

my life
my health



my life health

Hello!

We all have to go to the doctor – it's just part of life. At the moment you might take your parents or carers with you. You might even take a friend. **As you get older and feel more confident you will probably want to go by yourself.**

There are different reasons why you might take a friend or family member with you to the doctor. **Have a think about who you take and why.**

There's no right or wrong step – it's about where you feel comfortable.

Your aim should be to move onto the next step when you're ready! We have some great information to help support you. Check it out at buzz.org.uk/mylifemyhealth

What happens when you go to the doctor now?
Look at the steps and see where you are at the moment.

Step 3
I make my doctor's appointments myself and go on my own.

Step 2
I go to the doctor's appointment with my parent. We both talk to the doctor during the appointment. I don't feel quite ready to do this on my own yet.

Step 1
My parents book my appointments and they talk to the doctor during my appointment. I don't take part in the conversation.

Are you ready to go to the doctor by yourself?!

Do this quiz to find out.

1

You need a doctor's appointment. What do you do?

- No idea – my mum, dad or my carer always book them for me.
- I book my appointment myself.
- My mum or dad book them for me – I tell them which date and time are OK for me.

2

Eek! You've got an embarrassing problem 'down there'. What do you do?

- I will tell my parents and they will come with me to the doctor.
- I don't have to involve my mum or dad because I can book an appointment with my doctor myself.
- No way I'm telling my parents about it! I'll ignore it and hope it goes away.

3

You want to use sign language during your appointment. What do you do?

- I'll ask the doctor's surgery to arrange an interpreter for my appointment or we'll agree to use a video translation service.
- I'm not sure how to book an interpreter so I'll just struggle through it without one.
- I'll take a member of my family or a friend to interpret for me.

4

Ok, so you've arrived for your appointment. Do you speak to the receptionist yourself?

- Yep – I tell the receptionist my name and the time of my appointment.
- Yep – I sign in myself and remind the receptionist to come and get me when it's my appointment.
- No, whoever I'm with does it for me.

5

You've been in the waiting room for ages, but no one has come to get you. You are worried you have missed your appointment. What do you do?

- I don't do anything – mum sorts it all out.
- I'd feel embarrassed to ask the receptionist if I had missed my turn.
- I'd go to the receptionist to find out what's going on. I'd check they have remembered to come and get me when it's my turn.

6

Your doctor turns away when they are talking to you. What do you do?

- I'd be too embarrassed to ask what they'd said, so I'd just nod and smile.
- I'd remind them to face me when they talk to me and ask them to repeat what they said.
- I'd apologise and ask them to repeat it.

7

There's a question you really want to ask during your appointment. What do you do?

- I'd probably be OK to ask the question and then hope I understand the answer.
- I'd feel too nervous to speak. I'd just let mum or dad do all the talking.
- I'd ask the question then make sure the doctor explains their answer so that I understand. If I don't understand I'd ask them to explain it again.

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Now add them up!
Which colour came up the most?



Mostly blue - you're a bit like Confident Casey



Great – you are already really confident to do things on your own! Remember these top tips to make sure you get the support that you need.

- Even if your doctor's surgery does give you good support, sometimes things can go wrong. Remember what your rights are and be confident to stand up for yourself.
- Remind your doctor's surgery what you need from them.
- Tell your doctors' surgery about your experience so that they can continue doing things well or improve where they need to.
- Tell NDCS – we want to share your story!

Make sure you help other deaf young people to become as confident as you. Share your experience and give them useful tips on how to start doing more things on their own.



Mostly pinks - you're a Nervous Nat



At the moment you rely on your parents to arrange your doctor's appointments for you. That's ok. It might be a little while before you're going to appointments on your own but here are a few tips to help you get ready.

- Ask your parents how they book your appointments. Would you be able to book an appointment without their help in the future?
- Pay attention during your appointments – don't just rely on mum and dad to tell you everything later.
- Be confident to ask the doctor to repeat things you have missed or not understood – remember it's your health!
- Prepare some questions with your mum or dad before you go into your appointment then ask the doctor these yourself.



Mostly Orange - You're a bit like Getting There Georgie



You still need your parents to help with some things, but you'd like to start taking more control of your own health appointments.

Here are a few tips to help you take the next steps.

- Ask your doctor's surgery about the different ways you can book appointments. Explain that you want to start booking appointments yourself so they need to suggest a way that works for you – for example, using text or email.
- If you would like to start using sign language interpreters during your appointments, then let your family know. This might be a difficult conversation, but it's an important step towards doing things on your own.
- Take the lead during your appointment – explaining what is wrong, asking questions and checking information if you're not sure.
- Be confident to ask your doctor to repeat things you have missed or not understood – remember it's your health!
- Agree with your mum and dad how you will manage any medication you need to take after your appointment.

Feeling a bit unsure or nervous about explaining your communication needs? Use our 'I'm deaf' wallet card!

Hello, I'm deaf

ndcs

ndcs
every deaf child

Print this out double sided


Cut it out

Fill it in and put in your wallet for when you need it

I need...

- an interpreter
- you to face me
- you to speak clearly
- you not to shout or mumble
- you to not talk & type at the same time
- to see your mouth so I can lipread
- a quiet space/no background noise
- us to write stuff down
- us to be patient and not give up
-
-
-
-

Don't worry, it's easy



Print this out double sided

Cut it out

Fill it in and put in your wallet for when
you need it

www.buzz.org.uk

3. Show it when you meet someone new,
who doesn't know what you need.

2. Add your own ideas

1. Tick the boxes that you agree with

needs? **Use this card.**

Feeling a bit unsure or nervous about
explaining your communication

Hello,
I'm deaf

 ndcs
every deaf child

Booking an appointment to visit my doctor

Booking appointments for your doctor can be hard! If you don't use the telephone, and your doctor's surgery don't have other ways to book, it can be frustrating.

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Lots of deaf teenagers have to rely on friends or family to make an appointment for them, or they have to go to their surgery in person to book.

Being able to book appointments yourself will help you feel more confident and learn how to do things by yourself! This is really important for your future. Do you want to still be going to the doctor with your parent when you're 55?

“What we want is to be treated as equals.”

Top Tips

- 1 Find out what your doctor's surgery offers** – many now have online booking systems, or allow booking by text message or email. If they don't do any of these, ask if they can!
- 2 Tell your doctor's surgery what you need!**
What will support you?
- 3 Explain what you need to make booking appointments easier** – for example, offering a text, online or email service if they don't already.
- 4 You deserve equal treatment.** Remind your doctor's surgery that **it's important you are treated the same as everyone else.**
- 5 Find out what services are available to help deaf people in your local area** – they might have useful information for you.
- 6 If your doctor tells you they are going to refer you to the hospital** or another service, remind them to put on the **referral letter that you need an interpreter** so that the hospital books one for your appointment.

Use BSL?

Need a sign language interpreter for your appointment? You don't have to rely on friends and family! Check out this video to find out how to book an interpreter
buzz.org.uk/mylifemyhealth

ndcs
every deaf child



The law
The law says that all health services – like your doctor's surgery or hospital – have to ask what extra things they can do so that deaf people like you can get the health services you need.

Want more information?

Signhealth

Useful information about healthcare for BSL users.

Check out our videos for BSL users on the Buzz: buzz.org.uk/mylifemyhealth.

[#mylifemyhealth](https://twitter.com/mylifemyhealth)

Can't use the phone to book?

Tell your doctor's surgery the things they can do to make booking an appointment easier for you. For example, by giving you the option to book by text, online or by email.

Your rights

You have a right to be involved in discussions and decisions about your health and care, and to be given information to help you to do this.

Your doctor is responsible for making sure communication support is available for you.

Booking an appointment to visit my doctor

It should be easy to get help from your doctor's surgery, no matter what support you need. This includes making sure that your deafness doesn't get in the way of booking appointments.

Unhappy with your doctor?
If you are unhappy with your doctor you could consider changing to another.



Communicating when I visit my doctor

Sometimes going to the doctor can be difficult, right? Especially if you're deaf and it's hard to communicate!

Your doctor might turn away when they're talking to you, or you might not hear the receptionist when they call your name.

It is really important that communication with your doctor is clear so you don't miss out on important information that will help you stay in good health.

Remind your doctor to look at you when they are talking to you.

If you haven't understood, ask your doctor to say it again or in a different way.

If there is no visual or vibrating alert system, remind reception staff that you are deaf and that they need to come and get you when it's time for your appointment. This will mean you can relax knowing someone will come and get you.

my life
my health

“I find that really difficult when I go to the doctor's. It goes way over my head. I need them to use simple words – clear, brief language, give examples.”

Use BSL?

Interpreters are there to support you during your appointment. Check out this video to find out what it's like to have an interpreter in your doctor's appointment.

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Top Tips

- 1 Use the My Life, My Health 'I'm deaf' wallet card when you check in for your appointment.
- 2 If you won't hear staff when they call you, find out if there is a visual or vibrating alert system. If not, ask reception staff to come and get you when it's your turn to be seen. This will mean that you can relax.
- 3 Ask your doctor to face you when they are talking. Ask them to speak clearly and at a normal pace, and not to shout!
- 4 If you haven't understood something, ask them to repeat or rephrase it until you understand. Try writing things down if that helps.
- 5 Don't give up! Remember how important it is that you get this information.
- 6 Take notes or ask for print offs of the information.
- 7 Remember it's your health – you need to be involved to know what's going on!

#mylifemyhealth



Want more information?

Download our other things to help you:

- + 'I'm deaf' wallet card
- + List of health words
- + Template letters to send to your doctor

Your rights

Your doctor's surgery or hospital should be supportive and make you feel comfortable.

Doctors and nurses should have basic deaf awareness training so they know how to communicate clearly. They should make sure you understand what they are saying.

Communicating when I visit my doctor

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Useful health words and what they mean!

Appointments can be full of lots of confusing and new words. Here are some useful words for your health appointments.

Appointment

A time and date when you will meet with your doctor.

Confidential

Your doctor will always keep information about your appointment confidential, which means they will keep it secret. This is unless they think that you are at risk or a risk to someone else.

GP

GP is short for General Practitioner – a doctor who works in your local area and is trained to deal with the range of problems you might have.

Medication

Something your doctor will give you to help you feel better. It could be a cream, gel or tablet.

Nurse

A person who is trained to care for people who are unwell, they might take blood and give injections. They do slightly different jobs to doctors – so depending on what your health issue is, you might see the doctor or the nurse.

Prescription

A note written by your doctor which explains how your medicine should be taken and used.

Referral

Sometimes you might need to go and see someone who is an expert in a health condition. Your doctor might suggest you see them.

Side effects

The way medications might affect you that you are not expecting. For example, some medications might make you feel sleepy or sick. You might be told not to do certain things whilst on the medicine like driving.

Surgery / clinic

This is another name for your doctor's office. It is where you would normally go for your doctor's appointment.

Symptoms

The things that show you are not well – for example, a temperature, a swollen leg or a rash.

Treatment

The things that will help you feel better – this could be cream, gel, tablets or you may have to go for an operation.

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Everyone, including hearing people, finds it hard to understand what the doctor is saying sometimes. We hope this list will help you.



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“I am happy with mum coming with me but later I would like to do it more independent”

Ready to go to the doctor by yourself?
Feel ready to start going to the doctor on your own? Talk to your parents and doctor about how they can support you to do this.

Use BSL?

Using an interpreter will help you feel more confident and in control of your doctor's appointment

An interpreter's job is to help you communicate. They must keep information about your health appointment private.


Growing up as a deaf young person can be challenging. Many people, like your parents and doctor, have helped to take care of you and made sure you have got the things you need to stay healthy.

Now that you're getting older, you may want to take more control of your doctor's appointments.

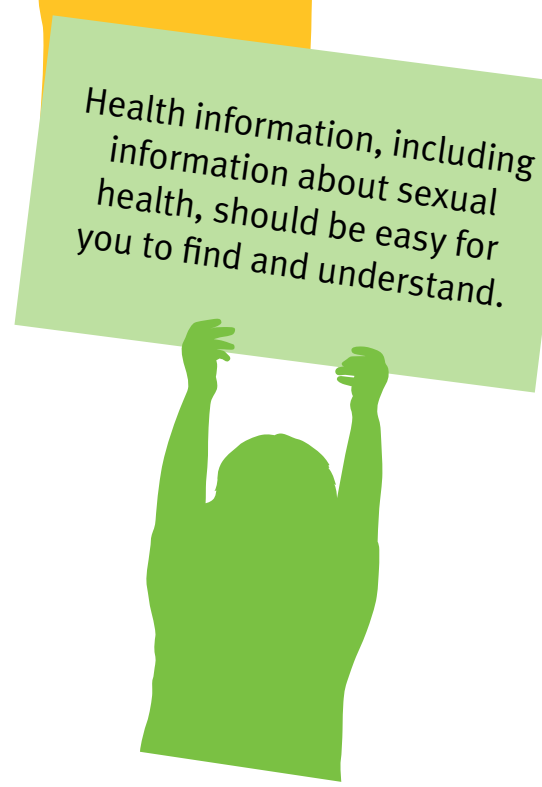
Top Tips

- 1 Tell your parents that you want to become more involved in your doctor's/hospital appointments.
- 2 Be honest about the communication support and help that you need – a sign language interpreter? Information written in simple English?
- 3 Agree with your parents the first steps you will take to start doing more things on your own. This could be booking the appointment yourself and answering the doctor's questions.
- 4 Pay attention during your appointments! Make sure you find out what your health condition is and how you will need to manage it.
- 5 Remind your parent and doctor that you need to be involved in the conversation too – it's your health!
- 6 If you are worried about communicating with your doctor on your own, write a list before you go of all the things you want to ask and any extra support you might need.
- 7 You may not want your parents to know that you're going to the doctor. Doctors have to keep information that you share with them private.
- 8 Ask what will happen after your appointment so you're clear about the next steps.
- 9 Find out what services are available to help deaf people in your local area – they might have useful information for you.

buzz.org.uk/mylifemyhealth
#mylifemyhealth



Your rights
If you go to an appointment on your own, your doctor must keep your information confidential – this is the same as keeping your information private.



Health information, including information about sexual health, should be easy for you to find and understand.

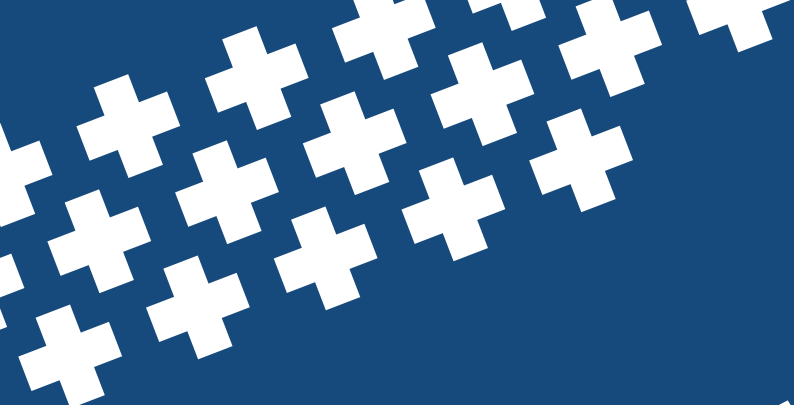


Ready to go to the doctor by yourself?

Supporting your deaf teenager to manage
**healthcare
appointments**

**For
Parents**





**“The only way the
child will develop
independence is
by doing things
themselves.”**



Before you read on it might help to have a think about the following questions.

- How do you currently support your deaf child to access their health appointments?
- What do you find difficult about your deaf child's healthcare appointments?
- What does your deaf child find difficult?

Introduction

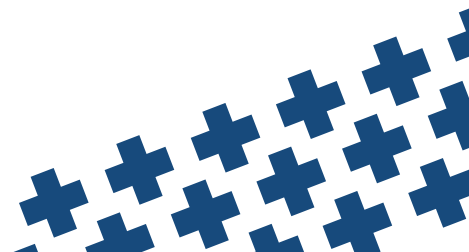
At the moment you may play an active role in all aspects of your teenager's health care - booking and attending appointments, speaking on your teenager's behalf and maybe even interpreting at appointments. There are lots of reasons why it's important for you to provide this support.

But parents have also told us how important it is that their child develops the confidence they need to gradually take ownership of their own health. This is because young people are likely to see their health as something private, and the ability to manage their own health will become very important to them.

Being independent is particularly important as your child transfers to adult healthcare services, because they work in a very different way to children's services. Whereas previously most appointments will have been set up by the professional, the emphasis will now be on your child to book their own appointments when they need support.

In this booklet, we share some ideas on how you can help your teenager to become more confident and independent in managing their health. We also explore some of the challenges that deaf teenagers might face when accessing healthcare services, and suggest some ways you can support your child to tackle these issues. Many of the ideas in this booklet come directly from parents of deaf teenagers.

This booklet is part of a campaign called My Life, My Health, which aims to support healthcare services to better meet the needs of deaf young people. To see the full range of resources in our campaign, visit ndcs.org.uk/mylifemyhealth.



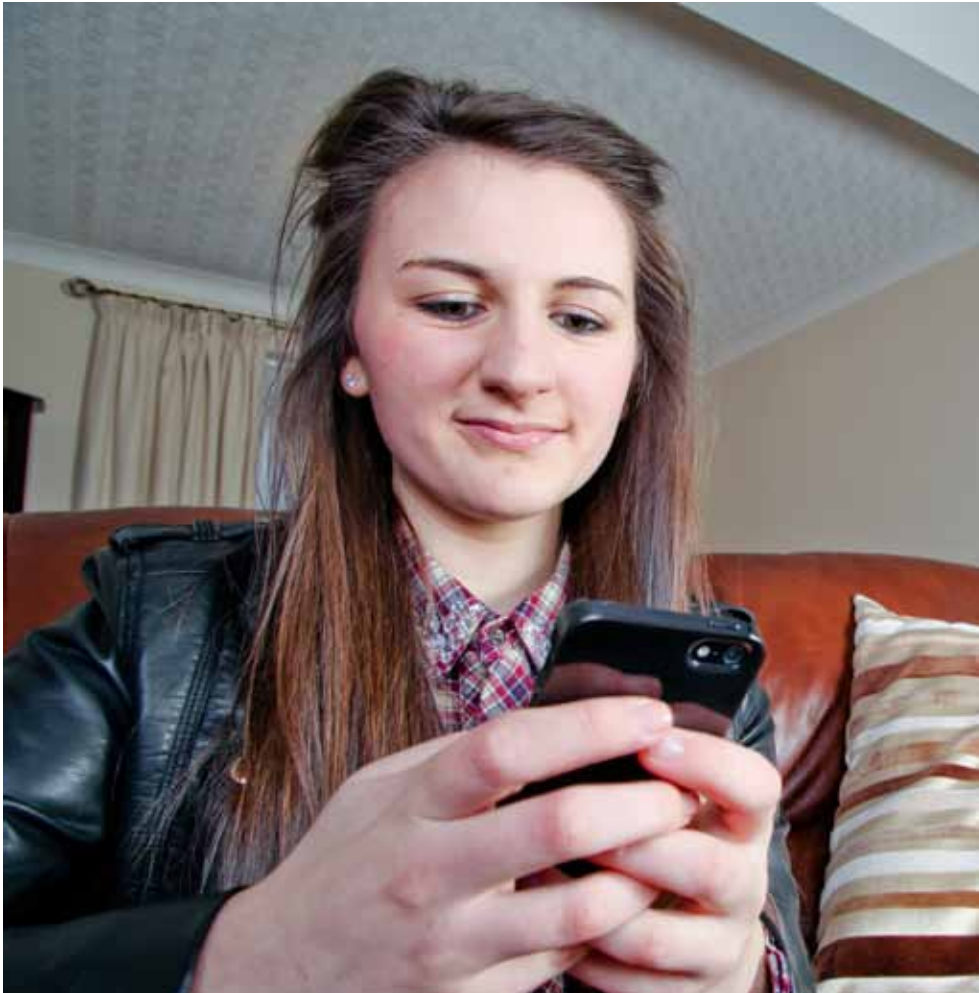


Thinking about the future

As your child grows up, the support that you give them will change. Here we look at a few ideas about how you can support your child to deal with the challenges of independently managing their own healthcare appointments.

As deaf children get older there are some things they need to learn so that they can access healthcare services independently. These include being able to:

- + book appointments independently,
- + request interpreters for appointments if they are needed,
- + attend appointments independently,
- + ask professionals for clarification when necessary,
- + understand and take responsibility for their own health for example taking medicine or picking up prescriptions,
- + know when to seek medical advice,
- + know what health services are available and when to use them,
- + be aware of all the services they can access.



“There’s a lack of knowledge of interpreters. I’ve tried to book interpreters before but the booking service at the hospital was not aware of them and had certainly not heard of SSE [Sign Supported English].”

“I have to arrange appointments as she [my daughter] finds using the phone difficult and there is no other way to make or alter appointments.”

Booking healthcare appointments

Challenge	How you can help
Appointments can only be booked by telephone	<p>You and your child can have a conversation with the healthcare provider about alternative ways to make appointments such as by email, text message or online.</p> <p>Visit buzz.org.uk/mylifemyhealth for more information.</p>
Access to interpreters is poor and the local healthcare service doesn’t understand why they are important	<p>Health services are responsible for ensuring deaf people can fully access their services.</p> <p>Make sure your child is aware that they have a right to an interpreter if they need one. This should help to give them the confidence they need to request one.</p> <p><i>“Don’t put up with really poor service.”</i></p>

Attending the appointment

Challenge	How you can help
Getting to the appointment	It's important to discuss and plan travel arrangements to and from the appointment with your child. Do they need to agree a meeting place or collection point? Do they need some help understanding the bus timetable?
A deaf person may not hear their name being called	<p>Make sure your child knows they should let the receptionist know that they are deaf and may not hear their name being announced. If there is no visual alert system, your child will need to ask the receptionist to come and get them when it is their turn to be seen.</p> <p>You and your child could talk to their healthcare provider about the possibility of providing a visual alert system.</p> <p><i>“Our doctor’s clinic has a screen which brings up your name – this is fantastic.”</i></p>
Reception and clinical professionals aren't deaf aware	<p>Give professionals our deaf awareness resource and go through some of the most useful tips with them that would help your child. You can find these on the Buzz website: buzz.org.uk/mylifemyhealth</p> <p><i>“I’ve found trying to talk to reception staff helps as they are usually not as deaf aware as the health professionals.”</i></p>
You worry that your child will not be able to explain their health needs as well as you	<p>Before the appointment, support your child to write down the key information that they want to tell their doctor and the questions they want to ask. Create a health information file with your child that they can take along to appointments. This could include information including medical history, questions that they may want to ask, medication they are on and any operations they may have had.</p> <p><i>“Talk to them in advance and brief them on things to tell the GP.”</i></p>



<p>It's difficult for deaf young people to understand all of the information given by professionals</p>	<p>Give your child our resource for young people about communicating at the doctor's surgery available from buzz.org.uk/mylifemyhealth. This resource includes practical advice around:</p> <ul style="list-style-type: none"> • booking appointments, • attending an appointment, • being more involved in appointments. <p><i>“Advise the child to write down notes of key points, e.g. diagnosis and action points.”</i></p> <p><i>“Let your child know that it's OK not to understand everything because hearing people are the same.”</i></p>
<p>Your child doesn't yet have the confidence to speak with professionals and ask for clarification</p>	<p>Encourage your child to talk directly with their healthcare professional and ask questions, even when you are present.</p> <p><i>“I encourage her to be more outspoken in appointments and really say what she wants if she's not happy with anything.”</i></p> <p><i>“Always get them to lead conversations.”</i></p> <p><i>“We've encouraged her to speak with adults at all appointments so she can put her point over confidently.”</i></p>



In day to day life

Challenge	How you can help
How to develop your child's independence, confidence and responsibility for their own health	<p>Make sure your child is aware of all of the health services on offer to them, and how to access them.</p> <p>Encourage them to take small steps and don't expect them to become fully independent in one go. For example, they could start by booking an appointment themselves, and build up to attending alone.</p> <p>If your child hasn't understood what the professional has said, encourage them to ask the professional to explain it in a different way, or write the information down.</p> <p>Support your child to practise speaking with adults about their deafness, explaining how it impacts on their daily life and answering questions.</p> <p><i>“The only way the child will develop independence is by doing things themselves.”</i></p> <p><i>“Encourage them to go out and about without you.”</i></p> <p><i>“Gradually try and be less involved in appointments.”</i></p> <p>Point your child in the direction of accessible resources on health by NDCS at buzz.org.uk/mylifemyhealth.</p>



Final thoughts

Here are some questions to consider as time goes by and you put into practice some of the ideas in this booklet.

- + What could you do differently at your child's next appointment?
- + What could your child do differently at their next appointment?
- + Have you noticed your child doing something new and out of their comfort zone at their appointments? Is there something you could praise them on?
- + Could your child practise some of these skills in other settings, such as in school, college or in their social life?
- + What stage do you want your child to be at with managing their health by the age of 18? How can you help them get there?

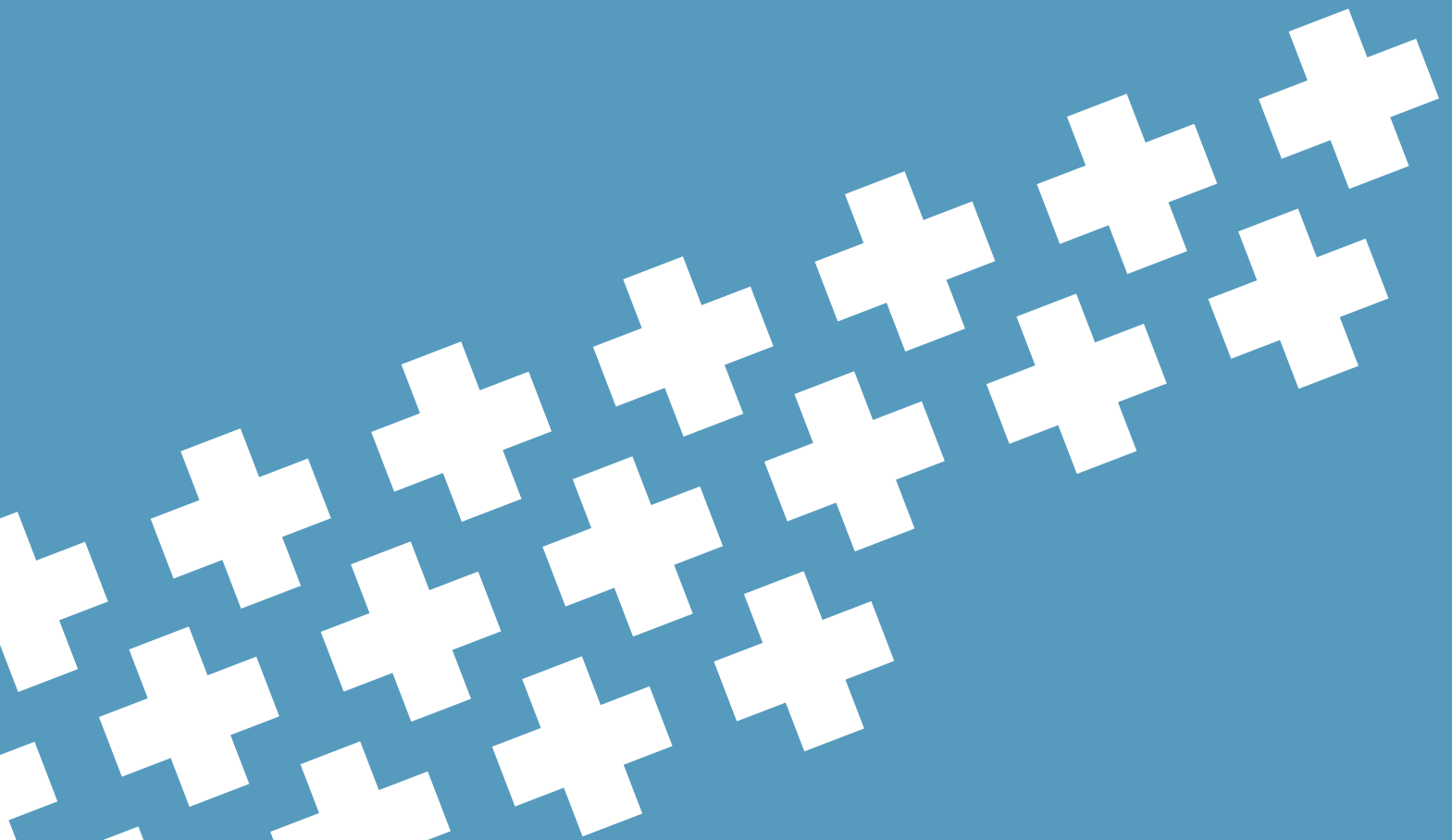
More Support and useful information

- + You can download other resources for young people and professionals from our My Life, My Health campaign from buzz.org.uk/mylifemyhealth.
- + Contact our Freephone Helpline at ndcs.org.uk/helpline, or by phone or minicom on **0808 800 8880**.
- + Each GP surgery or hospital will have a complaints procedure that they publish as a leaflet for patients – there will be a copy in the waiting area or ask the surgery manager for a copy. This outlines how to make a complaint locally and who to go to if you don't get a favourable response from the GP.
- + If you need additional help and support, or want to learn about health services in Wales, Scotland, Northern Ireland and England visit the Buzz website.
- + Encourage your teenager to sign up for the Buzz for deaf children and young people: www.buzz.org.uk.

Notes and ideas

A series of horizontal dotted lines for writing notes, spaced evenly across the page.

“Let your child know that it’s OK not to understand everything because it’s often the same for hearing people.”



NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.

**NDCS Freephone Helpline:
0808 800 8880 (voice and text)**

helpline@ndcs.org.uk

www.ndcs.org.uk/mylifemyhealth



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“My doctors always check that I understand and that I have heard. They also let me voice my opinion.”
Deaf young person

Every deaf young person is different.

Some might sign, lipread, or use speech. Some might use a bit of everything.

The best way to find out what they need is to ask them.

NDCS Freephone Helpline:
0808 800 8880
(voice and text)

helpline@ndcs.org.uk

ndcs.org.uk/mylifemyhealth

“We need to be more independent in preparation for our future life, it is good for your confidence, you shouldn’t always go with your parents all the time”

Deaf young person

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Supporting deaf teenagers during their appointments



Every deaf young person is different.

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Before their appointment

Is your booking service accessible?

Deaf people often need to book via email or text, as using the phone may not be suitable.

Are your reception staff comfortable talking to a deaf teenager?

Share the advice in this leaflet with them so they feel able to communicate in the best

way. It may be useful for the surgery staff to undergo some accessibility training together.

It's a good idea to have a longer appointment with a deaf young person, as communication may take longer. Please discuss this with your reception staff.

How do you announce appointments?

In many surgeries names are called out and a deaf young person could miss their appointment. An LED screen is the clearest way to announce appointments, but if you don't have one of these make sure the deaf young person is collected from the waiting area.

Who books interpreters if needed?

Your reception staff need to book interpreters. The young person should not have to rely on family or friends to interpret a confidential appointment. It may be possible for you to use Sign Translate www.signtranslate.com.



During their appointment

Has a parent or carer come with them?

The deaf young person may have brought a parent or carer with them for reassurance. Always speak to the deaf young person rather than their companion.

How do you know they have understood?

Encourage the deaf young person to ask questions, ask them if they have understood or if they would like you to write down a summary of what you have said.

Some easy steps you can take to improve the appointment.

- At the beginning of the appointment ask if there is anything you need to do to help them understand you.
- Keep background noise to a minimum.
- Don't stand with your face in the shadow or with a window behind you, as this makes it hard to read your lips.
- Keep still, it is hard to lipread someone who is moving around.
- Use visual clues, such as objects or charts. Use gestures to improve understanding.
- If you are not sure they have understood, don't give up. Try writing it down.
- Don't shout, talk slowly and clearly.

Action on Hearing Loss has some practical resources about how you can better support deaf patients www.actiononhearingloss.org.uk

Becoming independent

Many deaf young people will bring a parent or carer along for support or reassurance. Although this can be helpful, it can also hinder the young person becoming more independent.

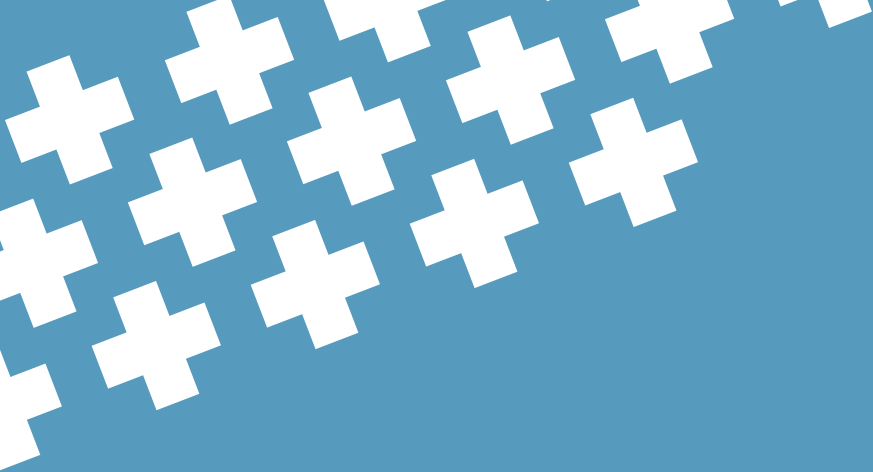
There are ways you can encourage deaf teenagers to become more independent.

- Speak to the deaf young person directly – it's their health.
- Ask the deaf young person if they would like to speak to you privately without the parent present. There may be something embarrassing they are not mentioning.
- Encourage the deaf young person to ask questions.

“They talk to my parents. [It] makes me very embarrassed because I'm 18.”

Deaf young person





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Deaf Young People's Experiences
of Health Services

Executive Summary

The National Deaf Children's Society 2014



Executive Summary

My Life, My Health

1. Introduction

The *My Life, My Health* consultation report was produced by the National Deaf Children's Society (NDCS) and its Young People's Advisory Board (YAB).

NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people. We help deaf children and young people and their families by providing practical advice and support.

The YAB is a group of 17 deaf teenagers recruited from all over the UK who work to identify and address issues that affect deaf children and young people. They chose healthcare as a key issue that they wanted to explore and improve for deaf young people.

2. Findings

More than 200 deaf children and young people across the UK took part in focus groups and an online survey, sharing their experiences of health services. Participants were aged 11-19 years, had different levels of deafness and communicated in different ways.

2.1. Deaf awareness

Deaf awareness was a real issue in healthcare settings. Experiences included:

- telephone booking systems with no accessible alternatives,
- lack of accessible technology including sign in screens and flashing LED visual alert systems so young people know when it's their turn,
- staff not looking at deaf young people when speaking,
- appointments taking place in rooms with background noise and poor acoustics.

2.2. Accessible health information

Deaf young people said that the information they receive from health professionals is often complex and hard to understand. Communication support was another issue:

- Many deaf young people did not realise they could access a qualified interpreter to attend appointments.
- Because of this, many deaf young people relied on family members to provide communication support. This resulted in inaccurate and missed information, friends and family feeling pressured and mis-communication.

What does NDCS mean by the term 'deaf'?

In this report, the term deaf is used to refer to all types of hearing loss from mild to profound. The term includes deafness in one ear or temporary deafness such as glue ear. It includes all children and young people that health professionals may identify as having a 'hearing impairment'.



2.3. Becoming independent

Most deaf young people said they would not consider going to their healthcare appointments alone because of lack of confidence, and worries about deaf awareness and inaccessible information. Many were heavily supported by family, who book and accompany them to appointments and often act as communicators.

Some deaf young people believed that their future partner or children would support them in the future. Others said they thought that their parents would continue to support them, however old they might be.

3. Recommendations

Deaf awareness

- All health professionals should complete basic deaf awareness training as part of their induction. Health professionals should also undergo refresher training where a deaf young person starts to come into regular contact with them.
- Medical records should make it clear that a child or young person is deaf and what their communication preferences are.
- Deaf awareness training should ensure health professionals are aware of the simple things they can do to improve communication, such as ensuring eye contact, good lighting and avoiding speaking too quickly.
- All health settings should have visual alert systems or pagers in place so that deaf children and young people know when it is their turn.
- A range of systems should be in place to allow deaf children and young people to book appointments so that they don't have to make a telephone call or rely on family members. This should include email and text messages.

Improved access to health information

- Health professionals should ensure that information provided to deaf children and young people is clear, easy to understand and free of jargon. Consideration should be given to presenting information visually through leaflets and video clips.
- Health professionals must break information down into chunks so that deaf children and young people have time to take it in and understand it. Health professionals should check the young person's understanding throughout and leave extra time to explain any difficult concepts.
- Deaf children and young people communicate in a range of different ways. Health professionals should ask what their communication preferences are and ensure this is recorded in their records.
- It is the responsibility of health professionals to ensure that communication support is in place and booked before a deaf

child or young person attends an appointment. It should never be assumed that family members will provide communication support.

- Deaf children and young people need more information about communication support and the role of interpreters. They should be empowered to exercise their rights in this area, as well as their rights to good health care.

Encouraging independence

- Ensuring basic deaf awareness is in place and that information given is accessible are both vital preconditions to independence.
- As deaf young people get older, health professionals must always talk to deaf young people directly, and not to their parents or interpreters.
- Deaf children and young people and their families need support to work out when and how they will begin their journey to independence. Health Professionals and parents have a role to play in encouraging deaf young people to take these steps to independence.
- Transition to adult services must be carried out in consultation with the young person and their family to ensure that deaf young people are ready and confident about the move.
- Deaf young people must be empowered, supported and encouraged to clarify, ask questions and make sure they understand. They should be provided with information about the importance of becoming independent in their health care and clear on the steps they can take themselves to progress this.

4. What next?

Research shows that deaf children and young people face many barriers when accessing healthcare services. Deaf children and young people are missing out on vital healthcare information and are being forced to depend on family when they should be moving to independence. This will have negative consequences for their future health and well-being, and may result in greater costs for the NHS if they grow up without understanding what they can do to promote good health.

Deaf children and young people should be involved in any changes made to healthcare services so that their needs are met and the goal of child-centred care is achieved.

5. Further information

NDCS has produced a range of resources for deaf young people, parents and health professionals to promote better deaf awareness, accessible information and greater independence for deaf young people. These are available online at www.ndcs.org.uk/mylifemyhealth, alongside the full research report.

