



Returning to Cleft Care **QUESTIONS & ANSWERS**

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CLAPA 
Cleft Lip & Palate Association

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Within this booklet, you will find answers to some of the most common questions about cleft in adulthood.

Look out for other documents and resources mentioned in pink which can be found elsewhere in the Leaver’s Pack.

For further information, visit www.clapa.com/adults.

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Accessing the Cleft Team

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

How do I find my nearest Cleft Team and get a referral?

- To visit an NHS Cleft Team, you need to visit your GP or dentist and request a referral.
- For more information, see the **referral pathway** and **Cleft Team list** found elsewhere in the Leaver's Pack. You can also visit clapa.com/adults.
- This process is supposed to be straightforward, but sometimes things can go wrong that can take some time to fix. As frustrating as this can be, please be patient and don't give up! If you need any help, contact CLAPA.

What happens if I move house?

- You can continue to be seen by the same Cleft Team as long as you're willing to travel. Just make sure you update your GP and/or Cleft Team with your new address.
- You can also switch to the Cleft Team most local to you. Check the **map** in this pack or visit clapa.com/CleftTeams to find your nearest team. To switch, you'll need to register with a GP in your new location and ask them to refer you to the local Cleft Team.
- If you're switching, 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 that you are 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 experience of treatment as you would expect in the UK.
- If you're travelling on a visa, it's worth checking that your visa includes cleft care, or that your travel insurance covers any emergency care that you might need related to your cleft.

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 varies depending on where in the UK you are based, whom you are waiting to see, and a variety of other factors.
- Generally, you can expect to be seen for an initial appointment within **3-6 months** of your referral being made.
- If you have not heard from the Cleft Team within 6 weeks of the referral being made, contact the Cleft Team directly to make sure they've received the referral.
- You can ask your GP for a copy of the referral letter for your own records.

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

- Returning to the Cleft Team as an adult may be a bit different to your memory of cleft services as a child. Different teams work with adults in different ways.
- 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're seen by the whole team, it will likely include a Surgeon, Orthodontist, Speech Language Therapist, Dentist, Clinical Psychologist, and sometimes other specialties such as a Geneticist. These clinicians are all cleft specialists in their field of healthcare.
- After the initial appointment, your future appointments will usually only be with the clinicians who are actively involved with your care. In some cases, you may continue to have appointments with the whole Cleft Team if appropriate.

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 carry more risk when you are older. If that is the case, your Cleft Team will discuss these risks and your options with you.

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

- Sometimes GPs and dentists are unfamiliar with how cleft care in the UK has changed, and may incorrectly believe you're not eligible for treatment.
- Enclosed within this pack is a **letter to GPs and dentists** that explains why you're eligible for a referral to a Cleft Team, and how they can arrange this. You can request additional 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.
- If they refuse to do this, contact your Cleft Team directly and ask for their help. They will usually contact your GP directly.

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

- You don't need to worry about working this out yourself!
- Visit your GP or dentist and ask them to refer you to the Cleft Team for a general assessment of your concerns.
- The discussion in your first appointment will help the Cleft Team decide which clinicians you need to see again to take your treatment further.

The Cleft Team & Clinical Psychology

This section explains why Cleft Teams include Clinical Psychologists, an overview of common psychological concerns related to cleft, as well as an explanation of the things that a Cleft Team psychologist can help with.

Why do Cleft Teams have a Clinical Psychologist?

- Having a cleft means having to face significant experiences others would not usually have to, like frequent hospital appointments and/or surgery. It also includes anything other experiences related to someone's cleft such as treatment not going as planned, or experiences of bullying.
- In some Cleft Teams, returning adult patients will see a Clinical Psychologist as part of the standard care pathway. This is to make sure you have an opportunity to discuss the feelings (past and present) you have about your cleft and related care, and to think about how further treatment such as surgery may affect you.

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

- Everybody born with a cleft will have different experiences, so there is no 'normal' way that being born with a cleft will affect someone.

- Some people do not feel their cleft has any significant impact on their life, whilst others find it very challenging. Some may have found it difficult only at certain times or around particular events like surgery, whilst others may have found it consistently hard.
- If someone's cleft does affect their wellbeing, the exact way it affects them will vary. For example, someone might worry that others will judge them negatively because of their cleft, meaning they feel very 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.
- As having a cleft often does present challenges, it is entirely 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 is very important to your emotional wellbeing.

What kind of issues do Clinical Psychologists in the Cleft Team support?

The Clinical Psychologist can offer support for any psychological or social issues related to your cleft. Common issues include:

- 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/bullying
- Coping with difficult past experiences (e.g. surgery, social experiences)
- Confidence and self-esteem
- Cleft-related difficulties in work/education

General Mental Health

This section provides an overview of general mental health conditions, as well as support services. 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.

I have (or think I may have) a mental health issue. Can the Cleft Team Clinical Psychologists help?

- A mental health issue impacts greatly and consistently on someone's life. It usually means a recognised group of symptoms that, when seen together, are given a diagnosis like 'anxiety' or 'depression'.
- Whether or not this is something the Cleft Team Clinical Psychologists 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 that 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 Team Clinical Psychologists would offer 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 (general anxiety) would therefore be provided by a local mental health team or talking therapies service.
- The best way to access this kind of general support is by talking to your GP.
- You also may be able to self-refer by searching ‘NHS Talking Therapies’ online.
- If the issues you experience are very serious (e.g. if you are risk of harm), the Clinical Psychologist with the Cleft 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 whether my cleft is related to my mental health issue?

- The Cleft Team Clinical Psychologists would be happy to see you to discuss this, and whether your concerns would best be supported inside or outside the Cleft Team.
- 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. Check the NHS website for details.

- 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?

- Use the **map** in this pack to find your nearest Cleft Team, or visit clapa.com/cleftteams. Once you have found your local team, contact the coordinator who will be able to advise you on how to do this.

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, anxious a lot of the time
- Difficulty doing things you need to in your daily life e.g. work, education, social activities
- Difficulties with relationships

- Difficulties with or changes to sleep 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.
- Talk to your GP if you would like to receive professional support. You can also find local services on the NHS website or by searching ‘**NHS Talking Therapies**’ online.
- Check **self-help** material on web.nth.nhs.uk/selfhelp/, which has resources on a wide range of mental health issues.
- 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?

- **Peer Support Service:** Talk or email with a trained volunteer one-to-one. These volunteers were born with a cleft and are experts by experience. They will be happy to talk to you

about any questions or concerns you may have, from getting back into treatment to coping with comments.

- **Online Facebook Support Group:** Our Facebook group for adults born with a cleft has over 2,000 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/CLAPAAadults.
- **Events:** CLAPA organises a variety of events for the cleft community. Visit clapa.com/events to see what's on.
- **Information:** CLAPA publishes a great deal of information on topics related to cleft, including mental health, and aims to make these as accessible to people as we can. Visit clapa.com/treatment for our online information resources.
- **Cleft Talk Podcast & Videos:** CLAPA has a series of podcasts and video panel discussions, including an episode on self-esteem. You can find details of the Cleft Talk panel discussions in a separate leaflet in this pack, and at clapa.com/CleftTalk.

Surgery & Recovery

This section provides an overview of surgical treatment options in adulthood. It also goes through what will happen on the day of surgery, as well as the impact that the recovery may have on your health, work life, financial situation, etc.

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?

- 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 in adulthood 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:** 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.
 - **Lip fillers:** procedure to add a substance (e.g. fat) to the lip to give it a fuller appearance.
- Consult with your Cleft Team about your concerns; they can advise what kind of treatment (surgical or otherwise) might be appropriate.

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 or not.
- Talk to trusted family, friends and your 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 on the CLAPA website. See clapa.com/adults for more information.
- The Clinical Psychologist with your Cleft 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 (for example, orthodontic treatment in preparation for jaw surgery). Make sure you chat to the Cleft Team about what would happen if you stop treatment.

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

- If you don't like needles, let your anaesthetist know before your operation. The best time to let them know is at your pre-admission clinic.
- 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 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 letting the team know, they can cater for your needs.
- The Clinical Psychologist in your team can provide therapy if you have worries related to treatment and think this would be helpful. Your team coordinator can put you in touch.

What happens on the day of surgery?

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

Most hospitals will also give you a booklet and other information about what to expect on the day. Have a read through of this booklet as it should answer most of your questions.

Generally, the process 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. It's **vital that you follow these instructions** exactly, and ask for clarification if you're not sure.
2. On the day, you'll arrive at the hospital and head to the **admissions area** indicated on your admissions letter. Here, they will check your name, date of birth, and the reason that you're in hospital. They may ask you multiple times to confirm this information throughout your stay. This is one of many ways they make sure the correct treatment is given to the correct 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 check your blood pressure, heart and lungs, etc., to make sure that you're still fit for the operation. You'll be asked about any illnesses or injuries you've recently had as well as any medicines you may be taking or allergies that 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, and (if applicable) to let them know if you'd prefer a gas induction to a needle.

4. Each surgical theatre has a 'list' for the day. This is the **order that the operations will happen that day**. If you are first on the list, you'll usually be taken to theatre around 8-9am. 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. Note that while you may be told how long your operation is likely to take, the preparation and recovery time involved means you'll probably be 'away' from any friends and family for a while longer. They 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 ready for visitors.
5. At some point, possibly 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. Any belongings will usually be put in a plastic bag that can be left with any friends or family, 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, so you might want to share a cuddle before you go. 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 it to a machine. You may also have a leg compression machine 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 some halothane gas.
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 runs 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. Once back in the ward, you'll be reunited with any family and friends.
9. How long you have to **stay on the ward** is something your team will let you know about. 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.

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 your feeling in the area while you're awake). The Cleft Team will let you know what kind of anaesthetic you will have.

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/sloppy diet for some weeks after surgery), whilst others have no particular restrictions for eating afterwards. However, even with no restrictions, people often find that factors such as discomfort following surgery or nausea following anaesthetic alter their appetite for a little while after surgery.
- As well as requiring only certain types of food, some procedures may require you to eat and drink using a plastic syringe, a teaspoon or a straw. This is due to any facial swelling you may have, as well as to protect the surgical site(s) in your mouth, which will often have stitches.
- As swelling reduces and you start to heal, you should be able to drink from a cup and eat with a dessert spoon.

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.
- 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 to months to reduce in redness.
- You may also be expected to wear bandages or other dressings for some time.
- If you have any concerns about coping with these visible aspects after surgery, you might find it helpful to talk to the Cleft Team Clinical Psychologist about how to manage this.
- 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 in the meantime. You may also experience short-term side effects like nausea and constipation.

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 have 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/activities sooner if what you do is not so physically demanding (e.g. working in an office).
- Having time off work as an adult can have a financial impact. Make sure to talk to your Cleft Team about this before your operation. The doctors at the hospital will be able to give you a doctor's note to show to your employer.

I was born with an isolated cleft palate, can I have surgery to change the shape of my nose (rhinoplasty)?

- You can only access treatment from the Cleft Team that relates specifically to your cleft type. As an isolated cleft palate does not affect the shape of the nose, you would not be eligible for a rhinoplasty.
- You would, however, be eligible for treatment for concerns arising from a cleft palate.

What support and follow up is available after surgery?

- This will vary depending on the procedure and on the team/consultant's practices. At your consultation before the surgery, make sure to ask what to expect after surgery. 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 our 'Considerations for Private and Non Cleft Team Treatment' document in the Leaver's Pack, as there are a few extra things to consider.

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, as well as the support available for them.**

Why might I want speech therapy?

- You may wish to visit a Speech 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 or vocal nodules.
- Sometimes these concerns can be resolved with speech and language therapy, surgery, or both.
- You may be referred onto your community Speech Language Therapist for treatment closer to where you live.

What can I do at home to improve my speech?

- Your Speech Language Therapist can assess you to figure out what is causing any difficulties you're having and help put together a treatment plan that's right for you.
- There are often exercises that you can practice at home which your speech and language therapist will be able to show you.
- Sometimes, Speech Language Therapy alone won't not be able to result in significant change. In these cases, surgery or physical appliances (such as a 'speech plate') may be suggested as a potential way of addressing speech concerns.

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

- Talk to your Cleft Team if you think you might be having difficulties with your hearing.
- You can talk to your GP to arrange a hearing test, or talk to the Audiologist on the Cleft Team.

- You may also talk to the Clinical Psychologist within your Cleft Team if you have any concerns you'd like to talk through, for example if you feel self-conscious about wearing hearing aids.
- Even if you think your hearing difficulties are not 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 (e.g. getting your ears syringed) might not be appropriate for people who were born with a cleft.

Dental & Orthodontics

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

How often should I see my General Dental Practitioner (family dentist)?

- Generally, up to twice a year for check-ups and cleaning. Your dentist will tell you if they need to see you more often.

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

- Even if you think there might not be any options for your teeth, or you've been told many years ago that there's no

further treatment available for you, it's worth checking with the Cleft Team dentist and/or orthodontist.

- Some options include dentures, crowns, bridges, braces, and in some cases, veneers. A veneer is material added to a tooth to change the colour of the shape of the tooth. Veneers are most commonly made from composite (a type of plastic), but also can be made from porcelain or laminate.
- Remember that cleft-related treatment conducted by the Cleft Team is **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 for all the same reasons that somebody without a cleft would see the dentist. For example, for check-ups, cleaning, to check for caries and cavities or because you're experiencing sensitivity and pain not related to cleft (e.g. an abscess in one of your lower teeth).
- You should see the Cleft Team specialist dentist for anything that you believe has happened as a result of 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, etc. 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 NHS Cleft Team:** no charge
- **General Dental Practitioner Services:** These will vary depending on whether you live in England, Northern Ireland, Scotland or Wales. 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?

- A fear or phobia of going to the dentist is very common, even for people who weren't born with a cleft.
- Go with a trusted friend, partner or family member for support, and/or talk to your dentist beforehand as they could have some strategies to help you calm down if you're feeling nervous. Some dentists may specify that they welcome nervous or phobic patients.
- Ask your dentist if you can listen to music if this is something that relaxes you.
- Speak to your Cleft Team Clinical Psychologist 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 has a helpline (01788 539780) for people to seek confidential help and advice on dental issues.

Private Treatment

This section provides an overview of what private treatment is, how to tell if the person doing your treatment is suitably qualified, and what you should consider before going ahead with any 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 can include Speech Therapy, Clinical Psychology/Counselling/Psychotherapy, Orthodontics, Dentistry, as well as surgery, medical tattooing or lip fillers. If you access any of these services through the NHS Cleft Team, this is not regarded as private treatment.

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

- Do not feel guilty, or worry that the Cleft Team will be offended by you seeking treatment elsewhere. NHS teams understand that patients may choose private treatment for a huge 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 are entitled to seek a second opinion from a different specialist within your team, or from another Cleft Team. Select another team (using the **map** in this pack, or visit clapa.com/CleftTeams) and get in touch to ask about arranging a consultation. Please note that although you are entitled to seek a second opinion, it may not always be possible to receive treatment from a different team.

Can Private Treatment do something that the NHS Cleft Team can't?

- In most cases, the NHS Cleft Teams are your best option for specialist, comprehensive treatment. 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.
- If your Cleft Team are firm about not performing any more surgery for a particular issue, this may be disappointing. 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 what your hopes and expectations are for the treatment you're seeking and to manage these appropriately. Even if the procedure is a success, there is always a risk that you'll find yourself disappointed with the results of treatment.
- Your Cleft Team Psychologist can help talk you through this, even for private treatment

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. Confusingly, 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 do 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 that you are going with someone reputable who has done 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?

- Make sure you understand and are happy with the follow up care you will receive and what is included in the cost of your treatment. This includes what may happen if things don’t quite go as planned, as you may have to pay for extra appointments.
- Ask what you should do if you start experiencing a problem suddenly, or out of hours, as there may be situations where it is best to attend an A&E department.

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

Why might a private clinic recommend a treatment which the Cleft Team haven't recommended?

- Unlike the NHS, private practices are generally run as businesses. If you are on the fence about treatment, it is often (not always) in their interests to sell you treatment.
- Some patients report having treatments suggested on top of those they had come to discuss, even if this is not something they had ever thought about before. This is called 'upselling'.
- Give yourself time and space to carefully consider what is being offered, and talk through your options with someone you trust.

Genetics

One of the most common questions adults who were born with a cleft have is whether their children will be born with one too. **This section provides an overview of the genetic component of cleft, as well as the support services available.** It's worth noting that you do not have to be in a relationship or thinking about having children right away to access these services.

What causes a cleft?

- We don't fully understand how a cleft is caused.
- What we do know is that 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.
- Most clefts are caused by multiple factors. 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'. Even the most carefully planned pregnancies can result in a child having a cleft.

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 pass this to their children.
- 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 pass it on.
- This chance can be higher if your cleft is the result of a syndrome.
- A genetic specialist (like 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.
- Genetic testing can be used to find out whether a person is carrying a specific altered gene (genetic mutation) that causes a particular medical condition such as cleft.
- A genetic counsellor will often start by drawing a family tree to determine any history of cleft or other condition in your family to give you an idea of the likelihood of your child having a cleft.
- Sometimes they may choose to do 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 that 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: nhs.uk/conditions/genetics/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, at your next appointment you can ask to be referred to the Geneticist.

- You can access Genetic Counselling at any time. You do not have to wait until you are in a relationship and planning to have children to see the genetic specialist.
- As Genetic Counselling is part of NHS cleft treatment, it is free of charge.

Bullying & Discrimination

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

What is bullying and harassment?

- Bullying and harassment is behaviour that 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 subtler than that.
- As an adult, you are most likely to experience bullying, harassment or discrimination in the workplace. This is known as workplace bullying.
- Workplace bullying is rarely overt behaviours such as physical aggression, but does often incorporate one or more subtle behaviours. These 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, or being expected

to work extra hours without pay. Workplace bullying can happen face to face, by letter, email or telephone.

- 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 which may 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 that 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).
- 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 is available on the Government website at: www.gov.uk/workplace-bullying-and-harassment.
- You may also ask for a referral to the Clinical Psychologist on the Cleft Team to talk through the bullying and to come up with strategies to manage this.

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

- If you've experienced bullying in the past, this may create 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 have a chat with the Clinical Psychologist.



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