

STAMMERING & PATIENT CONTACT

STAMM  A

STAMMA

STAMMA exists to create a world that makes space for people who stammer. Where a stammer is embraced as just a difference. We have been representing people who stammer since 1978. Our members include those who stammer and those who don't. It includes those who are proud to stammer, those who want to sound fluent and all the shades of opinion in between. Find out more at stamma.org.

Stammering is variable and not all the information in this document will apply to everyone. However, flexible communication options will benefit many, not just those who stammer.

We'd love to help make your organisation more inclusive and improve your patient experiences with tailored training and guidance. Contact us at training@stamma.org.



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The Equality Act and the Disability Discrimination Act protect individuals from discrimination when accessing healthcare services. Those providing a public service have a legal duty to ensure their services are accessible for all patients, regardless of speech fluency.

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Kellie @xKellieLou · 1d
 Replying to @stammer @gmcuk and 4 others
 Every time, I call up my GP surgery to book an appointment the amount of time I have been told to 'hurry up', speak more clearly etc and they have hung up the phone on many occasions it's devastating we still aren't accepted.

15:07 · 22 Aug 23 · 510 Views
 1 Repost 1 Quote 4 Likes 1 Bookmark

Kellie @xKellieLou · 1d
 Replying to @HealthwatchE
 I've raised it a few times with my local GP surgery and that said they would investigate and get make to me and months later, I am still waiting. It's like they don't care. I hate calling them and now have to do everything online 🙄

Some responses on social media to our story about the difficulties people who stammer face.

Chris Nelson @chris_nelson · 2d
 Replying to @chris_nelson
 Even today, an adult with a professional career, phoning the NHS & stammering to NHS reception staff is often humiliating.

Some are great. But many, sadly, are so stressed & overworked that they become impatient, rude & unpleasant. Been insulted & hung up on. I fear them!

Comments

teevan49 · 2 d
 It's a pretty bad state of affairs when my bank is better at treating me with respect than our health service.

Mike Grant @Michael_R_Grant · 1d
 Replying to @stammer @gmcuk and 4 others
 I'm extremely lucky with my GP, as they use an online application to tell them what's wrong where you can add detailed notes. Then you get a call back at some point to arrange your appointment, and the receptionist is already in the know. It really helps.

audley.anna · 6 d
 I used to have panic attacks before I had to call a GP

greentrecrafts · 5 d
 Even face to face they can be harassing you to go faster. I always spell my name before I say it as it helps me say it but each time I do they look at me like I'm possessed or something.

tammieconnolly · 2 w
 Ringing the doctors is a nightmare for me. I have to build up the courage to ring them and i always have my sister on hand incase i can't get my words out. I know having a stammer is nothing to be embarrassed about but i do get embarrassed and end up apologising.

katieeslavinn · 7 d
 I once had a Dr at the hospital tell me I was taking a stroke because of mine. The pharmacist once wouldn't give me my prescription because I couldn't get my address out quick enough ...

akinbulumosharon · 7 d
 I don't like calling my doctors sometimes they can be so unhelpful makes me more frustrated and then I get annoyed, and my words start pouring out I can feel myself struggling to speak the person on the other end couldn't care less, so disheartening

alliemeeek · 1 w
 I hate getting a gp appointment also via the phone. I managed to find an email address for my last appt, tried to use it again but no response and it's been a week or 2. There should be more accessible ways to get for both the speech and hearing impaired.

" I HAVE HAD A PRESCRIPTION FOR A CONTROLLED DRUG FOR THE PAST 5 YEARS. EVERY YEAR I HAVE TO HAVE A REVIEW AND THIS YEAR THE PHARMACIST HAS ADDED A NOTE TO MY PRESCRIPTION SAYING 'SPEECH WAS SLOW, CHECK BEFORE ISSUING'.

INTRODUCTION

At least 1% of adults stammer. Some people stammer openly. Some choose to and are able to swap words or avoid situations to mask their stammer. So, while you may not pick up on those pauses, swapped words, and the exhausting preparation involved in sounding fluent, the person stammers. You just don't hear it.

Add in those who might have dysfluent speech for other reasons such as those with Parkinson's or who've had a stroke and you are looking at a considerable number of patients who potentially face real difficulties reaching you when they need help.

At the end of 2023 STAMMA conducted a survey with members about their conducted a survey with people who stammer about their experiences booking healthcare appointments. We expected some of the barriers that people told us about - being hung up on - but not all. Respondents also told us about other challenges they face as people who stammer in healthcare settings.

We've summarised the impact of the barriers that people who stammer face in this guide, and the structural changes that you might consider making in your healthcare setting. We'd be happy to provide bespoke guidance and training. In the meantime we hope you find the following pages useful.

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THEY ACTUALLY REFUSED TO SPEAK TO ME ABOUT MY OWN MEDICAL CONDITION AS I WAS "BEING HESITANT" WHEN GIVING MY DATE OF BIRTH SO THEY BELIEVED I WAS NOT THE PATIENT.

ABOUT STAMMERING

RECOGNISING STAMMERING

Stammering is when someone does one or more of the following: repeats sounds or words, prolongs sounds, has silent blocks when trying to say sounds or words. There might also be signs of visible tension as the person works hard to get the word out. Or they may look away to avoid seeing people's negative reactions.

Some people try to conceal their stammer. They might do so because they're tired of or worried about negative responses from other people. They'll swap words for ones that are easier to say, avoid saying certain words, and even avoid speaking situations. **So while the customer might not always appear to stammer, there can be huge amounts of work (and worry) going on under the surface.**

CAUSES

We don't know exactly what causes stammering, but research indicates that **it is primarily neurological**. This means that the way speech is produced in the brain is different for people who stammer. So stammering is just the way some people talk.



PREVALENCE

At least 1% of all adults stammer. That's over half a million people in the UK. It is often hereditary, but it is not related to ethnicity or personality. Everyone occasionally repeats or hesitates when speaking, but for someone who stammers it can happen almost every time they speak.

EXPERIENCE

- People do not stammer because they are less intelligent or have a nervous personality.
- Stammering varies from person to person. No two people stammer the same way.
- Some people may stammer more when they start to speak and stammer less as the conversation progresses.
- It fluctuates. Someone might stammer more on different days, or in certain situations.
- It can be exhausting and stressful for a person who stammers to try to speak fluently.

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I WAS REALLY STRUGGLING ON THE PHONE, LIKE THE KIND OF BLOCK WHERE YOU'RE NOT EVEN SAYING ANYTHING. AND THE GP RECEPTIONIST WAS SO RUDE/BUSY THAT THEY JUST HUNG UP ON ME. DIDN'T END UP CALLING AGAIN .



OUR RESEARCH

After reading through all the stories, we grouped the issues faced under the headings below. You can read the full, anonymised accounts [here](#).

■ Mental Distress

If the phone is the only channel to making an appointment, many worry and suffer a sleepless night before making the call. Some will ask a relative or a friend to ring for them and have to share personal information. Others will delay or just not make the call.

■ Blocking & Getting Disconnected

Some will get through on a call and 'block' before speaking, where no sounds come out. Pressurised staff often quickly hang up on the caller, believing it to be poor signal, requiring the caller to ring again and go to the back of the queue.

■ Lack of Training

Staff members who don't recognise stammering or know how to respond may laugh or make a joke. Or rush the patient to speak more quickly, or finish their sentences for them. This is common when a caller takes longer to say their name.

■ Giving My Details

Words that can't be swapped, such as name, address, date of birth, can be the hardest to say for those who stammer.

■ Voice Activated Responses

These services can be impossible to navigate. These can cut out before the patient has finished speaking or continue to ask them to repeat themselves, before ending the call.

■ Explaining My Symptoms

Someone who stammers may find it hard to quickly explain their medical condition over the phone to a hard-pressed staff member, or too exhausting to explain to a healthcare professional about the symptoms they are experiencing in much detail unless they are given time to do so.

■ Misapprehensions

Healthcare professionals sometimes mistakenly assume that stammering is the symptom of a medical condition, or a sign of drug-taking or evidence of a mental impairment. For people who stammer, stammering is simply the way that they talk. Misuse of stammering as a diagnostic feature can have significant consequences for that patient's treatment.

STRUCTURAL CHANGES

Simple changes can improve the patient journey and lead to better patient health outcomes through amendments to procedures, added communication channels and training.

- 1 Flexible Communication Channels**
Ensure there's more than one way for your patients to communicate with you. Offer patients the facility to book sameday appointments online or be able to contact you via email, WhatsApp or an app as well as the phone.
- 2 Voice Recognition**
If you use a voice automated system, provide an alternative to enable dysfluent patients to speak directly with a receptionist trained in communication differences. Or simply ensure the technology allows customers to speak at their own pace, without time limits, with options to pause and resume the call.
- 3 Implement a profile flag feature**
Implement a flag for 'communication differences' or 'stammering', which can be added to the patient's profile with their consent. Ensure your new patient registration forms captures these details and advertise the facility on your website.
- 4 Alternative ID Procedures**
Ensure that your practice receptionists are aware that saying one's name, address, date of birth can be hard to say and discuss alternative ID procedures that patients can opt into or alternative ways of confirming details.
- 5 Training**
Train practice receptionists, GP nurses, and all those dealing with patients to recognise stammering and to listen empathetically, patiently, and without interruption to patients who stammer.
- 6 Ask**
It is OK to ask someone if they stammer. Better that than make an incorrect diagnosis.
- 7 Call Back**
Offer a call-back service at a set time to allow people who stammer to prepare for the call. Keep to the agreed time for the call.
- 8 Software**
If your systems must receive information verbally, considering incorporating optional text-to-speech software.



TALKING TO PATIENTS

People who stammer often find those words which can't be swapped or changed (like name, address, date of birth), the most difficult to say, so your receptionist should expect this and be wait. Don't joke and suggest that the patient has forgotten their name.

Stammering is how some people talk. It's not good or bad. Just different. Some people who stammer experience more stammering when they start to speak and less stammering as the conversation progresses. Or they may stammer more on some days than others. That's normal.

- 1. Don't interrupt or speak over or finish a sentence**
Allow people to finish their sentences at their own pace. Guessing what they're trying to say is well-meant, but people often find it rude, humiliating and unhelpful.
- 2. Don't mistake stammering for something else**
Hesitation, pausing or changing words doesn't indicate nervousness or an attempt to avoid a question for people who stammer. It's just stammering. Nothing more.
- 3. Don't hang up**
If you pick up the phone and hear nothing, don't hang up. Give the caller time to speak. If you're unsure whether there's someone there or worried that it's a prank call, try our suggested 'script for silent calls' later in this guide.
- 4. Do Wait**
Give people enough time to say what they need. Actively encourage patients to take their time. Rushing patients who stammer tends to make it harder for them to speak.
- 5. Focus on the content**
Focus on what your patient is saying, not how they say it.
- 6. Make space**
If your patient is working hard to speak, it really is just about waiting patiently. You don't need to say anything about the stammering unless the person mentions it or seems very upset. If so, when they have finished you could say something like, 'I want you to know that you can take as long you need to speak. If I can help in any way, please let me know.'

"

IN ONE INSTANCE, THEY THOUGHT I WAS TRYING TO IMPERSONATE SOMEBODY ELSE BECAUSE I COULDN'T SHARE MY DETAILS FAST ENOUGH.

OTHER ACTIONS

Other ways of providing an accessible environment for people who stammer include:

- **Feedback.** Encourage feedback from patients with communication differences and use it to improve your services. This might include providing additional staff training, introducing new technologies and communication tools, and reviewing and adapting policies and procedures to better meet the needs of patients who stammer.
- **Share information on accessibility** on your website and practice newsletters. Ensure that you include communication differences and stammering so that disfluent patients are acknowledged and know about your services. You could include information about the availability of assistive technologies or accommodations for people who stammer, such as offering extended time for phone calls or allowing customers to select their preferred channels of communication.
- **Workshops.** STAMMA offers workshops and resources on stammering inclusivity. These sessions can be tailored to meet your needs and can be conducted remotely or in person. Contact us at EmploymentSupport@stamma.org or via our helpline or web chat service.

SILENT CALLS

You *"Welcome to [your practice name]. How can we help?"*

Caller [Silent or occasional sounds.]

You *Wait at least 15 seconds, then...*

"I know it's difficult for some people to start speaking on the phone. I can't hear you at the moment, but I'm happy to wait."

Caller [Silent or occasional sounds.]

After another 30 seconds...

You *"I can't hear you and I'm not sure if you can hear me or not. If you'd like me to stay on the line, can you tap on your phone twice, just so that I know you're there?"*

If caller taps twice, you know to keep waiting and repeat the cycle one more time. If no tap OR if the caller still hasn't spoken after you've been through the cycle twice, wait another 20 seconds and then say something like...

You *"I'm not sure if you're there and want to talk to us or not. I'm going to finish the call now, but you're very welcome to call us back. If the phone is difficult for you and you'd prefer to chat in a different way, you can also contact us by (outline alternative contact methods). Thank you for calling and we really hope to chat with you next time. Bye."*

End the call.



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IT'S HOW WE TALK