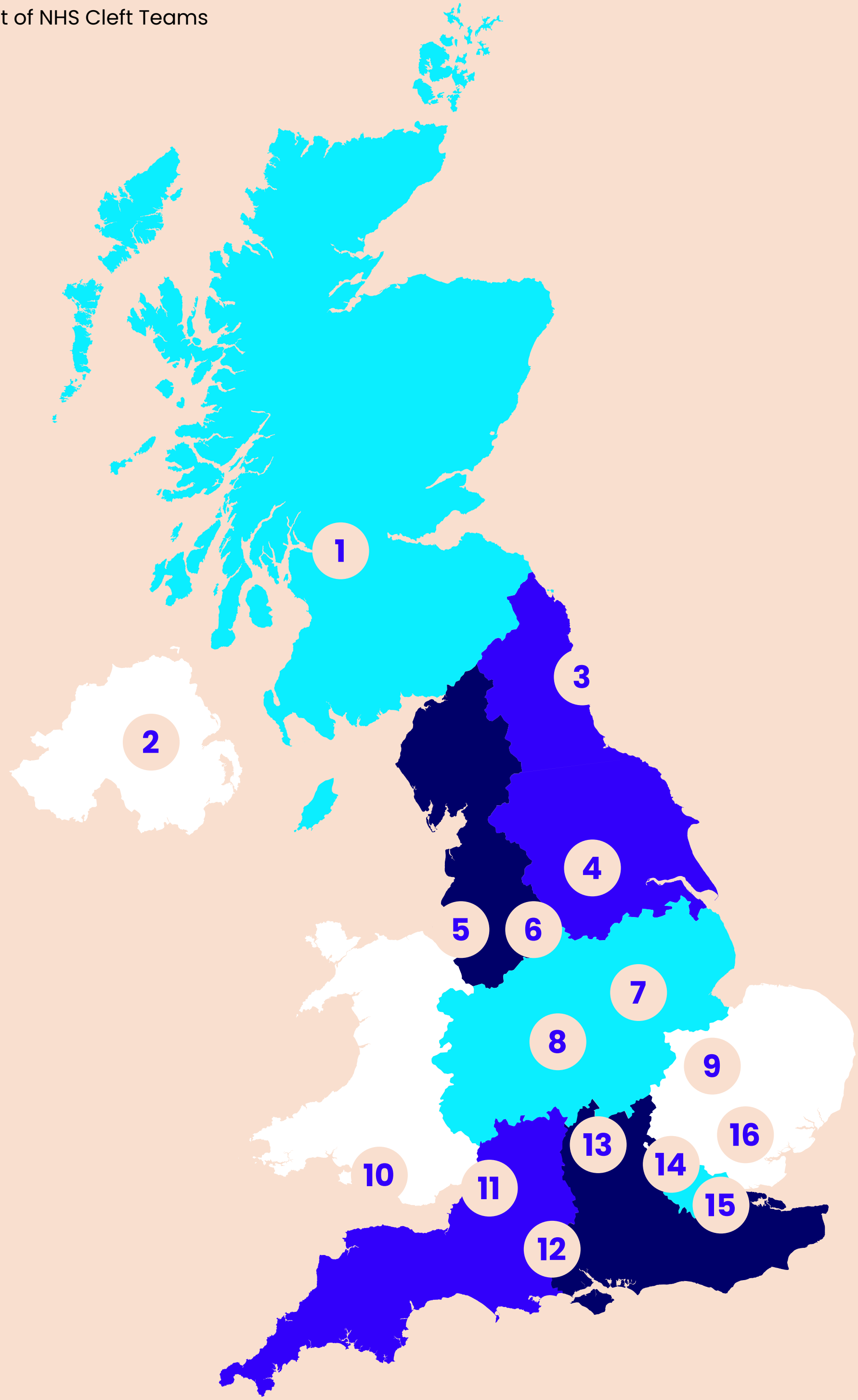


# NHS Cleft Teams

There are nine regional specialist NHS Cleft Services in the UK.

Within these Cleft Services are one or more Cleft Teams based at specific hospitals.

Some are **children's hospitals**, but because this is where the Cleft Team is based, this is where you'll be referred to initially.

Visit **clapa.com/nhs** to get the most up-to-date contact details and information on how each Cleft Team handles referrals.

For general information on getting a referral, see Page 7.

**1. Royal Hospital for Sick Children: GLASGOW**

National Cleft Surgical Service for Scotland

T: 0141 451 6524

**2. Royal Belfast Children's Hospital for Sick Children: BELFAST**

Northern Ireland Cleft Service

T: 028 9615 5961

**3. Royal Victoria Infirmary: NEWCASTLE-UPON-TYNE**

Northern & Yorkshire Cleft Service

T: 0191 282 0750

**4. Leeds General Infirmary: LEEDS**

Northern & Yorkshire Cleft Service

T: 0113 392 5115

**5. Alder Hey Children's Hospital: LIVERPOOL**

Northwest England, Isle of Man & North Wales Cleft Service

T: 0151 252 5209

**6. Royal Manchester Children's Hospital: MANCHESTER**

Northwest England, Isle of Man & North Wales Cleft Service

T: 0161 701 9091

**7. Nottingham City Hospital: NOTTINGHAM**

Trent Cleft Service

T: 0115 969 1169

**8. Birmingham Children's Hospital: BIRMINGHAM**

West Midlands Cleft Service

T: 0121 333 8459 or 0121 333 8235

**Queen Elizabeth Hospital (Over 16s): BIRMINGHAM**

T: 0121 371 4991 or 0121 627 2000

**9. Addenbrookes Hospital: CAMBRIDGE**

Cleft Net East

T: 01223 596 272

**10. Morriston Hospital: SWANSEA**

The Welsh Centre for Cleft Lip and Palate

T: 01792 703 810

**11. University of Bristol Dental Hospital: BRISTOL**

South West Cleft Service

T: 0117 342 1177

**12. Salisbury District Hospital: SALISBURY**

Spires Cleft Service

T: 01722 345 521

**13. John Radcliffe Hospital: OXFORD**

Spires Cleft Service

T: 01865 226 965 / 234 339 / 231 450

**14. Great Ormond Street Hospital: LONDON**

North Thames Cleft Service

T: 020 7829 7922

**15. Guy's & St Thomas' Hospital: LONDON**

The Evelina Centre for Cleft Lip and Palate

T: 020 7188 1321

**16. Broomfield Hospital: CHELMSFORD**

North Thames Cleft Service

T: 01245 516 201

# Accessing the Cleft Team

**This section provides an overview of how you can access NHS cleft care as an adult patient.**

- How do I get a referral to my local Cleft Team?
- What if my GP or dentist won't refer me to the Cleft Team?
- How do I self-refer to a Cleft Team?
- What if I am referred to the wrong place?
- Is there an age limit to returning to cleft treatment?
- What if I don't know which specialist I need to see?
- How long should I expect to wait before the Cleft Team will see me?
- What happens when I see the Cleft Team as an adult?
- What happens if I move house?
- Or if I move overseas?

## How do I get a referral to my local Cleft Team?

Most Cleft Teams in the UK require a referral **from your GP or dentist**, although some Cleft Teams will accept a **self-referral**. This will depend on where you live.

To get a referral from your GP or dentist, tell them you would like to be referred to your local Cleft Team for specialist assessment. This can be for a particular concern related to your cleft, or for a general assessment.

It can be helpful to know the hospital where your local Cleft Team is based and the name of the service.

**You can find a list of local Cleft Teams on Page 5**.

You can share this with your GP or dentist to help ensure they refer you to the right place.

Please note that a referral to a Cleft Team does not guarantee you treatment, but it will ensure you get the chance to talk to specialists who can give you the best possible advice.

If you need any help, or are finding it difficult to have a referral processed, visit **clapa.com/adults** or **contact CLAPA (Page 2)**.

## What if my GP or dentist won't refer me to the Cleft Team?

Sometimes GPs and dentists are unfamiliar with how cleft care works and may incorrectly believe you're not eligible for treatment as an adult.

**Adults entitled to receive NHS services may return to cleft care at any age** and may seek a specialist assessment from a Cleft Team for any reason related to their cleft, **even for cosmetic concerns**.

If your GP or dentist won't refer you, they should explain why and what the next steps are. If you don't think this is right and still want to see the Cleft Team, you can ask them to reconsider.

At this point it may be helpful to show them the **letter to GPs and dentists** enclosed in this guide which explains why you're eligible for a referral to a Cleft Team and how they can arrange this. You can request additional printed copies of this letter or download a copy at **clapa.com/adults**.

If your dentist or GP is still reluctant, ask them to phone the Cleft Team for advice. It may help to provide the contact details found at **clapa.com/NHS**.

If they refuse to do this, contact your local Cleft Team directly and ask for their help. They will usually contact your GP directly.

You can also **contact CLAPA** for support; see **Page 2** for details.

## How do I self-refer to a Cleft Team?

Some Cleft Teams accept self-referrals, meaning you do not need to go through your GP or dentist. See **clapa.com/NHS** for an up-to-date list of which teams accept self-referrals.

You can also contact your Cleft Team directly by phone or email to ask if they accept self-referrals.

The process for self-referring to a Cleft Team will be slightly different for each team. It's best to get in touch directly to ask about how you can do this.

## What if I'm referred to the wrong place?

When asking your GP or dentist to make a referral, it can help to provide them with details of your local Cleft Team to make sure they send you to the right place.

Some adults returning to cleft treatment are mistakenly referred to a **generic plastic surgery, maxillofacial or ENT department**, either at the same hospital as the Cleft Team is in, or in a different hospital altogether.

If you think this may have happened, either call the number on your appointment letter, or ask at your appointment whether or not you have reached the adult cleft clinic. If it is not the cleft clinic, you can request a re-referral to the correct place.

## Is there an age limit to returning to cleft treatment?

Adults are entitled to return for specialist assessment under the Cleft Team **at any age**.

Some treatments have more risks when you are older. If that is the case, your Cleft Team will discuss these risks and any other options with you.

## What if I don't know which specialist I need to see?

You don't need to know which specialist you want to see before you seek a referral.

Visit your GP or dentist and ask them to refer you to the Cleft Team for a general assessment of your concerns related to your cleft.

The discussion in your first appointment will **help the Cleft Team understand your concerns and decide which specialists you need to see** in order to continue with your treatment, if appropriate.

## How long should I expect to wait before the Cleft Team will see me?

The length of time it takes for a referral to be picked up depends on where in the UK you are based, which specialist(s) you are waiting to see, and a variety of other factors.

You can ask your GP for a copy of the referral letter for your own records so you can keep track of dates and other details.

You can contact the Cleft Team directly at any time for an update on the progress of your referral.

## What happens when I see the Cleft Team as an adult?

Returning to the Cleft Team as an adult patient may be a little different to your memory of cleft services as a child. Different teams work with adults in different ways.

If your letter regarding your appointment does not specify what your first appointment involves, then you can always contact the Cleft Team and ask them what it entails and how long it will take.

Your first appointment as an adult might be with the whole Cleft Team (also called a 'multi-disciplinary team' or MDT) all at once. Alternatively, it may be with one or two members of the team who will refer you onwards as necessary. If you have any concerns about this, please speak to your Cleft Team beforehand.

No matter which clinicians you see, you'll be able to talk about any aspects of your cleft you'd like help with. They will take your concerns to other clinicians in the team as necessary and come up with a plan for your treatment.

If you have concerns or questions, it may be helpful to prepare a list in advance and to take a notebook and pen with you. You may also wish to bring a friend or family member along to support you.

After that first appointment, your future appointments will usually only be with the clinicians who are actively involved with your treatment.

In some cases, you may continue to have appointments with the whole Cleft Team if appropriate.

A list of people you may see in the multi-disciplinary Cleft Team can be found at: **clapa.com/nhs**

## What happens if I move house?

You may be able to be seen by the **same Cleft Team** as long as you're willing to travel. You will need to make sure you update your GP and/or Cleft Team with your new address.

If you want to switch to a **Cleft Team closer to you**, you will need to get a new referral to that team. This could be a referral from your current Cleft Team or through a GP or dentist.

Depending on where you are moving to, the Cleft Team may be able to accept a self-referral.

If you're switching, make sure to **let your existing Cleft Team know** where and when you are moving.

## What happens if I move overseas?

Depending on the health system in the country you're moving to, you may not be able to access cleft treatment as an adult, or you may have to pay for it.

Not all countries have dedicated Cleft Teams, so you may not get the same treatment as you would expect in the UK.

If you're travelling on a visa, it's worth checking if your visa includes cleft care, or if your travel insurance covers any emergency care that you might need related to your cleft.

If you're under the care of a UK Cleft Team, talk to them about your plans to make sure they'll be able to send any records to the right place.

They may also advise on your travel plans with regards to any recent or upcoming surgeries.

> I always enjoy meeting up with others like me, and sharing our experiences and just talking freely about stuff with no judgement. It's always nice when new people come along and you can hear about their situation and hopefully reassure them and tell them about how things have been for you."

# The Cleft Team & Clinical Psychology

**This section explains why Clinical Psychology professionals are part of the Cleft Teams, provides an overview of common psychological concerns related to cleft, and explains what the Cleft Team Clinical Psychologist can help with.**

- Why do Cleft Teams have a Clinical Psychologist?
- Do people born with a cleft normally have issues with emotional wellbeing?
- What kinds of issues do Clinical Psychologists in the Cleft Team offer support for?

## Why do Cleft Teams have a Clinical Psychologist?

Being born with a cleft often means having to face experiences others would not usually have to, such as frequent hospital appointments and/or surgery. It may also involve treatment not going as planned, receiving negative comments or having challenging interactions related to your cleft.

In some Cleft Teams, returning adult patients will see a Clinical Psychologist as **part of the standard care pathway**.

This is to ensure you have the opportunity to discuss the feelings (past and present) you have about your cleft and related care, to discuss your hopes and expectations of further treatment, and hear about the role of psychology and options for support, if appropriate.

## Do people born with a cleft normally have issues with emotional wellbeing?

Everyone born with a cleft will have different experiences, so there is no 'normal' way this will affect someone.

Some people don't feel their cleft has a significant negative impact on their life, whilst others find it very challenging. Some may have found it difficult only at certain times, or around particular events such as surgery, whilst others may have considered it to have impacted their lives more broadly.

If someone's cleft affects their wellbeing, the exact way it affects them will also vary. For example, someone might worry others will judge them negatively because of their cleft, leading to them feeling anxious when meeting new people.

Another person may not worry about this but struggle daily with the frustration of others not being able to understand their speech.

Because having a cleft can present challenges, it is completely understandable if you do **experience difficult thoughts and feelings**.

Nobody in the Cleft Team will judge you for this and, importantly, you should not judge yourself either.

Talking about these things can be very helpful for your emotional wellbeing.

## What kinds of issues does the Clinical Psychology team offer support for?

The Clinical Psychology team within a cleft service offers support for any psychological or social issues related to being born with a cleft.

Common issues or concerns include:

- Difficult feelings about being born with a cleft
- Feelings about treatment (i.e. decision making, expectations, anxiety)
- Difficulties in social situations or relationships (e.g. social anxiety, feeling 'different')
- Coping with comments and questions
- Coping with teasing and bullying
- Coping with difficult past experiences (e.g. surgery, social experiences)
- Impact on confidence and self-esteem
- Cleft-related difficulties in work/education

# Mental Health

**General mental health conditions may be made worse by your cleft-related experiences but are not usually caused entirely by having been born with a cleft.**

**This section provides an overview of these conditions and the support available.**

- I have (or think I may have) a mental health issue. Can the Cleft Clinical Psychology team help?
- What if I'm not sure if my cleft is related to my mental health issue?
- I would like to see or speak to one of the Cleft Team Clinical Psychologists. How do I do this?
- How do I know if I might be having an issue with my mental health?
- How can I receive support for my mental health?
- What services does CLAPA provide to support emotional wellbeing?

## I have (or think I may have) a mental health issue. Can the Cleft Clinical Psychology team help?

Mental health issues can impact different areas of one's life significantly. A 'mental health issue' usually means a recognised group of symptoms that, when seen together, are given a diagnosis such as 'anxiety' or 'depression'.

Whether or not this is something the Cleft Clinical Psychology team would help with **depends on if you feel it is related to your cleft**. For example, if someone experiences a high level of anxiety when meeting people, with the main worry being they will be judged negatively because of their cleft, the cleft is a clear part of the concern. This concern (cleft-specific social anxiety) is something that the Cleft Clinical Psychology Team would therefore consider offering support for.

If someone experiences the same level of anxiety, but mostly in situations unrelated to cleft (e.g. worrying that every task in their daily life will go wrong somehow), the cleft is not a clear part of the concern. Support for this concern (generalised anxiety) may therefore best be provided by a different service such as a local mental health team or talking therapies service.

The best way to access general mental health support is by talking to your GP. You may also be able to self-refer by searching **'NHS Talking Therapies'** online.

If the issues you experience are very serious (e.g. if you are at severe risk of harm), the Cleft Clinical Psychology Team will always refer you to an appropriate mental health team who can give you more frequent, closely managed care.

## What if I'm not sure if my cleft is related to my mental health issue?

The Cleft Clinical Psychology Team can discuss this with you and take time to understand whether your concerns would best be supported by their team or another service.

If you suspect an issue is probably not related to your cleft, it is a good idea to seek a referral to your local mental health team as soon as possible, either online or through your GP. This is because some mental health teams have a long waiting list, so waiting until after you have seen the Cleft Team to join this list would mean a longer wait. You may also be able to self-refer to some local mental health services. For details search 'NHS Mental Health'.

Unfortunately, the Cleft Team Clinical Psychologist cannot make a referral to a mental health team any faster than your GP or by self-referral.

## I would like to see or speak to one of the Cleft Team Clinical Psychologists. How do I do this?

You need to get a referral to your local Cleft Team. See '**Accessing the Cleft Team**' on **Page 7** for more information.

Once you're under a Cleft Team's care, you should be given the contact details for the Cleft Clinical Psychology Team or you can raise this at your next appointment.

## How do I know if I might be having an issue with my mental health?

There are many different symptoms of mental health issues, and the presence of any of these does not necessarily mean there is a problem.

Signs you *might* have an issue with your mental health include:

- Difficulty with mood e.g. feeling low, angry and/or anxious a lot of the time.
- Difficulty doing things you need to do in your daily life e.g. work, education, social activities.
- Difficulties with relationships.
- Difficulties with or changes to sleeping and/or eating.
- Using drugs and/or alcohol to cope with problems.

## How can I receive support for my mental health?

- Talk to someone you know and trust about it.
- Check out **self-help** material on the NHS website by searching **'NHS mental health self-help'** to find resources on a wide range of mental health issues.
- For professional support, talk to your GP or find local services on the NHS website by searching '**NHS Talking Therapies**' online.

- For 24 hour support, call **Samaritans** on **116 123** for their free counselling service.
- If you think you are having a mental health crisis and need urgent help:
  - Call your local crisis number (if your local mental health team has already given you one)
  - Search for 'NHS Mental Health Crisis' for local phone numbers and resources
  - Contact your GP and ask for an emergency appointment
  - Call NHS 111 (for non-life-threatening concerns) or 999 if you think your life may be at risk

## What services does CLAPA provide to support emotional wellbeing?

CLAPA offers a range of support services and resources to support your emotional wellbeing. These include one-to-one support services, groups, events, online videos, podcasts and other information.

These services are free of charge and are open to all adults in the UK who were born with a cleft.

You can find a list of **CLAPA's support services for adults** on **Page 45** or visit **clapa.com/adults**.

# Surgery & Recovery

**This section provides an overview of surgical treatment options in adulthood, the process on the day of surgery, and recovery.**

- What surgical treatment is available for adults born with a cleft?
- If treatment is available, do I have to have it done?
- Can I change my mind about a treatment plan or procedure?
- I'm scared of needles – are there other options for anaesthetic?
- What happens on the day of surgery?
- Will I be able to eat and drink normally after an operation or dental procedure?
- How long will it take me to recover?
- How much time off work/study/leisure activities will I need?
- Do I need to give my employer details of my surgery?
- What support and follow-up is available after surgery?

**We would strongly recommend going to your Cleft Team with any questions or concerns if you're considering further treatment, as they will be able to give you more personal, relevant answers.**

## What surgical treatment is available for adults born with a cleft?

There are a number of potential surgical treatment options available as an adult. Not all options are suitable or available for all people, so talk to your Cleft Team about what treatment may be suitable for you.

Some common procedures for adult cleft patients include:

**Fistula Repair**: Surgery to repair any holes left in the roof of your mouth that can affect speech, cause food to become stuck, or lead to food and/or fluid coming down your nose.

Surgery to address **speech concerns** (e.g. palate lengthening).

**Jaw surgery** (orthognathic surgery): Major surgery to bring your top and bottom jaws in line with each other. This may be to address concerns with function (i.e. chewing, biting) and/or appearance.

**Rhinoplasty**: Surgery to change the shape of the nose. This may be to address concerns with breathing and/or appearance.

**Lip revisions:** Surgery to change the shape of the lip. This may be to address concerns with discomfort (e.g. scar tightness) and/or appearance.

Consult with your Cleft Team about your concerns – they can advise what kind of treatment (surgical or otherwise) might be appropriate for you.

To get surgical treatment from the Cleft Team, the issue the surgery is addressing **must relate to your specific cleft type**. For example, if you were born with an isolated cleft palate (a gap in the roof of the mouth only), this would not affect the shape of your nose, so you would not be eligible for a rhinoplasty through your Cleft Team.

## If treatment is available, do I have to have it done?

Treatment as an adult is **optional**, so it's up to you whether to have it done or not.

Talk to trusted family, friends and you Cleft Team about treatment options before you make your decision.

It may help to talk to others born with a cleft about their experiences of decision-making for treatment or read through their stories. Visit **clapa.com/adults** to read stories from other adults or see the list of **CLAPA Support Services** on **Page 45** which can put you in touch with another adult with experience of returning to cleft treatment.

The Cleft Clinical Psychology team can talk things through with you to help you come to a decision and make sure your expectations are in line with what's possible.

## Can I change my mind about a treatment plan, dental or surgical procedure?

**Yes.** Talk to your Cleft Team about your concerns and they will support you with any changes and arrangements.

You can also ask to be removed from a waiting list if you are currently waiting for treatment.

It's important to be aware that, very occasionally, treatment that you've already started cannot be reversed (e.g. orthodontic treatment in preparation for jaw surgery).

Make sure you talk to the Cleft Team about what would happen if you should change your mind about any planned treatment.

## I'm scared of needles – are there other options for anaesthetic?

If you have a fear of needles, make sure to raise this with your Cleft Team before your operation. This could be when meeting with your surgeon, anaesthetist, or anyone involved with your surgery. You can also contact them about this at any time before your operation.

The team will discuss other options with you. These could include applying EMLA cream to numb your skin prior to injection.

If your needle phobia is severe, you may be able to have a gas induction instead. During a gas induction, you'll have a mask placed over your face and asked be to breathe in some gas  which will send you to sleep. Once you are asleep, the needle will be put in; you won't see or feel a thing.

**Don't be afraid to let them know** if you don't like needles. By informing the team, you're helping them to take better care of you.

The Clinical Psychologist in your team can provide therapy if you have worries related to treatment and think this would be helpful.

## What happens on the day of surgery?

Every hospital's procedure will be a little different, so it's worth asking for details at your pre-operative appointment (usually a couple of weeks before your procedure) for more specific information.

Most hospitals will also give you a booklet and other information about what to expect on the day. This should answer most of your questions.

It may not be safe for you to go in for surgery if you have a cough or a cold in the days leading up to it.

Contact your Cleft Team if you are unwell, as the surgery may need to be rescheduled. To be in the best health for the surgery, and to give yourself the best chance at healing, it's important to follow any advice from your Cleft Team (such as avoiding smoking) before the surgery and until the wounds are completely healed.

**The process on the day of surgery will be something like this:**

1. Depending on the instructions on your admissions letter, you will probably not be able to eat anything after a certain time the night before your surgery. You might also not be able to drink anything after a certain time.

   For your own safety, it's **vital that you follow these instructions** exactly and ask for clarification if you're not sure.

2. Once you arrive at the hospital on the day of your surgery, you'll head to the **admissions area** indicated on your admissions letter. Here they will check your name, date of birth, and the reason you're in hospital. They may ask you multiple times to confirm this information throughout your stay. This is one of many ways the hospital makes sure the right treatment is given to the right person.

   You'll also be given a bracelet to wear on your wrist which contains your name, address, and date of birth. You'll keep this on throughout your entire stay in hospital.

3. Once you've been 'checked in' a **nurse and/or anaesthetist** will ensure you're still fit for the operation; this might involve checking your blood pressure and other details. You'll be asked about any recent illnesses or injuries, as well as any medicines you may be taking, or allergies you may have.

   Your surgeon will also visit to have a chat. This is a great time to ask any final questions before going to theatre.

4. Each surgical theatre has a 'list' for the day. This is the **order the operations will happen that day**.

   If you are first on the list you'll usually be taken to theatre around 8-9 in the morning. If you're further down the list you may not be taken to theatre until the afternoon. Feel free to ask where you are on the list to give you an idea of when you might go to theatre. **You can't eat or drink before the surgery** and you may be waiting a while, so take a book or something else to keep you occupied while you wait.

5. At some point, usually before the nurse and/or anaesthetist checks you over, you will be asked to **change into a hospital gown** and put compression stockings on your legs. Blankets will be available to keep you warm. Your belongings will usually be put in a plastic bag which can be left with any friends or family accompanying you, or passed on to the ward in which you will be recovering.

6. When it is time for your operation an orderly will come and collect you to **take you to theatre**. Any family or friends won't be able to follow you past this point. Some hospitals will wheel you into theatre on the bed, other hospitals will ask you to walk to theatre if you're able to do so.

7. Once you arrive in **theatre** you'll be asked to lie on the bed. You will have a few sticky pads put onto your chest and abdomen so the anaesthetist can monitor your heart and lungs while you're asleep. These pads may be cold, but they won't hurt. They will then clip wires into each of the pads and connect them to a machine.

   You may also have a leg compression device placed on your legs if you're going to have a long operation or be bedbound for a while afterwards. This machine will help to stop blood clots from developing in your legs.

   Once you're ready to be put to sleep, the **anaesthetist** will talk to you and start the process usually by placing a needle (cannula) in your hand or arm, or sometimes by getting you to breathe in anaesthetic gas through a mask.

   Some procedures, such as some lip revisions, do not require a general anaesthetic (which puts you to sleep), but are instead done using local anaesthetic (which numbs sensation in the area while you're awake). The Cleft Team will let you know what kind of anaesthetic you will have.

8. The next thing you know, you will **wake up in the recovery ward**. It may feel a bit disorientating at first, but a nurse will be right there monitoring you the whole time, so you can be assured you're in safe hands.

   Sometimes during long operations, the doctors need to insert a **catheter**, which is a tube that goes into your bladder and allows it to empty without you having to go to the bathroom. This will be removed once you are able to walk around.

   You'll be kept on the recovery ward for a little while until the anaesthetic wears off and you can be wheeled back up to the ward where you'll stay after the surgery.

9. You may be told **how long your operation is likely to take**, but keep in mind that this is usually the length of the operation itself and might not account for the preparation involved and the time you spend 'waking up' in the recovery ward. This means that you'll probably be 'away' longer than the time given.

   Any **family or friends** with you should provide a contact number so this can be passed on to the ward you'll be recovering in. Ward staff will call this number when you're settled in the ward after surgery and ready for visitors.

10. How long you have to **stay on the ward** is something your team will let you know. You may be out on the same day, or have to stay a night or two depending on the treatment you have and how your recovery goes.

## Will I be able to eat and drink normally after an operation or dental procedure?

Some treatments have very strict dietary requirements afterwards (e.g. a soft diet for some weeks after surgery), whilst others have no particular restrictions regarding what you can eat.

However, even if there are no dietary requirements, you might find that side effects from the anaesthetic or discomfort following surgery change your appetite for a short while.

The surgical team will be able to provide more detailed instructions at the time which are procedure specific.

If a special diet is required, it's a good idea to make sure you have some suitable foods already at home for when you return.

## How long will it take me to recover?

This will depend on the operation, so it is best to ask your Cleft Team what to expect in your case. Everyone heals at different rates, so this may vary for you.

To help your body heal, it's important to avoid smoking both before and after the surgery.

Some procedures may result in soreness, tenderness or discomfort. You will be given advice on pain relief.

Recovery from the anaesthetic and other medications can take some time too, and may make you feel very sleepy. You may also experience short term side effects including nausea and constipation.

Bruising (e.g. dark bruises under the eyes if you have had a rhinoplasty) can take a few weeks to settle down.

Most swelling will go down in the first week or two, but don't be surprised if it takes a few months for all of the swelling to completely disappear.

Some procedures are not thought to have reached the 'final' result until a year afterwards.

Any new scars made (e.g. from a lip revision) can take weeks or months to reduce in redness.

You may also be expected to wear bandages or other dressings for some time after surgery.

If you have any concerns about coping with these visible changes after surgery, you might find it helpful to talk to the Clinical Psychology Team about how to manage this.

## How much time off work/study/leisure activities will I need?

This will depend on the type of work and activities you do and the treatment you've had. You will need to speak to your Cleft Team for more advice on this. However, you would generally expect to be back to work, study and other activities sooner if what you do is not very physically demanding (e.g. working in an office or from home).

Having time off work as an adult can have a financial impact. Make sure you check your employer's policies around this and ask any questions around this in advance to ensure you are confident about taking the time you need to recover.

## Do I need to give my employer details of my surgery?

Legally, all you need to tell your employer is that you will be taking medical leave and provide a doctor's note confirming how long this is expected to last. You do not need to tell your employer that you are having surgery or what it is for.

If you feel comfortable to do so, it can be helpful to explain what the surgery is for and if, for example, there will be changes to your appearance, or if you will need any other support upon returning to work. This is entirely up to you, however.

Some employers' medical leave policies will not cover surgery which is 'purely elective' or 'cosmetic'. If your employer refuses your request to take medical leave on these grounds, talk to your Cleft Team.

They may be able to provide proof to your employer that your surgery is medically necessary.

**Search 'sick leave' on Gov.uk or Acas.org.uk** for more information about your rights and what you can do if you believe you are facing discrimination from your employer.

## What support and follow up is available after surgery?

This depends on the procedure and on the Cleft Team or consultant's practices. Your consultation before the surgery is a good chance to ask about what to expect afterwards.

For example, if you need to come back in to have stitches removed, or what to do if you experience excessive bleeding, etc.

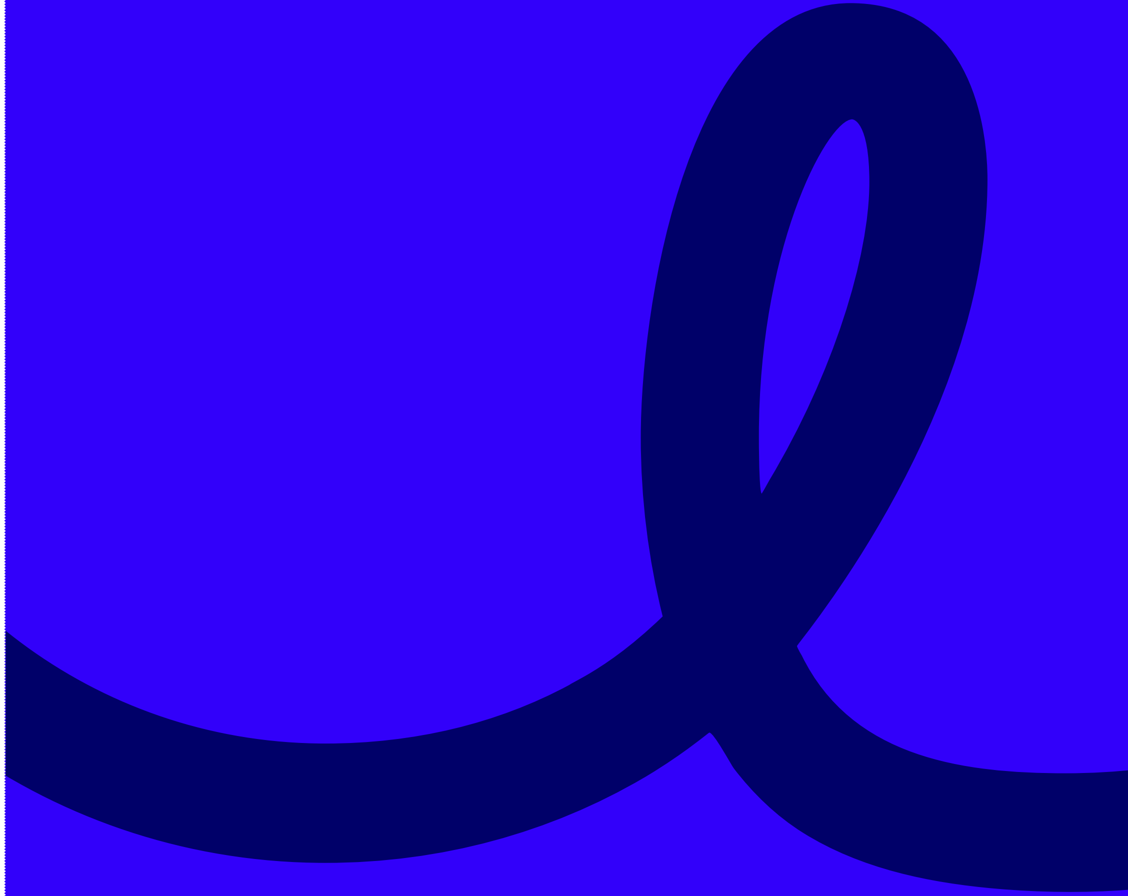
If you're having surgery done privately, make sure to have a look at the section on Private Treatment on Page 34, as there are a few extra things to keep in mind.

> It was very reassuring to hear that I wasn't alone. I'd hit a bad spot in my adult life and lots of memories as a child dealing with a cleft had come flooding back to me. [My peer supporter] offered a way to seek help for my teeth issues through a referral from my GP to the cleft team. This made me feel so much better about myself, that there was help out there.

# Speech & Hearing

**While cleft-related speech and hearing issues are usually resolved in childhood, it's not uncommon for some to persist or reoccur in adulthood. This section gives you an overview of speech and hearing concerns and the support available for them.**

- Why might I want speech therapy?
- What can I do at home to improve my speech?
- What support is available if I'm having difficulties with my hearing?



## Why might I want speech therapy?

You may wish to visit a speech and language therapist for a number of different concerns in adulthood, such as:

- **Hypernasality:** too much air coming through the nose when you speak.
- **Hyponasality:** too little air coming through the nose on certain sounds.
- **Articulation disorders:** difficulties making specific sounds.
- **Voice disorders:** breathiness, hoarse voice or vocal nodules.

Sometimes these concerns can be resolved with speech and language therapy, surgery or both together.

You may be referred to your community speech and language therapist for treatment closer to where you live.

### What can I do at home to improve my speech?

Your speech and language therapist can assess you to figure out what is causing the difficulties you're having and help put together a treatment plan that's right for you.

There are often **exercises** you can practise at home which your speech and language therapist will be able to show you.

Sometimes, speech and language therapy alone won't result in significant change. In these cases, surgery or physical appliances (such as a 'speech plate' or 'nasal obturator') may be suggested as a potential way of addressing speech concerns.

## What support is available if I'm having difficulties with my hearing?

You can talk to your GP to arrange a hearing test or you can talk to your Cleft Team if you think you might be having difficulties with hearing because of your cleft. They may be able to arrange for you to see someone in Audiology or ENT (Ear, Nose and Throat) with your Cleft Team or locally.

You may also talk to the Clinical Psychology Team within your Cleft Team if you have any concerns you'd like to talk through, e.g. if you feel self-conscious about wearing hearing aids.

Even if you think your hearing difficulties are **nothing to do with your cleft**, it is still advisable to **let your Cleft Team know** and to seek their advice.

This is because some of the routine treatments for hearing difficulties **might not be appropriate for people who were born with a cleft**.

If you are concerned about your hearing at any point, you can get a hearing test done at most opticians.

Many of them offer this service for free, so it's always worth checking.

You may find more information on hearing loss at **rnid.org.uk**

# Restorative Dental & Orthodontics

**This section provides an overview of dental care and orthodontics, cleft-specific dental concerns, and information about the support and treatment available.**

- How often should I see my General Dental Practitioner (family dentist) and what care will they provide?
- What dental treatment may be available to me as an adult through the Cleft Team?
- When should I see my General Dental Practitioner (family dentist) vs the Cleft Team?
- What will it cost to visit the dentist?
- What can I do if I'm scared of going to the dentist?

## How often should I see my General Dental Practitioner (family dentist) and what care will they provide?

Generally, you should see your General Dental Practitioner (family dentist) up to twice a year for checkups and cleaning. Your family dentist will tell you if they need to see you more often.

They should check if you are keeping your mouth clean enough, consider your gum health, and look closely at your teeth to check if any are developing cavities. Your dentist should also provide any cleaning and most of the dental treatment you need.

For some treatments, your dentist will ask for specialist advice and support from a consultant in restorative dentistry, who usually works as part of the Cleft Team.

## What dental treatment may be available to me as an adult through the Cleft Team?

If you are referred to see the Cleft Team, the team will work together to look for a solution to your problems, including any dental issues. Even if you think there may not be any options for your teeth, or you were told many years ago no further treatment is available for you, it's worth checking with the Cleft Team's restorative dentist and/or orthodontist.

The restorative dentist will restore teeth and replace missing teeth, as well as help you achieve better dental health. The treatments include fillings, dentures, crowns, braces, bridges, veneers, and, in some cases, dental implants.

- A **denture** is a removable plate or frame holding one or more artificial teeth. They are made of acrylic, or acrylic with a metal alloy of cobalt and chromium.
- A **crown** is a type of fixed dental restoration that completely covers a tooth. A crown may be needed when a large dental cavity cannot be restored with a filling.
- A **bridge** is a fixed dental restoration that's used to replace one or more missing teeth by joining an artificial tooth to one or more of the adjacent teeth.
- A **veneer** is a fixed dental restoration that is bonded to the tooth surface, to change the surface, shape or shade of a tooth. They are usually thin layers of porcelain or composite resin.
- A **dental implant** is a titanium metal screw which can be surgically placed into the socket bone from where a tooth is missing. The implant can then be restored with a crown, a bridge, or a denture.

Remember that cleft-related treatments conducted by the Cleft Team are **free of charge**, so always check with the Cleft Team first before exploring private treatment.

## When should I see my General Dental Practitioner vs the Cleft Team?

You should visit your General Dental Practitioner (family dentist) for the same reasons somebody without a cleft would. This would be for check-ups, cleanings, to check for decay, caries and cavities, or because you are experiencing sensitivity and pain not related to cleft (e.g. an abscess in one of your lower teeth).

You should see the Cleft Team's specialist restorative dentist for anything you believe has happened due to being born with a cleft, e.g. missing or extra upper teeth, differences in the shape of the upper teeth, pain or sensitivity in teeth near the cleft site. The restorative dentist can then advise you on the best course of treatment and who can provide this.

If you're unsure, contact your Cleft Team for advice on who to see.

## What will it cost to visit the dentist?

**Services through the Cleft Team**: Treatment related to your cleft, delivered by the Cleft Team, is free of charge.

General Dental Practitioner (family **dentist) services**: You will continue to see your family dentist for all your routine dental care, both during and after any treatment you have with the Cleft Team. There will usually be a charge for this, which depends on the treatment you require.

Charges will vary depending on whether you live in England, Northern Ireland, Scotland or Wales, and if you are registered with an NHS or private dentist.

Search **'NHS dental treatment costs'** and the country or region you live in to find up-to-date information.

## What can I do if I'm scared of going to the dentist?

If you are worried about seeing a dentist or having treatment, go with a trusted friend or family member for support, and talk to your dentist beforehand. They will be ready to help and calm you if you're feeling nervous. Some dentists advertise that they welcome nervous patients.

Speak to your Cleft Clinical Psychology Team if you are particularly worried about visiting the dentist, especially if fear is preventing you from visiting the dentist as often as you should.

The Oral Health Foundation provides confidential help and advice with dental issues. You can find their contact details here: **www.dentalhealth.org/contact**

# Julia's story

## "If I hadn't come across CLAPA I don't know where I'd be."

After struggling for many years, Julia now accesses regular treatment with her local NHS Cleft Team - thanks to CLAPA.

"I came across CLAPA in spring 2022, after I'd had the most horrendous visit with my regular dentist.

"I was in absolute floods of tears. I don't know how I drove home because I was crying so much. When I got in, I Googled 'cleft' and that's when I found CLAPA."

Julia, who was born with a bilateral cleft lip and palate, contacted CLAPA - and was immediately sent our 'Adults Guide to Returning to Cleft Care', including a letter for her dentist or doctor to refer her to an NHS cleft team.

"My GP was brilliant – the day I made contact a referral was sent off, and I'm now in the wonderful care of the NHS cleft team. It's been life changing.

"I now have a plate that fits properly from a cleft restorative dentist, I've seen a psychologist and speech therapist, and I'm on the waiting list for an operation.

"If I hadn't come across CLAPA I don't know where I'd be."

Julia attended our adult's conference last year and regularly attends CLAPA's monthly Adult's Lounge online.

"CLAPA has improved my life so much. I don't feel as isolated with my cleft and I'm so much more comfortable now talking about it.

"The support from CLAPA is just really nice and reassuring, like a big comfort blanket."

Julia said she found the adult's conference last summer particularly supportive.

"Being around so many people with cleft, in discussion groups and talks with different professionals, was just fantastic. I was so happy to be with all those people together in one room from all over the country.

"Talking to people older and thinking, 'well, they had an even worse journey than me, but they've come through it, and they're happy to talk about it', was eye-opening. And whatever someone can learn from me helps the generation below to get better treatment.

"Above all else, it's holding on to the fact that we're not alone anymore."

Julia said she's always shied away from the camera because of her cleft. At the adult's conference she had a photo session.

"I wasn't going to at first and then I thought, 'why not, what have I got to hide, why shouldn't I?'

"Afterwards I was chatting to the photographer, and he said he now understands how we feel - as he was the odd one out, not having a cleft.

"And it just brought tears to my eyes. I was in a room of all these people who looked like me and he was the odd one out - whereas all my life, I've been the odd one out in the room."

# Private Treatment

**This section provides an overview of what private treatment is, how to tell if your practitioner is suitably qualified, and what you should consider before going ahead with any private treatment.**

- What is Private Treatment?
- Can I see my NHS Cleft Consultant or another NHS Cleft Consultant privately?
- Should I tell my Cleft Team if I'm thinking about private treatment?
- Does Private Medical Insurance cover cleft treatment?
- Can private treatment do something the NHS Cleft Team can't?
- Are private practice practitioners always qualified?
- What happens if something goes wrong with private treatment?

## What is Private Treatment?

Any treatment done outside of the NHS is private treatment.

You usually have to pay for private treatment, although services paid for by a health insurer, or any free treatment through a charity, would also be considered private treatment.

Please note that CLAPA cannot fund or part-fund any treatment costs.

Private treatment might include speech therapy, clinical psychology/counselling/psychotherapy, orthodontics, dentistry, surgery, medical tattooing, or lip fillers.

## Can I see my NHS Cleft Consultant or another NHS Cleft Consultant privately?

Many NHS Cleft Consultants also operate privately so if you are considering private treatment, seeking out an NHS Consultant's private practice could be a good place to start.

Whilst we always recommend treatment on the NHS, there are many reasons why you may consider treatment privately, particularly as an adult. If the timing of an operation is important to you, then you may consider having surgery privately to have it done quicker. Or if you want a second opinion, whilst you can get this on the NHS, you may want to consider a private consultation.

If you choose to see a clinician privately that doesn't also work on an NHS Cleft Team, we recommend you ensure that they have experience in treating clefts.

## Should I tell my Cleft Team if I'm thinking about private treatment?

If the procedure or treatment is cleft related, it's likely it would be available free of charge through the Cleft Team, so it's worth asking them first.

If it's not available on the NHS, it is still recommended you talk to your Cleft Team so they can make sure it's the right thing for you.

Don't feel guilty or worry that the Cleft Team will be offended by you seeking treatment elsewhere. NHS teams understand patients may choose private treatment for a number of reasons. Some may be able to recommend private clinicians with appropriate experience.

If you're looking into private treatment because you're unhappy with your current Cleft Team clinician(s), you can seek a second opinion from a different specialist within your team, or from another Cleft Team.

To do this, talk to your Cleft Team or GP about your concerns and what you would like to do. Be aware that if you request a re-referral to another team, you will usually be treated as a new patient, and this can involve a long wait.

## Does Private Medical Insurance cover cleft treatment?

This depends on your individual policy; it's important to check the details and ask if you are unsure.

Some aspects of cleft care may be covered whilst others are not. For example, your policy may have a mental health provision but may not cover surgery. It's always worth checking with your provider on a case-by-case basis.

## Can private treatment do something the NHS Cleft Team can't?

In most cases, the NHS Cleft Teams are your best option for specialist, comprehensive treatment for concerns related to your cleft.

Your Cleft Team will have a good understanding of your medical history, individual needs, and the particular issues involved with treating a patient with a cleft.

A private practitioner may not have this understanding, and may make recommendations based on incomplete information.

It may be disappointing if your Cleft Team refuse to perform any more surgery for a particular issue. However, if you wish to seek surgery from elsewhere, carefully consider the risks in going against your team's recommendations. If you do decide to seek private treatment, make sure your private practitioner is informed about the reasons behind the Cleft Team's decision so this can be taken into account.

If you're unhappy with what your Cleft Team have told you, we would recommend seeking a second opinion from another Cleft Team before considering private care.

It's important to understand your hopes and expectations for the treatment you're seeking and to manage these appropriately. Even if the procedure is a success, there's always a risk you'll find yourself disappointed with the results of treatment.

Your Cleft Team Psychologist can help talk you through this, even for private treatment.

**If a private practice is recommending a treatment which your Cleft Team haven't recommended**, make sure you understand the reasons behind this and that you have enough time to think it over before agreeing to anything.

Private practices are generally run as businesses, so it is often (not always) in their best interests for you to have more treatment and therefore spend more money. It's important to remember your own goals for treatment and give yourself time and space to carefully consider any options available.

## Are private practice practitioners always qualified?

Most healthcare professions in the UK are protected titles. This means that a practitioner must be registered with a recognised professional body to be able to call themselves a practitioner and to practice in the UK, including in private practice. These professional bodies include the General Medical Council, Nursing & Midwifery Council, Health & Care Professions Council (HCPC), etc.

**If someone has the title 'Dr', this does not necessarily mean they are a medical doctor.** Some people who use the title 'Dr' have a non-medical professional doctorate degree for a different clinical profession (e.g. dentists and clinical psychologists).

Others may have an academic PhD that does not relate to clinical practice.

Surgeons who do have a medical degree (so were once called 'Dr'), traditionally revert to using the title Mr/Mrs/Ms if they complete their training in the UK.

**A good clinician will make their job title and qualifications clear and will not be offended if you ask them to clarify this.**

Some practitioners are not health professionals and do not have to be registered with the HCPC. This includes beauticians, who may perform procedures such as lip fillers or lip tattooing, or nutritionists who give dietary advice. In these professions, there are vast differences in the amount of training different practitioners have had, so you want to be sure you are with someone reputable who has performed your procedure many times before. Some local authorities regulate beauty salons, many others do not. Contact your local authority if you have any questions about a particular beauty salon.

## What happens if something goes wrong with private treatment?

The practice should explain exactly what follow-up care is included in the cost of your treatment and what will happen if things don't go as planned, including any potential extra costs.

You should also be told what to do if you start experiencing problems suddenly or out of hours.

Some treatments are more complicated or need to be performed differently when somebody has been born with a cleft. Make sure you feel comfortable that the practitioner understands, and is experienced with, cleft.

# Genetics

**One of the most common questions for adults who were born with a cleft is whether their children will be born with one too. This section provides an overview of genetic component of cleft, as well as the support services available. You do not have to be thinking about having children now to access these services.**

- What causes a cleft?
- Will my child(ren) be born with a cleft?
- What is genetic counselling?
- How do I access genetic counselling?
- I also have a syndrome linked to my cleft. How can I access more information and support?

## What causes a cleft?

There is no single cause. A cleft can be caused by many different factors, most of which are not in our control.

Cleft can occur by itself or as part of a wider condition or syndrome (such as Stickler Syndrome).

Most clefts are caused by many different factors coming together while a baby is growing in the womb.

This is usually a combination of the genes we inherit from our parents and the environment we are exposed to during pregnancy.

Some examples of environmental exposure could include hyperthermia (being too hot), stress, maternal health, lifestyle and diet factors, occupational exposures and infection.

A cleft is not anyone's 'fault'. In the vast majority of cases, there is no single cause identified for why the cleft has happened.

## Will my child(ren) be born with a cleft?

In around 1 in 50 cases, adults born with a cleft who have no other affected family members will have a baby born with a cleft.

Generally speaking, the more people who have a cleft in your family and the closer they are to you in your family tree, the more likely you are to have a baby with a cleft.

This chance can be much higher if your cleft is the result of a syndrome.

A genetic specialist (such as a consultant geneticist or genetic counsellor) will be able to help you understand your specific situation and give appropriate advice.

## What is genetic counselling?

Genetic counselling provides support, information and advice about genetic conditions. You can have genetic counselling through your NHS Cleft Team.

Genetic testing can be used to find out whether a person is carrying a specific alteration in a gene (known as a genetic variant or 'mutation') that can cause a particular medical condition such as cleft.

A consultant geneticist is a medical doctor with specialist training in genetic conditions. A genetic counsellor is a non-medical clinician with specific expertise in providing information and support about genetic conditions. You may meet one or both of these specialists in a genetic appointment.

A geneticist will often start by drawing a family tree to determine any history of cleft or other condition in your family. They will give you an **idea of the likelihood of any future children having a cleft**.

Sometimes they may take a saliva or blood test to check for specific syndromes or conditions.

Most people find genetic counselling to be a reassuring experience.

If there is another condition in your family you are concerned about, you can let the geneticist know whether you would like to know more about this.

More information on genetic counselling is available on the NHS website; search for **'NHS Genetic Services'**.

## How do I access genetic counselling?

You can access genetic counselling through your Cleft Team. If you're currently being seen by someone else on the team, you can ask to be referred to the geneticist at your next appointment.

You can access genetic counselling **at any time**. You don't have to wait until you are in a relationship and planning to have children to see the genetic specialist.

Because genetic counselling is part of NHS cleft treatment, it is free of charge.

**I also have a syndrome linked to my cleft. How can I access more information and support?**

If you have a syndrome linked to your cleft or suspect you may have a syndrome and would like more support, please contact your local Cleft Team for advice.

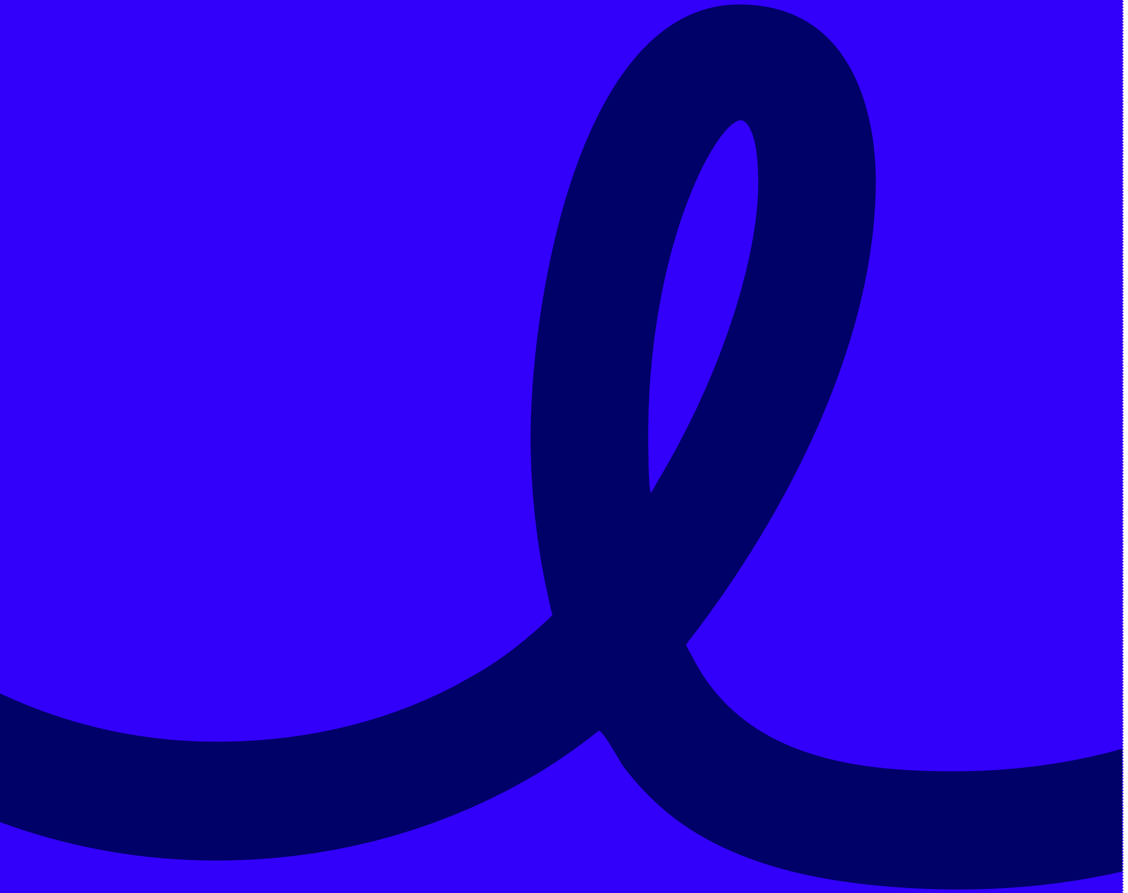
Alternatively you can contact Unique, a charity that specializes in rare genetic conditions and syndromes, at **rarechromo.org**

> It was helpful to hear about other people's experiences, feel understood, and get support/ advice on how to approach health services in regard to cleft related issues.

# Bullying & Discrimination

**This section explains what bullying, harassment and discrimination are, what support is available, and your legal rights around discrimination.**

- What is bullying and harassment?
- What effect does bullying have?
- What can I do if I'm experiencing bullying?
- What can I do if I experienced bullying in the past?



## What is bullying and harassment?

Bullying and harassment is behaviour which makes someone feel intimidated, excluded or offended.

Harassment is unlawful under the Equality Act 2010.

Bullying can include arguments and rudeness, but it can also be more subtle.

Some adults born with a cleft experience bullying, harassment, or discrimination in the workplace.

Sometimes this may be related to their cleft or could be related to other things. This is known as workplace bullying.

Workplace bullying rarely involves overt behaviours such as physical aggression; it is usually more subtle.

This can include:

- Spreading malicious rumours
- Being treated unfairly
- Being regularly picked on or undermined
- Being denied training or promotion opportunities
- Being excluded
- Not being credited for your contribution
- Being overloaded with work
- Being expected to work extra hours without pay

Workplace bullying can happen face to face, by letter, email, text messages or phone calls.

You may find yourself targeted by bullying for any number of reasons, which may include your appearance or speech.

## What effect does bullying have?

Bullying can make you feel miserable and can sometimes lead to significant mental health issues.

It can make you not want to go to work, find it hard to motivate yourself, and cause you to lose confidence in yourself and your abilities. This can lead to feeling isolated, withdrawn, angry, upset or unwell.

## What can I do if I'm experiencing bullying?

Don't be ashamed to tell people what's going on.

Bullying is serious, and you may need help from other people to solve it. By sharing your experiences you may discover other people are experiencing it too.

Recognise that bullying does not happen because you deserve it. It reflects only the bully's own behaviour and is often an attempt to intimidate, undermine and/or control you.

Don’t be tempted to explain your behaviour – rather, ask them to explain theirs (if you feel comfortable to do so).

Keep a diary of the bullying. This may be useful if you decide to take action later.

If you’re experiencing bullying in the workplace, you should speak to someone who can help. This may be an employee representative, such as a trade union official, someone in your Human Resources (HR) department, or your manager or supervisor (unless they are the one who is bullying you). More information and advice is available by searching ‘**workplace bullying**’ at **gov.uk**

You may also ask for a referral to the Cleft Clinical Psychology team to talk through the bullying and to come up with strategies to manage it.

## What can I do if I experienced bullying in the past?

If you’ve experienced bullying in the past, this may cause distress in adulthood. For example, worrying that new people you meet will treat or judge you badly too (and possibly feeling that you deserve this).

If you wish to talk to someone about the bullying you experienced when younger, and the impact it may be having on confidence or relationships in adulthood, request a referral to the Cleft Team and ask to speak with a member of the Clinical Psychology Team.

# CLAPA’s Support Services

**CLAPA is the UK’s cleft lip and palate support charity. We offer free services to adults in the UK who were born with a cleft.**

You can learn more about our services at **clapa.com/adults**

## Contact CLAPA

Email **adults@clapa.com** to contact CLAPA’s Adult Services Coordinator

Call 0207 833 4883 to leave a message with your name, phone number and enquiry for a call back

## Peer Support

Talk, text or email one-to-one with a trained volunteer. These volunteers were born with a cleft; they have knowledge of CLAPA's adult services and are experts by experience. They'll be happy to talk to you about any questions or concerns you may have, from getting back into treatment to coping with comments.

Visit **clapa.com/adults** to self-refer.

## Counselling

Free counselling is available through CLAPA for adults born with a cleft. The volunteer counsellors can help you to talk through your concerns, make sense of difficult feelings and events, work on problem-solving strategies, and more.

Visit **clapa.com/adults** to self-refer.

## Facebook Support Group

Our Facebook group for adults born with a cleft has thousands of members. Every day they swap stories and photos, share highs and lows, and help us ensure that no one has to go through the difficult times alone.

Visit **facebook.com/groups/clapaadults**.

> "Joining this group and sharing the same issues is the best thing that happened to me when I was struggling on my own. Thank you so much!"
>
> **Adult Facebook Support Group member**

## Events

CLAPA organises a variety of events for the cleft community. Most of these are online, so you can choose whether to take part or just listen in.

These include regular online support groups on topics like 'recovering from surgery', 'dental treatment', and 'sharing your cleft story'.

We also have regular live Q&As with medical professionals, recordings of which are available on our website and on YouTube at:

**YouTube.com/clapacommunity**

Visit **clapa.com/events** to see what's on.

> "I was nervous to attend, but I was made to feel so welcome and included that I soon felt like I was with friends."
>
> **'CLAPA Lounge' Attendee**

## Stories from other adults

Read stories and case studies from other adults who were born with a cleft at **CLAPA.com/adults**

You are also welcome to submit your own story.

## Information

CLAPA publishes a great deal of information on topics related to cleft, including mental health and wellbeing. This information is grounded in the needs and experiences of the UK cleft community and is supported by cleft health professionals.

Visit **clapa.com/adults** for online and downloadable resources

> "Having been away from Cleft Care for 35+ years (when there wasn't the support there is now) I feel like I'm starting a new journey and although it's scary it is also nice to know that you guys are there to support/guide/offer advice. Thank you SO much."
>
> **Adult born with a cleft**

## Follow CLAPA on social media

CLAPA's vibrant social media channels post daily stories, opportunities and updates from the UK's cleft community. Follow us **@clapacommunity** on Facebook, Instagram and TikTok, or visit our website at **clapa.com** to learn more and sign up to our e-newsletter, **CLAPA Connect**.

# Acknowledgements

We would like to acknowledge all the people who made the Adults Guide to Returning to Cleft Care possible. Thank you to the cleft clinicians involved at all stages, CLAPA Adults' Conference and Leavers Pack Workshop attendees, the Centre for Appearance Research, CLAPA's Adult Focus Group, and everyone who gave their support and expertise towards creating this resource.

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This resource was created by CLAPA for the benefit of the UK cleft community. You are welcome to use and adapt the text in this resource free of charge as long as credit is given. We welcome any feedback which will help us to improve it further.

Cleft Lip and Palate Action (CLAPA) is the operating name of Cleft Lip and Palate Association, a registered Charity in England and Wales (No. 1108160) and Scotland (SC041034), which is a company limited by guarantee registered in England and Wales Company (5206298). Registered office: The Green House, 244-254 Cambridge Heath Road, London, E2 9DA

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COMMUNITY FUND

For the UK
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Genetics

Accessing the Cleft Team

Psychology

Speech & Hearing

Mental Health

Dental & Orthodontics

Bullying & Discrimination

Private Treatment

Considering Surgery

**The Adults' Guide to Returning to Cleft Care is a resource created to support adults in the UK who were born with a cleft.**

**We hope it answers any questions you may have about your cleft and what treatment and support is available to you.**

**For more information, support and services, visit clapa.com**

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