



Talking to your parents about common sibling issues

A brief guide to **communicating with your parents** for adult siblings of people with life-long learning disability and/or autism

Sibs is the UK charity for brothers and sisters of disabled children and adults
Registered charity number 1145200. Limited company number 7834303.

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What's in this guide about communicating with your parents?

This guide is for adult siblings of someone with a lifelong learning disability and/or autism. It briefly outlines common questions we receive from adult siblings about communicating with their parents and provides practical tools for getting conversations started.

Questions about how to talk to parents are some of the most common we receive at Sibs. Many siblings feel a sense of dread at having to raise a sensitive issue, don't feel confident with setting boundaries or worry about how their parents will react to changes they suggest. Siblings may be keen to maintain as much harmony as possible within the family and may wish to avoid confrontation at all costs. This quiet (or loud) ongoing anxiety takes up space in the mind and distracts from other important things in life.

Alongside this, siblings often tell us they have a pressing need to bring up the conversation because they have felt ignored for so long and because something needs to change. It can be very difficult for siblings to have these conflicting feelings.

Being a sibling can be a complex and challenging experience. You are not alone – visit www.sibs.org.uk to meet other siblings at a support group or become a volunteer support group facilitator yourself.

The information in this guide was accurate at the time of writing - November 2018.

I'm worried about my sister's future care but my dad refuses to discuss it. How do I get a conversation started?

It is very common for siblings to have significant and continued worries for their disabled brother or sister's future care. When you raise these worries with parents it can be incredibly painful to have them ignored. It leaves you with practical questions unanswered and an emotional burden unshared. It often heightens and prolongs the worry – which may be at the forefront of your mind or quietly eating away at you in the background.

If your sister is still living with your dad – and always has done – it may be very difficult for him to imagine a time when she will not be there. The transition of moving from the family home to another setting is incredibly emotive. Talking about it forces parents to consider their own ageing process and their own mortality. This may be too painful for your dad to consider at the moment, and may be why he avoids the subject.

Approaches you can try are:

1. **Little and often.** There is a lot to consider with future care so break it down into small chunks. For example, ask your dad one question per week. Take care over the time, place and way that you bring up the topic. Change takes time. Try this over the course of a year.
2. **Come back to it at a later date.** If you feel the little and often strategy isn't working, wait a while before raising the topic again. This may feel counter-intuitive and exactly the situation you are trying to avoid - but people take action in their lives for different reasons. It may be easier to engage your dad in a discussion when there has been a change in the situation e.g. your sister's needs have changed, or your dad's ability to cope or provide care has changed.
3. **Identify someone else who can raise the issue.** There may be someone else who can start the conversation with your dad - another sibling, another relative or friend or a trusted professional. They may be able to raise the topic whilst you are with your dad or they may be able to persuade your dad to talk to you about it.

Even if your dad isn't able to engage this you on this topic it doesn't mean you should bury your questions and worries. Write down all your concerns and all your wishes. What would *you* like for your sister in the future? How much involvement would you like in her life and in what ways would you like to have this? Talk to a trusted friend, do research

online or seek counselling. When the time comes, hopefully you will be able to share this with your dad.

Everything still revolves around my brother and I'm tired of feeling ignored. What can I do to change this?

Siblings often want to have time with their parents that is focused on things other than care and support issues. However for many siblings the pattern from their childhood, of their parents' main focus being on their disabled son or daughter, does not change with adulthood. This can be very disappointing and siblings can feel that they are missing out on sharing their adult lives with their parents.

It is important that you clearly tell your parent what you need. Whilst it may feel obvious to you, it may not be obvious to them. It also may be hard for them to acknowledge that they have not met some of your needs up until now. Take it a topic at a time and make your suggestions specific and achievable.

Consider the difference between:

"You always talk about my brother, but I want you to talk more about what's going on in my life"

and

"Let's talk about my brother first for about fifteen minutes and then let's talk about my children; job-hunting; decorating..."

The second statement clearly states that you want to discuss a specific topic in your own life and still provides space to discuss your brother.

My mum treats me and my autistic brother like children. She just can't see that we've grown up. How can I change her behaviour?

When children grow up and leave the family home, it takes parents time to adjust to this and get used to seeing them as responsible adults with their own lives. This happens in many families, not just those where there is a disabled son or daughter. When an adult has a disability where they don't reach developmental milestones in the same way, sometimes they don't leave the family home at the same time as their peers do. If your brother's developmental milestones haven't changed for some time, it may be that your mum's responses to him haven't changed either - it may be very difficult for her to see him as an adult at all. Parents often revert to old patterns of family behaviour when they are with their adult sons and daughters.

You may not be able to change your mum's behaviour. You can however change your own. And changing your behaviour is another way of communicating with your mum, of demonstrating what is OK for you and what is not. When your actions shift, your mum's will also shift in response to this.

For yourself

Make a list of the things your mum says or does that make you feel treated like a child. Then for each item, identify how you usually respond to this. How could you respond differently? What would you say to a friend who treated you in this way?

In many cases, meeting words with silence or ignoring the behaviour can be a powerful way to let your mum know that you do not accept what she has said or how she has treated you.

Something else you can do alongside this is to notice and point out the occasions when your mum does acknowledge your role and life as an adult – however rare this may be. A simple *"thank you"* or *"I appreciate that you..."* will help to encourage more of this.

For your disabled brother

See how you feel after you have experimented with changing your responses to how your mum treats you. If some of your techniques have worked, can you share them with your brother so he can try the same? If he is not able to, and you would like to support

him with this, try a more direct conversation with your mum about this issue. Think of the specific ways in which you feel his life could be more like that of his adult peers. Break this into manageable chunks, and think carefully about making suggestions one at a time.

Make sure you are aware of the difference between actions that would actually improve your brother's life, and actions that you dislike but do not actually impact on him that much. For example, it may make you cringe if your mum uses a childish nickname for your brother – but he may like this and it may not have an impact on his wider life. On the other hand, your mum may discourage your brother from social activities, because she is afraid of him being hurt or bullied. This does impact on his wider life and it is important to help him with this. Also, acknowledge the fact that your mum may see your brother as a child for the rest of her life and you may have to simply accept that it won't change.

You may find it helpful to read "*Decision-making and the law: when your brother or sister can't make a decision, who does?*" which is a guide produced by Sibs about mental capacity laws. Visit the links at the end of this document.

I'm co-ordinating my sister's care, I'm looking after my ageing mum and step-dad and I've got two young children of my own. My parents just don't listen to me and I feel like I've got extra children! How can I get them to take me seriously?

It sounds like you are part of the sandwich generation – caught between caring for older parents and your own children. When an adult sibling is part of the sandwich generation, they often have the additional responsibility of being involved with their disabled brother or sister's care. Make sure you are aware of caregiver burnout during this period of your life.

Looking after your children and looking after your parents may feel similar at times, because of their dependence and vulnerability. You may even be doing similar practical tasks for both your parents and children, such as preparing meals or assisting with washing and dressing. On the surface, the two situations can feel alike.

As a parent yourself, you know what age-appropriate decisions your child can make for themselves. But your parents are different to your child. They are adults in their own right, with their own experiences and preferences. It can be hard to remember this, when you may feel a parental sense of protection and obligation towards them since the roles have been reversed.

Here are some practical tips for communicating with your older parents:

1. Consider what caring tasks you can outsource. Many siblings of the sandwich generation can feel so rushed that they aren't able to take the extra time needed over conversations with their parents. Outsourcing whatever tasks you can, will free up some of your time to address this e.g. online food shopping or sharing the school run with a friend.
2. The parent-child role reversal can be difficult for parents, and as a result they may be resistant to accepting your advice. Don't offer advice unless it's asked for – provide encouragement and support instead. Advice may be best given from someone else e.g. a family friend or professional.
3. Have a look at the conversation strategies in this guide when you are considering raising a particularly sensitive topic with your older parents.

Whereas your children have more predictable developmental milestones, your older parents do not. You may have taken on caring responsibilities for your parents and your disabled sister gradually, as their level of independence has changed. It can be easy for the additional responsibilities to slip into your life with little awareness on your part. Set a time in your diary, perhaps once every few months, to re-assess your own needs, as their care needs change.

I feel like I have to constantly impress my parents to compensate for my brother who has a severe learning disability. How do I change this?

Perfectionism is very common in adult siblings and often begins in childhood. Children have an innate need to gain attention from their parents in order to have their basic needs met. Without consciously deciding to, many siblings automatically develop an identity as "the good child" because it may give them rare moments of positive interaction with their parents.

As child siblings become teenagers, they may be more consciously aware of their parents' caregiver stress in relation to their disabled brother or sister. This may lead to over-compensation for their disabled brother or sister's abilities, by performing well at school or by taking on more of the household chores. Also, many siblings do not want to add to their parents' concerns by expressing their own worry, anger, frustration or sadness.

Parents are often noticeably relieved by this behaviour. To them, it may seem that their sibling child is happy and well-adjusted in the home environment. As a result, a sibling child may become more independent with tasks at an earlier age, because their parents see how well they are coping. Noticing this relief in their parents, and seeing how their independence and success is appreciated, a sibling child may then continue with this behaviour.

There may be another environment, such as school or a relative's house, where the sibling child can express and process feelings such as anger, frustration, disappointment, fear and anxiety. However, where there is no other opportunity to do this, it is possible that the sibling child may suppress such feelings for a long time. They may feel it is shameful and unacceptable to be anything other than "the good child" at all times. Everyone experiences a range of emotions and needs to make mistakes to learn and grow. It is OK not to be perfect.

The need to be perfect may continue into a sibling's adult life. The key to leaving perfectionism behind is to:

1. **Start small.** Just acknowledging where and when it happens in your life is an important start. You can't change something that you don't know is there.
2. **Practice.** Pick a task that feels safe and do it slightly less well than you usually do. This may feel terrifying, but pay attention to the results. How do you feel? Increase to a slightly more challenging task and eventually work up to interactions with your parents.
3. **Approve of yourself first.** When you share a personal disappointment with your parents, make sure you have worked through it yourself first. This will give you time to form your own opinions and build your self-esteem. Don't avoid sharing these topics altogether, as continually editing your conversations will take more mental and emotional energy in the long run.

4. Be honest about your feelings. When feelings are suppressed, they don't disappear, they find somewhere else to go and this can be unhealthy. For example - unconsciously, you may find it safer to express anger with your broadband provider or express anxiety at work. Start by being honest with yourself and find a way to express your feelings.

There is a difference between perfectionism and healthy striving. Perfectionism is about your need to receive approval from others (*"I want my parents to say how proud they are when I get this promotion"*). Healthy striving is about your need to improve, for your own development (*"I want this promotion because I enjoy my job and I'm keen to take it further"*). You can let go of perfectionism and still aim for healthy striving.

Keep a note of when perfectionism arises so that you can become more aware of any recurring patterns. If you find perfectionism is causing you significant anxiety, consider seeing a counsellor to explore it further. Join a sibling support group to hear from other siblings who have struggled with this.

Me and my mum can't agree on anything about my sister who has Down syndrome. It's like my mum is from a different planet. We're completely at odds and I don't know what to do next.

In a way, your mum *is* from a different planet. You are a generation apart. Think about the era and the location she grew up in – things were different then. What messages did your mum receive about disability and parenting when she was young? Yes, you have shared genes and an overlap in your personal histories. But you are different people and it's normal to have completely different opinions. Remember that you both have different relationships with your sister.

Here are some ideas for working through disagreements:

1. **Get calm.** You and your mum both care deeply about your sister. The more important the conversation, the more heated it could be. If you feel this is happening take time to pause, breathe and keep the conversation as calm as possible. This helps you both stay focused on the content.

2. **Listen.** You cannot come to an agreement if you don't fully understand *why* your mum wants what she wants. Ask more about her reasoning, as this will put you in a more informed position to negotiate.
3. **Prioritise.** If you are disagreeing on several topics around your sister's care, address which are most important and discuss those first. If there are topics that are more superficial and you can abandon them, then do so.
4. **Get support.** Don't underestimate how emotionally and mentally draining having intense conversations can be. Make sure you are supported before and after the conversations. Discuss with your partner, share with a trusted friend or connect with a sibling support group.
5. **Consider counselling.** If you feel communication with your mum is beyond repair, consider family counselling to help mediate the situation. If your mum doesn't want to attend, then go by yourself. This may sound pointless, but discussing the situation openly with someone neutral can help you enormously. You may be able to re-enter the conversation from a fresh standpoint and feel more empowered.
6. **Take action.** In some cases, the issue you disagree on may be a safeguarding concern. If you feel your sister is at risk of abuse or neglect, you do not need your mum's opinion or permission to report this yourself. Take action and contact adult social care in your sister's local authority. Visit the links at the end of this document for further advice on reporting safeguarding concerns.

Practical tips to get a conversation started

Why talk to your parent about sibling issues?

It's really important to know why you want to talk to your parent about sibling issues. When you are clear on this, write it down. Trying out new communication techniques takes time and it takes practice. When you encounter natural stumbling blocks, re-read your intention and remind yourself of why this is important to you.

"My kids wanted to start football practice and I needed to give them a lift there. I spoke to my father, and I cut down on the amount of support I was giving my brother on the weekends, so that I could take them. Originally I just thought it was a necessary practical arrangement but when I thought more about it I realised it's really important to me to see my children enjoying themselves, developing skills, and to cheer them on during a match. They will grow up fast, and I don't want to miss it." Sadiq, adult sibling.

Where and when to talk to your parent

Before you start

It may feel odd to consider planning a conversation with your parent, especially when you cannot plan their response. However like many tasks, preparing for a conversation can improve its success, build your confidence and reduce any anxiety. It could improve the outcomes for yourself, your disabled brother or sister and your parent too.

Before you approach an important conversation with your parent:

1. **Have clear aims.** What do you want, and why? What is important to you and what are you willing to compromise on? Write this down and re-read it privately before you begin. Stick to one topic at a time.
2. **Practice your skills.** How will you put across what you want or need? Have a look at the conversation strategies in this guide before you start the conversation.
3. **Acknowledge how you feel.** Are you feeling anxious, angry, upset, ignored or hurt? Write about your feelings first. Getting clear on how you feel about a topic can help you to communicate this to your parents. It can also help reduce the intensity of strong feelings, which can help prevent you or your parents being side tracked by them during the conversation.

4. **Have a support plan ready.** What might you need during the conversation? For example, if you find your parents often put you on the spot or go off topic, have a key phrase ready that you can reach for if your mind goes blank.
5. **Keep an open mind.** Approach the topic as an open discussion or a problem to be solved between you. Thinking of the situation as having a right or wrong outcome can close your mind off to further possibilities.

Learning any new skill takes time and practice. Trying out new communication techniques is no different. Give yourself time to learn and don't worry if it doesn't go to plan first time. Look at how it went and adjust your plan for next time.

Where?

It's important to think about where you will have your conversation as people's responses can change in different environments. Think of the difference between the calm and softly lit room a counsellor may offer sessions in compared with a cold and intimidating police interview room.

You may find that because of current circumstances that your only option is to hold the conversation at yours or your parent's home. If this is the case, try and limit distractions and keep the environment as quiet and comfortable as possible.

Some people respond better to difficult conversations when they are carried out during a routine activity, such as washing up or driving a car. It can put people at ease by adding a sense of normality and reducing some of the intensity. If you are nervous, it can help to keep your hands occupied with something like cleaning. It might help if it is an activity you are both doing together. Do not talk about these issues in the presence of your disabled brother or sister.

Another option is to try a neutral location that is comfortable and pleasant to be in such as a coffee shop or local park. It may be very difficult to achieve this if time with your parent is already limited, but it is worth trying if possible. A neutral location can be helpful for some people as it is a fresh environment without the physical reminders of the family home. It reduces every day distractions and helps people to focus on the topic. It can help both parties to feel they are on an even ground and to consider each other's points of view.

When?

Wherever possible, try and have these conversations as soon as possible. Expressing your concerns as they arise means they are a manageable size. Holding onto concerns can create a build-up in pressure as your worry increases over time. When this is finally released, it's normal to experience a much more intense level of emotion than when the issue first arose.

Depending on the topic, you may find one of the following helpful:

1. **Indirect – little and often.** Bring up the topic regularly and with a little bit of context. For example, *"I recently set up a bank account for my daughter and it made me think about money that I'd also like to put aside for Sarah's future. Do you and dad have a trust fund for Sarah?"* This informal approach can feel more natural and it gives your parents time to digest the information, as you introduce it gradually over a period of time. Keep it to one small question at a time, and whatever the answer, acknowledge that and move on. Don't bombard your parents with a large amount of emotionally challenging questions unexpectedly – they are unlikely to be able to give you answers straight out of the blue.
2. **Direct - set aside a day and time.** For difficult topics, it's best to plan in advance. Tell your parents that you'd like to talk about the topic and mutually agree on a day and time for the conversation to take place. Don't be disheartened if they are dismissive of this at first – your request may just have taken them by surprise. Leave it for now and bring it up again soon. Be gently persistent with your need to arrange the conversation, as this lets your parents know how important it is to you.

How to talk to your parent

Listening

Some siblings have naturally honed their listening skills through regularly listening to others and rarely expressing their own opinions. Alternatively, siblings may find it difficult to listen well if they have seldom been listened to themselves – by their school, their parents and services for their disabled brother or sister.

To listen means to pay attention to what the other person is saying. Listening helps you to understand and understanding helps you to negotiate. Approaching the situation as a

negotiation can help achieve a better outcome for everyone. When you listen to others, it also means you are more likely to be listened to in return.

1. **Let them speak.** When your parent is speaking, don't interrupt or correct, even if you strongly disagree with what is being said. Wait until they have finished.
2. **Focus entirely on them.** Focus on their face, body language, words and tone of voice.
3. **Aim to understand.** When your parent is speaking it is tempting to construct a response in your mind. But this distracts you from listening until the end and you may miss key information. Keep your mind focused on simply understanding what they are saying at this stage.
4. **Check understanding.** If something is not clear once they have finished, ask them to repeat parts or say "*I'm not sure what you mean, can you help me understand?*". It's important not to make assumptions about what is being said.
5. **Summarise.** When they have finished, try summarising what they have said in your own words. This acknowledges that you have listened and understood. It gives them the opportunity to correct you if you have misunderstood.

Language

No matter how hard we try, it is easy to be misunderstood. Thoughtful use of language can help to reduce this.

1. **Use simple sentences.** The topic you are discussing may be emotionally challenging. When people are upset it can be harder to listen and take information on board. Use short sentences to get key information across.
2. **Own your feelings.** Your feelings are yours alone. They are your subjective experience. A statement such as "*You make me so angry*" can be argued with, and the listener may feel blamed. A statement such as "*I feel angry*" is harder to argue with, as it is simply about how you feel and not about placing blame.
3. **Be specific.** Hints or indirect statements may go unnoticed, so be clear about what you need. Stick to specific actions and give a suggestion of what you would like to change. This helps your parents to see something positive that they could do differently, rather than feeling they are entirely flawed as a person. Notice the difference between "*You never give me enough time to talk. I want you to start listening to me*" and "*When our phone conversations are cut short, I feel really hurt. I'd love to share more with you. Can we try talking for twenty minutes next time?*"

4. **Use "let's" and "this"**. It can be difficult for parents to hear advice from their children. Instead of using "you", try "let's" or "this" where appropriate. For example, "You really need to get this sorted" can be rephrased as "Let's sort this together" or "This is important and this needs to be sorted". It can feel less accusatory and keeps the discussion open.
5. **Use "and" instead of "but"**. The word "but" discounts what has been said before it. Consider the difference between "I know this is hard for you but it's hard for me too" and "I know this is hard for you and it's hard for me too". The second statement has the same information and acknowledges you both. It can feel strange to use "and" instead of "but" at first, so practice until it feels more comfortable.

Assertiveness

Being assertive involves expressing your needs whilst respecting the views of others. Being assertive is often confused with being aggressive (forcefully demanding what you want and being disrespectful to others in the process of getting it). At the other end of the scale is being passive. When a person is passive, they may not express their needs at all. Consider what influences you have received from your family, education and culture about communicating in a passive, assertive or aggressive way.

Here's an example of what these look like:

"I know you normally go to that relaxation class on a Thursday but I need you to take your brother swimming"

	Passive	Assertive	Aggressive
Verbal	<i>"Sure. I'll take him. The relaxation class was daft anyway. I can do it at home."</i>	<i>"I'd love to take my brother swimming. It's a shame that it clashes with my relaxation class though. The class is really important to me and keeps me going through the week – I can't miss it. Is there a different night we could go swimming?"</i>	<i>"You think I'll just drop everything to take my brother to some stupid swimming pool! I can't believe it! Don't ask me anything like that again!"</i>

Non-verbal	<ul style="list-style-type: none"> • Hesitance or silence • Quiet volume • Dismissive or disparaging of own needs • Looks down or makes little eye contact • Slouched posture, body closing in 	<ul style="list-style-type: none"> • Relaxed and firm voice • Sincere and respectful tone • Appropriate volume • Maintains natural eye contact • Open body language (e.g. uncrossed legs/arms) 	<ul style="list-style-type: none"> • Sharp or aggressive tone of voice • Disrespectful of other's opinions • Use of sarcasm, belittling remarks, threats or blaming • Loud volume of speech or shouting • Defensive body language (e.g. invading other's personal space or arms crossed) • Scowling or staring
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Identifying how you usually respond is the first step. If you are already happy with your assertiveness skills then this will support and sustain healthy communication with your parent.

If assertiveness is an area you'd like to improve on, start experimenting by using some of the features listed above. Try one new thing at a time and practice in a situation you don't feel too strongly about to begin with. For example, if your friend always chooses the TV show you watch together, voice your preferences too.

If you'd like to take this skill further, look for self-help books, local courses or one-to-one training sessions to help you develop.

Boundary setting

Boundaries can be physical, mental or emotional barriers that you create to protect yourself from harm. Having healthy boundaries helps you to separate your own feelings from those of others and maintains your personal space.

Setting a boundary might sound like drawing a hard line under an issue, but it is actually a much more compassionate process than that, and it is simply about stating what is OK for you, and what is not OK for you.

Adult sibling, Erin, gives a great example:

"My mum used to call me at all hours of the day and night, worried about my sister who has a learning disability. It was emotionally draining, and led me to worrying about them both. I wanted it to stop but I also didn't want to leave my mum alone with her worries. After some discussion, we agreed that she would need to text me first and ask if it was a good time to call – I would then call her back if it was. She could ring directly only in an emergency."

When you set a boundary like this, you both need to stick to it. This can be difficult and it takes time to practice:

"The first few times we tried this, mum would text me but then she would ring straight afterwards anyway. I would answer and ask her not to do this – but it continued. I felt guilty if I didn't answer and I hated the thought of her being alone. But then I realised – as long as I keep answering, she will keep calling. It was hard at first, but I knew I had to stick to our arrangement as much as she did."

It's important to keep practicing in order to see the benefits:

"This arrangement has worked out much better – not just for me, but for mum and for my disabled sister too. When mum was ringing all the time, I was snappy and dismissive about her concerns because I was so emotionally exhausted – I just wanted to get her off the phone! But now that I can ring her back at a better time, I can listen to her properly. As a result, she seems much calmer overall and we actually problem solve things together about my sister's care."

Review

Is what you're doing working? Take time to monitor your strategies and your efforts in this area. Practice and re-adjust your plans as needed. Most importantly, be kind to yourself, be patient and make sure you are supported. Ask yourself these questions:

1. How did that go?
2. What will I do next?
3. How can I support myself during this?

Use a note-making app on your phone or write it on piece of paper and place it somewhere you can see it, so you will be reminded to continue your efforts.

Further reading

Directory of private therapists and counsellors

<https://www.bacp.co.uk/>

Relate family counselling

<https://www.relate.org.uk/relationship-help/help-family-life-and-parenting/family-counselling>

"Decision-making and the law: when your brother or sister can't make a decision, who does?"

<https://www.sibs.org.uk/support-for-adult-siblings/guides/>

Taking action on safeguarding concerns

<https://www.sibs.org.uk/support-for-adult-siblings/safeguarding-concerns/>

Next steps in supporting yourself and your disabled brother or sister

What two actions will you take this month as a result of reading this guide?

1.
2.

Further support

Being a sibling can be a complex and challenging experience. You are not alone – visit www.sibs.org.uk for more information, to talk to someone about sibling issues, or to meet other adult siblings at a support group.

About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. There are over half a million young siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK.

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Sibs relies on donations and grants to support siblings – please consider making a donation through our website.