

A Guide To Effective Self-Advocacy

Self-advocacy is not about being the loudest person in the room or challenging every decision. It is about making sure your needs, wishes and priorities are understood, respected and considered.

Adults born with a cleft become advocates for themselves throughout life. Whether you are asking questions during a clinic appointment, discussing treatment options, requesting workplace adjustments, returning to an adult cleft team or explaining your cleft to others, you are advocating for yourself.

Being an effective self-advocate means building positive relationships with the professionals involved in your care while ensuring your own voice remains at the centre of every decision.

Remember, you are the expert in your own lived experience. Healthcare professionals bring clinical expertise, but you bring knowledge of your experiences, priorities and goals. When these work together through shared decision-making, the best outcomes can be achieved.

Working in Partnership

Your multidisciplinary cleft team is made up of healthcare professionals with different areas of expertise.

These professionals may include:

- Clinical Nurse Specialists
- Plastic Surgeons
- Speech and Language Therapists
- Orthodontists
- Restorative Dentists
- Audiologists
- Clinical Psychologists
- Geneticists

Every member of the team brings specialist knowledge, but no one knows your experiences better than you.

Effective self-advocacy is about developing respectful partnerships where everyone works together towards the same goal - achieving the best outcomes for your health and wellbeing.

Preparing for Appointments

Appointments can often feel rushed, particularly if there is a lot to discuss. Spending a few minutes preparing beforehand can help you feel more confident and ensure your concerns are addressed.

Before your appointment ask yourself:

What do I want the team to know?

What questions do I have?

What would I like to happen after today's appointment?

It can also be helpful to bring:

- A notebook containing questions you've written down since your last appointment.
- Copies of clinic letters.
- A list of medications.
- Photographs if they help explain any concerns.
- Any relevant reports or correspondence.
- A family member, friend or advocate if you would find this helpful.

Asking Questions with Confidence

There is no such thing as a silly question.

Healthcare professionals expect people to ask questions and want patients to feel involved in decisions.

If something is unclear, ask.

You might find these phrases helpful:

"I'd like to understand this a little better."

"Could you explain that in a different way?"

"What are the benefits of this option?"

"Are there any alternatives?"

"What happens if I decide to wait?"

"Can I have some time to think about this before making a decision?"

Good communication helps everyone make informed decisions together.

Keeping Good Records

Many adults find it helpful to keep all information about their cleft journey together.

This might include:

- Clinic letters
- Appointment dates
- Treatment plans
- Surgical information
- Speech or hearing reports
- Dental information
- Questions for future appointments

Having information organised can help you feel more prepared and makes it easier to refer back to previous discussions.

Following Up After Appointments

After an appointment, take a few minutes to reflect on what was discussed.

Ask yourself:

- ☐ Do I understand the next steps?
- ☐ Do I know who to contact if I have further questions?
- ☐ Have all of my concerns been addressed?
- ☐ Is there anything I need to do before my next appointment?

If you are unsure about anything, contact your cleft team. It is perfectly acceptable to ask for clarification after an appointment.

When You Feel Unsure

Sometimes people leave appointments feeling uncertain, overwhelmed or worried that they forgot to ask something.

This is completely understandable.

You do not have to have every answer immediately.

If you need more information, you can:

- Contact your Clinical Nurse Specialist.
- Speak with your GP.
- Contact your regional adult cleft team.
- Contact CLAPA for information and peer support.
- Arrange another appointment if needed.

Good healthcare is built on ongoing conversations - not just one appointment.

Building Positive Relationships

Self-advocacy works best when everyone feels listened to and respected.

Simple approaches can make a big difference.

Try to:

- Listen carefully to the information being shared.
- Ask questions if you are unsure.
- Share your concerns honestly.
- Be clear about what is important to you.
- Recognise that decisions are usually made together.

Trust Your Instincts

You know your own body and your own experiences better than anyone.

If something doesn't feel right, trust your instincts and speak up.

Whether your concern relates to speech, hearing, dental treatment, appearance, confidence, emotional wellbeing or recovery after surgery, your observations are important.

Even if your concern turns out not to require further treatment, raising it allows professionals to provide reassurance, advice and support.

Top Tips for Effective Self-Advocacy

- ✓ Prepare for appointments.
- ✓ Write down your questions.
- ✓ Keep important information together.
- ✓ Ask for clarification if something is unclear.
- ✓ Don't be afraid to ask for more time to make decisions.
- ✓ Share your experiences—they matter.
- ✓ Build positive relationships with professionals.
- ✓ Remember that you are an important member of your healthcare team.

Reflection

Think about one small change you could make before your next appointment.

Perhaps you could:

- ☐ Write down your questions in advance.
- ☐ Use the Three Questions.
- ☐ Ask for clarification if you don't understand something.
- ☐ Keep a notebook specifically for appointments.
- ☐ Contact your Clinical Nurse Specialist if you have unanswered questions.

Every small step helps you become a more confident self-advocate.

Communication Skills that Make a Difference

Communication is at the Heart of Effective Self-Advocacy

Every conversation you have about your cleft is an opportunity to advocate for yourself.

Whether you are speaking to a surgeon, speech and language therapist, dentist, employer, GP or family member, clear communication helps others understand your experiences and work with you to find the best solutions.

Self-advocacy does not need to involve confrontation.

The most effective self-advocates are often those who communicate calmly, confidently and respectfully.

Good communication helps build trust, encourages partnership and ensures your views are understood.

Remember, asking questions and expressing concerns is not being difficult - it is an important part of being involved in your own healthcare and decisions.

Taking an Active Role in Conversations

Self-advocacy means becoming an active participant in conversations about your health, wellbeing and future.

Preparing for appointments, asking questions, expressing your views and sharing your experiences helps ensure decisions are made **with you, not for you**.

You may wish to:

- Prepare your questions in advance.
- Explain how your cleft affects your daily life.
- Share any concerns or goals that are important to you.
- Ask for clarification if something isn't clear.
- Take time to consider your options before making decisions.

Every opportunity to speak up builds confidence and strengthens your self-advocacy skills.

Using “I” Statements

“I” statements are a simple but effective way of expressing concerns without placing blame. They help others understand how a situation is affecting you while keeping conversations positive, respectful and solution-focused.

Instead of saying:

“You never explain things properly.”

Try saying:

“I’d appreciate a little more information so I can understand the treatment plan.”

Instead of saying:

“No one is listening to me.”

Try saying:

“I’m concerned that my views haven’t been fully understood, and I’d like the opportunity to explain what matters most to me.”

Other useful examples include:

- “I’m worried about...”
- “I’d like to understand...”
- “I’m finding it difficult to...”
- “I’d appreciate some advice about...”
- “Could you help me understand...”
- “I’d like some time to think about this.”
- “I’d like to discuss the options available to me.”

These small changes can encourage open discussion, reduce defensiveness and help keep the conversation focused on finding a solution.

The SEWR Technique

When emotions are running high, it can sometimes be difficult to explain your concerns clearly. The SEWR technique provides a simple structure to help you communicate calmly and effectively.

S – State the Facts

Describe what has happened. Keep to the facts without making assumptions.

Example:

“I’ve noticed that my speech has become less clear over the past few months.”

E – Express the Impact

Explain how the situation is affecting your health, wellbeing or everyday life.

Example:

“This is affecting my confidence at work, particularly during meetings and presentations.”

W – What Would You Like?

Be clear about the support, information or action you are requesting.

Example:

“I’d like to discuss whether I can be referred to the adult cleft team for an assessment.”

R – Reinforce the Benefits

Explain why your request would help.

Example:

“I think an assessment would help me understand what is causing the change and whether any treatment or support is available.”

The complete SEWR statement could be:

“I’ve noticed that my speech has become less clear over the past few months. This is affecting my confidence at work, particularly during meetings. I’d like to discuss whether I can be referred to the adult cleft team for an assessment. I think this would help me understand what is happening and what support may be available.”

The Broken Record Technique

Sometimes you may feel that your concerns or requests are not being fully addressed. The Broken Record Technique involves calmly and respectfully repeating your main message without becoming argumentative.

For example:

“I understand there is a long waiting list, but I’d still like to know what support is available to me while I wait.”

If the conversation moves away from your concern, gently return to your main point:

“I understand what you’re saying, but I’d still like to know what support is available while I wait.”

You may need to repeat your request several times. Try to keep your wording simple, your tone calm and your focus on the outcome you are seeking.

Remaining calm, clear and consistent is often more effective than becoming frustrated or introducing several new points at once.

The Sandwich Technique

The Sandwich Technique can be useful when raising a concern with a healthcare professional, employer, education provider or another organisation.

The structure is:

1. Begin by recognising something positive.
2. Raise your concern clearly.
3. Finish by focusing on a constructive way forward.

For example:

“I appreciate the time the team has taken to explain the treatment options. I’m still concerned that I don’t fully understand how the proposed surgery may affect my speech and recovery. I’d like us to go through this again so I can make an informed decision.”

A workplace example might be:

“I value the support my manager has already provided. I’m finding it difficult to contribute during large online meetings because of the sound quality and people speaking over one another. I’d like us to explore whether any adjustments could make it easier for me to participate.”

This approach recognises positive efforts while making sure your concern and requested outcome are clearly understood.

Staying Calm During Difficult Conversations

Some conversations can feel emotional. If you begin to feel overwhelmed:

- Pause before responding.
- Take a slow breath.
- Ask for a moment to gather your thoughts.
- Refer to notes you prepared beforehand.
- Ask to take a break.
- Request another appointment if you need more time.

It is perfectly acceptable to say:

“Could I have a few moments to think about that?”

or:

“Would it be possible to come back to this question?”

You could also say:

“I don’t feel ready to make a decision today. I’d like some time to consider the information.”

You do not need to make an important decision immediately. Taking time to understand your options is an important part of informed choice and self-advocacy.

Asking Questions That Open Conversations

Open questions encourage discussion and can help you gain a fuller understanding of your options.

Examples include:

- “Can you explain how this treatment might help me?”
- “What other options are available?”
- “What are the possible risks and benefits?”
- “How might this affect my speech, hearing, appearance or recovery?”
- “What might happen if I decide not to have treatment at this time?”
- “What support is available while I wait?”
- “Could I be referred to another member of the cleft team?”
- “Can I speak with someone about how this is affecting my confidence or wellbeing?”
- “Who should I contact if anything changes?”
- “Could I have this information in writing?”
- “How can I access a second opinion?”

These questions encourage shared decision-making and help ensure that you are actively involved in conversations about your healthcare, wellbeing and future

Looking for Solutions Together

Most healthcare professionals want to provide safe, effective and person-centred care.

Even when conversations are difficult, approaching discussions with openness, respect and a willingness to work together can often lead to better outcomes.

This does not mean that you should minimise your concerns or accept an outcome that does not feel right. It means communicating clearly, listening to the information provided and keeping the focus on what needs to change.

Self-advocacy is about building constructive partnerships while ensuring that your voice, experiences and preferences remain central to decisions.

Support Networks

Your NHS Cleft Team

Your multidisciplinary cleft team will often be your first point of contact for questions or concerns relating to your cleft.

Depending on your needs and the structure of your regional service, your team may include:

- Clinical Nurse Specialist
- Plastic or cleft surgeon
- Speech and Language Therapist
- Orthodontist
- Restorative or specialist dentist
- Audiologist
- Clinical Psychologist
- Geneticist
- Cleft Coordinator

You may not need support from every member of the team. The professionals involved will depend on your individual circumstances and the issues you wish to discuss.

If you are unsure who to contact, your Clinical Nurse Specialist or Cleft Coordinator can usually help direct you to the most appropriate member of the team.

Adults who have not been seen by a cleft team for some time may still be able to seek advice about returning to specialist cleft care. CLAPA provides information and resources for adults considering a return to treatment.

UK-Wide Support

CLAPA

CLAPA is the UK charity supporting people affected by cleft lip and palate.

CLAPA offers a range of information and support specifically for adults born with a cleft, including:

- Adult peer support
- One-to-one support from trained adult volunteers
- Emotional wellbeing and mental health information
- Workplace support resources
- Online support groups
- Adult events, webinars and discussion sessions
- Information about returning to cleft treatment
- Information about speech, hearing, dental care and other cleft-related issues

Email: info@clapa.com

VITAL

VITAL is an independent, user-led advocacy charity that helps people understand their rights, develop self-advocacy skills and communicate their needs and interests.

VITAL provides self-advocacy workshops and resources designed to help people recognise their needs, reflect on their experiences and build confidence in having their voices heard.

Email: hello@vitalprojects.org.uk

VoiceAbility

VoiceAbility is an independent advocacy organisation.

It can help people:

- Understand their rights
- Prepare for meetings and appointments
- Communicate their wishes and concerns
- Take part in decisions about their health or care
- Understand how to make an NHS complaint
- Access NHS complaints advocacy in areas where VoiceAbility provides the service

Telephone: 0300 303 1660

Email: helpline@voiceability.org

Availability of specific advocacy services can vary by area. If VoiceAbility does not provide the service locally, it may be able to signpost you to another organisation.

The Patients Association

The Patients Association provides free, confidential information and guidance to help people understand healthcare services, patient rights and how to navigate the NHS.

Its helpline can support people with questions about:

- Accessing healthcare
- Understanding treatment and care
- Patient rights
- Making a complaint
- Getting a second opinion
- Communicating with healthcare services

Free helpline: 0800 345 7115

Email: helpline@patients-association.org.uk

Citizens Advice

Citizens Advice provides free, confidential and independent information on a wide range of issues.

It may be able to help with:

- Employment rights
- Workplace problems
- Disability discrimination
- Reasonable adjustments
- Benefits
- Housing
- Education
- Equality rights
- Debt and finances

Citizens Advice also provides information about dealing with discrimination at work and requesting reasonable adjustments where legal criteria are met.

Support in England

Patient Advice and Liaison Service

PALS can help with questions, concerns or problems relating to NHS services. It can explain NHS processes, help with communication and provide information about making a complaint or accessing independent support.

Healthwatch England

Healthwatch is the independent champion for people using health and social care services in England.

Local Healthwatch organisations:

- Listen to people's experiences
- Provide information about local services
- Signpost people to support
- Use feedback to help improve health and social care services

Independent NHS Complaints Advocacy

Independent advocacy may be available if you need help making a complaint about NHS care. The organisation providing this service varies by local area. VoiceAbility or your local PALS service may be able to help you find the appropriate provider.

Support in Wales

Llais

Llais provides free, independent and confidential complaints advocacy for people raising concerns about NHS or social care services in Wales.

Its advocates can:

- Listen to your concerns
- Explain your options
- Help you prepare your complaint
- Support you through the complaints process
- Help ensure your needs are understood

Citizens Advice Cymru

Citizens Advice Cymru provides free, confidential advice on matters including employment, benefits, housing, debt, discrimination and legal rights.

Support in Scotland

Patient Advice and Support Service

PASS provides free and confidential information, advice and support to people using NHS Scotland.

It can help you:

Understand your rights

- Access treatment or support
- Raise a concern
- Provide feedback
- Make a complaint about NHS care

Advice line: 0800 917 2127

Scottish Independent Advocacy Alliance

The Scottish Independent Advocacy Alliance promotes and supports independent advocacy across Scotland.

It does not provide advocacy directly, but its directory can help you find an independent advocacy organisation in your local area.

Citizens Advice Scotland

Citizens Advice Scotland provides free and independent advice about matters including employment, benefits, housing, debt and legal rights.

Support in Northern Ireland

Patient and Client Council

The Patient and Client Council provides free information, advice and support to people using Health and Social Care services in Northern Ireland.

Freephone: 0800 917 0222

Email: info@pcc-ni.net

Citizens Advice

Citizens Advice services in Northern Ireland can provide information about benefits, employment, housing, debt and legal rights.

Knowing Who to Contact

If you need information about cleft treatment

Contact:

- Your NHS cleft team
- Your Clinical Nurse Specialist or Cleft Coordinator
- Your GP, particularly if you need a referral
- CLAPA

If you want to return to cleft care as an adult

Contact:

- Your regional NHS cleft team
- Your GP or dentist to discuss a referral
- CLAPA for information about returning to treatment

If you would like emotional or peer support

Contact:

- CLAPA's adult Peer Support Service
- CLAPA's adult counselling or wellbeing services
- Your GP
- A local mental health or counselling service

If you need help understanding your rights

Contact:

- Citizens Advice
- VoiceAbility
- A local independent advocacy organisation
- VITAL for self-advocacy information and workshops

If you need advice about work or reasonable adjustments

Contact:

- Your employer or Human Resources department
- An occupational health service
- Citizens Advice
- A trade union, if you are a member

- CLAPA's workplace support resources

If you need support raising concerns about NHS care

Contact:

- **England:** PALS or your local NHS complaints advocacy provider
- **Wales:** Llais
- **Scotland:** PASS
- **Northern Ireland:** Patient and Client Council

If you need independent advocacy

Contact:

- VoiceAbility or another local advocacy provider
- VITAL for self-advocacy support and resources
- The Scottish Independent Advocacy Alliance directory if you live in Scotland
- Llais if your concern relates to health or social care in Wales

Building Your Support Network

Every adult's experience of living with a cleft is different, but no one should have to navigate challenges alone.

Your support network may include:

- Family members
- Friends or partners
- Your NHS cleft team
- Your GP or dentist
- Other adults born with a cleft
- CLAPA's peer support community
- Your employer or occupational health team
- Counsellors or mental health professionals
- Community groups
- National charities
- Independent advocacy organisations

You may need different kinds of support at different stages of your life. Some people may help with practical matters, while others provide emotional support, specialist advice or advocacy.

Asking for help does not mean giving up control. It can help you access information, consider your options and feel more confident making your own decisions.

Key Takeaways

- Support is available at different stages of your adult cleft journey.
- Your NHS cleft team is usually the best source of specialist advice about cleft treatment and care.
- You may be able to return to specialist cleft services even if you have not attended for many years.
- CLAPA provides information, counselling, workplace resources and peer support specifically for adults born with a cleft.
- Independent advice and advocacy organisations can help you understand your rights and communicate your concerns.
- Every UK nation has services that can support you to navigate NHS care or raise concerns.
- Asking for support is an important self-advocacy skill.
- You remain at the centre of decisions about your health, wellbeing and future.
- You do not have to manage everything on your own.