

A Parent Guide to Advocacy and Self-Advocacy in Cleft Care

Prepared by VITAL

Effective Advocacy

Advocacy is not about being the loudest person in the room or challenging every decision. It is about making sure your child's needs, wishes and best interests are understood, respected and considered.

Parents and carers become advocates from the moment they begin navigating their child's cleft journey. Whether you are asking questions at a clinic appointment, speaking with your child's school, discussing treatment options or explaining cleft to family and friends, you are advocating.

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

Remember, you are the expert on your child. Healthcare professionals bring clinical expertise, but you bring lived experience. When these work together, children receive the best possible care.

Working in Partnership

Your child is supported by a multidisciplinary cleft team made up of healthcare professionals with different areas of expertise.

These professionals may include:

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

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

Effective advocacy is about developing respectful partnerships where everyone works towards the same goal - achieving the best outcomes for your child.

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 that 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.
- Information from school or speech and language therapy.
- Another adult for support if you would find this helpful.

Asking Questions with Confidence

There is no such thing as a silly question.

Healthcare professionals expect parents to ask questions and want families 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 we 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 families find it helpful to keep all information about their child's cleft journey together.

This might include:

- Clinic letters
- Appointment dates
- Treatment plans
- Surgical information
- Speech therapy reports
- School correspondence
- 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?
- ☐ Does my child understand what will happen next?

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 parents 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 to your GP.
- Contact your regional cleft team.
- Speak with 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

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 your family.
- Recognise that decisions are usually made together.

Trust Your Instincts

Parents often notice small changes before anyone else.

If you feel something is not quite right, trust your instincts and speak up.

You know your child better than anyone.

Whether your concern relates to speech, hearing, feeding, 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 and support.

Top Tips for Effective 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 observations - they matter.

✓ Build positive relationships with professionals.

✓ Remember that you are an important member of your child's cleft team.

Reflection

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

Perhaps you could:

- ☐ Write down your questions in advance.
- ☐ Encourage your child to answer one question themselves.
- ☐ 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 advocate and helps your child learn that their voice matters too.

Communication Skills That Make a difference

Communication is at the Heart of Effective Advocacy

Every conversation you have about your child is an opportunity to advocate.

Whether you are speaking to a surgeon, speech and language therapist, teacher, dentist or family member, clear communication helps others understand your child's needs and work with you to find the best solutions.

Advocacy does not need to involve confrontation. The most effective advocates are often those who communicate calmly, confidently and respectfully.

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

Remember, asking questions and expressing concerns is not being difficult - it is an important part of being involved in your child's care.

Being Clear About Your Concerns

Before starting an important conversation, take a moment to think about exactly what you want to say.

Ask yourself:

- What is worrying me?
- Why is this important?
- What would I like to happen?

Having a clear focus can help you explain your concerns more confidently and keep conversations on track.

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 your child and your family while keeping conversations positive 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:

"The school isn't helping."

Try:

"I'm concerned that my child's speech difficulties are affecting their confidence in class and I'd like to discuss how we can work together to support them."

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..."

These simple changes encourage open discussion rather than defensiveness.

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 that helps you communicate effectively.

S – State the Facts

Describe what has happened.

Keep to the facts without making assumptions.

Example:

"My child has become increasingly reluctant to attend school since returning after surgery."

E – Express the Impact

Explain how the situation is affecting your child or family.

Example:

"They're becoming anxious each morning and have started saying they don't want to go."

W – What Would You Like?

Be clear about the support you are requesting.

Example:

"I'd like to discuss what additional support school can put in place."

R – Reinforce the Benefits

Explain why your request would help.

Example: "I think this would help rebuild their confidence and make returning to school much easier."

The Broken Record Technique

Sometimes you may feel that your concerns are not being fully addressed.

The Broken Record Technique involves calmly repeating your main request without becoming argumentative.

For example:

"I understand the waiting list is long, but I'd still like to know whether there are any additional sources of support while we wait."

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

Remaining calm and consistent is often more effective than becoming frustrated.

The Sandwich Technique

The Sandwich Technique can be particularly useful when discussing concerns with professionals or schools.

Start with something positive.

Raise your concern.

Finish by focusing on working together.

For example:

"I really appreciate everything the school has done to support my child. I'm concerned that they're becoming less confident about speaking in class. I'd like us to work together to explore what additional support may help."

This approach recognises positive efforts while clearly explaining your concerns.

Staying Calm During Difficult Conversations

Some conversations can feel emotional, especially when discussing surgery, treatment decisions or concerns about your child's wellbeing.

If you begin to feel overwhelmed:

Pause before responding.

Take a slow breath.

Ask for a moment to gather your thoughts.

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 do not need to make important decisions immediately.

Asking Questions That Open Conversations

Open questions encourage discussion and help you gain a better understanding.

Examples include:

Can you explain how this treatment will help?

What are the alternatives?

What are the risks and benefits?

How might this affect my child at school?

What support is available while we wait?

Who should I contact if things change?

These questions encourage shared decision-making and help you feel more involved.

Helping Your Child Join the Conversation

One of the most valuable communication skills you can develop is knowing when to step back and allow your child to speak.

You might encourage them to:

Answer the first question during clinic.

Ask one question they prepared beforehand.

Explain how they have been feeling.

Describe any worries in their own words.

Small opportunities like these gradually build confidence and prepare children to become active participants in their own care.

Communication Tips

- ✓ Listen carefully before responding.
- ✓ Ask for clarification if something is unclear.
- ✓ Write down important information.
- ✓ Summarise what you've understood.
- ✓ Don't be afraid to ask someone to repeat information.
- ✓ Be honest about your concerns.
- ✓ Focus on working together to find solutions.
- ✓ Remember that your experiences and observations matter.

Reflection

Think about a conversation you've had recently about your child's cleft care.

What went well?

What would you do differently next time?

Is there one communication technique from that you could try before your next appointment?

- ☐ Using an "I" statement
- ☐ Preparing questions beforehand
- ☐ Using the SEWR technique
- ☐ Asking more open questions
- ☐ Encouraging my child to answer first

Key Takeaways

Good communication is one of the most powerful advocacy tools you have.

You do not need to know all the answers or use complicated language. Asking questions, sharing your concerns honestly and working in partnership with professionals helps ensure your child receives the support they need.

Every conversation is an opportunity to strengthen your confidence, support your child and build the skills that will one day help them become their own advocate.

If You Need Additional Support

Sometimes families benefit from someone helping them navigate services or communicate their concerns.

Support may be available from:

- Your Clinical Nurse Specialist.
- Your GP.
- CLAPA.
- Independent advocacy organisations.
- Patient Advice and Liaison Services (or equivalent services in your nation).

Asking for support is not a sign of weakness - it is an important part of advocacy.

Understanding NHS Support Services

If you are unable to resolve a concern directly with your healthcare team, there are independent services that can offer advice and guidance.

England

Patient Advice and Liaison Service (PALS)

PALS provides confidential advice and can help resolve concerns about NHS services before they become formal complaints.

PALS can:

- Answer questions.
- Explain NHS processes.
- Help improve communication.
- Support families to resolve concerns informally.

Wales

Llais

Llais provides independent support to people using NHS and social care services throughout Wales.

They can:

- Help you understand your rights.
- Support you to raise concerns.
- Signpost to additional services.

Scotland

Patient Advice and Support Service (PASS)

PASS provides free, confidential and independent advice for anyone using NHS Scotland.

They can help you understand your options and support you if you wish to raise concerns.

Northern Ireland

Patient and Client Council

The Patient and Client Council offers information, advice and support to people using Health and Social Care services across Northern Ireland.

Making a Complaint

Most concerns are resolved through discussion and partnership.

However, if you remain dissatisfied, you have the right to make a formal complaint.

Before making a complaint, consider:

- Have I discussed my concerns with the team?
- Have I explained what outcome I am hoping for?
- Do I have notes or copies of relevant correspondence?
- Have I contacted PALS, PASS, Llais or the Patient and Client Council for advice?

Complaints should focus on improving services and resolving concerns rather than assigning blame.

Looking for Solutions Together

The vast majority of healthcare professionals want the very best for your child.

Even when conversations are difficult, approaching discussions with openness, respect and a willingness to work together often leads to the best outcomes.

Advocacy is about building partnerships - not creating conflict.

Support Networks

Your NHS Cleft Team

Your multidisciplinary cleft team will often be your first point of contact.

Depending on your child's needs, your team may include:

- Clinical Nurse Specialist
- Plastic Surgeon
- Speech and Language Therapist
- Orthodontist
- Paediatric Dentist
- Audiologist
- Clinical Psychologist
- Geneticist
- Cleft Coordinator

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.

UK-Wide Support

CLAPA is the national charity supporting everyone affected by cleft lip and palate throughout the United Kingdom.

They provide:

- Parent-to-parent support
- Information about cleft treatment
- Feeding support
- Counselling services
- Family events
- Youth activities
- Adult peer support
- School resources
- Online information and webinars

Telephone: 020 7833 4883

Email: info@clapa.com

Website: www.clapa.com

VITAL

VITAL is an independent advocacy charity that helps people understand their rights, develop self-advocacy skills and build confidence when accessing health and social care services.

VITAL also delivers workshops and resources that support individuals and families to have their voices heard.

Website: www.vitalprojects.org.uk

Email: hello@vitalprojects.org.uk

Contact

Contact supports families raising disabled children and children with additional needs.

They provide advice on:

- Education
- EHCPs
- Disability benefits
- Parent support
- Family finances
- Caring responsibilities

Freephone: 0808 808 3555

Website: www.contact.org.uk

VoiceAbility

VoiceAbility is one of the UK's largest independent advocacy organisations.

They can help people understand their rights, prepare for meetings and appointments, and support them to have their voices heard when decisions are being made about their health or care. They also provide NHS complaints advocacy in many areas of England.

Telephone: 0300 303 1660

Email: helpline@voiceability.org

Website: www.voiceability.org

The Patients Association

The Patients Association provides independent information and support to help people understand healthcare services and navigate the NHS.

Their free helpline offers advice about patient rights, healthcare concerns and accessing services.

Helpline: 0800 345 7115

Website: www.patients-association.org.uk

Citizens Advice

Citizens Advice offers free, confidential and independent advice on a wide range of issues, including:

- Benefits
- Employment
- Housing
- Education
- Equality rights
- Debt and finances

Website: www.citizensadvice.org.uk

England

Patient Advice and Liaison Service (PALS)

PALS provides confidential advice, information and support for patients, families and carers using NHS services. They can help resolve concerns informally, explain NHS processes and advise on the complaints procedure. Your local hospital will have a PALS service.

Ask your hospital switchboard or visit the NHS website to find your local PALS service.

Website: www.nhs.uk

Healthwatch England

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

They:

- Listen to people's experiences.
- Help improve NHS services.
- Signpost people to local support.
- Provide information about patient rights.

Website: www.healthwatch.co.uk

Wales

Llais

Llais is the independent body that supports people using health and social care services across Wales.

They can:

- Help you understand your rights.
- Support you to raise concerns.
- Provide independent complaints advocacy.
- Help ensure your voice is heard when services are being planned or reviewed.

Website: www.llaiswales.org

Patient Advice and Liaison Services (NHS Wales)

Each Health Board in Wales provides patient support and advice services to help people resolve concerns and navigate NHS services.

Information is available through your local Health Board or NHS Wales.

Website: 111.wales.nhs.uk

Citizens Advice Cymru

Provides free, confidential advice across Wales.

Website: www.citizensadvice.org.uk/wales

Scotland

Patient Advice and Support Service (PASS)

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

They can help you understand your rights, resolve concerns and access the NHS complaints process.

Website: www.cas.org.uk/pass

Scottish Independent Advocacy Alliance (SIAA)

SIAA promotes and supports independent advocacy across Scotland.

They can help you locate advocacy organisations in your local area.

Website: www.siaa.org.uk

Citizens Advice Scotland

Free, independent advice on benefits, education, housing, employment and family matters.

Website: www.cas.org.uk

Northern Ireland

Patient and Client Council

The Patient and Client Council supports people using Health and Social Care services throughout Northern Ireland.

They provide information, advice and support, including help with raising concerns and complaints.

Freephone: 0800 917 0222

Email: info@pcc-ni.net

Website: www.pcc-ni.net

Citizens Advice Northern Ireland

Provides free, confidential advice on benefits, employment, education and legal rights.

Website: www.citizensadvice.org.uk/about-us/northern-ireland

Knowing Who to Contact

If you need...

Information about cleft treatment

→ Contact your NHS Cleft Team or CLAPA.

Emotional support from other parents

→ Contact CLAPA.

Advice about school or education

→ Contact your child's school, local authority or Contact.

Help understanding your rights

→ Contact Citizens Advice or VoiceAbility.

Support raising concerns about NHS care

- England – PALS
- Wales – Llais
- Scotland – PASS
- Northern Ireland – Patient and Client Council

Independent advocacy

→ VITAL (Bradford & Districts) or VoiceAbility.

Building Your Support Network

Every family's journey is different, but no one should have to face challenges alone.

Your support network may include:

- Family and friends
- Your NHS cleft team
- Other parents
- School staff
- Community groups
- National charities
- Advocacy organisations

Don't be afraid to ask for help. Reaching out for support can make a significant difference - not only for your child, but for your own wellbeing too.

Key Takeaways

- Support is available throughout every stage of your child's cleft journey.
- Your NHS cleft team is usually the first point of contact for questions about treatment and care.
- National charities and advocacy organisations can provide additional information, emotional support and practical guidance.
- Every UK nation has independent organisations that can help if you need support navigating health services or raising concerns.
- You do not have to manage everything on your own.

