

# 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](https://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 patients' experiences with tailored training and guidance. Contact us at [training@stamma.org](mailto: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  
**greentreecrafts** 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, and everyone stammers differently. Some stammer a lot and others less. Some find it easier to move onto next words than others. Some people go to great lengths so that their stammer isn't noticeable. They might swap or avoid certain words or work hard to use a technique to control it. So, while you may not pick up on those pauses, swapped words, and exhausting preparation involved in sounding fluent, the person might stammer. 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 people who stammer about their experiences booking healthcare appointments. We expected some of the barriers that people told us about, such as being hung up on - but not all.

In this guide we've summarised the impact of the barriers that people who stammer face 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 or 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 peoples' 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 patient 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. Stammering 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

- 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.
- Speaking can be exhausting and stressful for a person who stammers.
- People do not stammer because they are less intelligent or have a nervous personality.

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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 from our survey, 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 for making an appointment, many people who stammer worry and suffer a sleepless night before making the call. Some will ask a relative or a friend to ring for them, and consequently have to share personal information. Others will delay or just not make the call.

### ■ Blocking & Getting Disconnected

When phoning, some people 'block' when starting to speak, with no sounds coming out. Pressurised staff often quickly hang up, believing it to be a 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 Details

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

### ■ Voice Activated Response Systems

These systems can be impossible to navigate if you stammer. They often don't give enough time for those struggling to speak and cut the person off. Or they don't recognise stammered speech and keep asking the caller to repeat their answers, before ending the call.

### ■ Explaining Symptoms

Someone who stammers may find it hard to describe their symptoms over the phone, particularly if they feel rushed.

### ■ Misapprehensions

Healthcare professionals sometimes wrongly assume that stammering is the symptom of a medical condition, or a sign of dishonesty or drug-taking, or evidence of a mental impairment. For people who stammer, stammering is simply the way that they talk. Unless the stammering has started recently, 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 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 capture these details and advertise the facility on your website.
- 4 Alternative ID Procedures**  
Ensure that your staff are aware that saying one's name, address or date of birth can be hard to say. Discuss alternative ID procedures that patients can opt into, or alternative ways of confirming details.
- 5 Training**  
Train staff 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. Keep to the agreed time for the call.
- 8 Software**  
If your systems must receive information verbally, consider 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 or date of birth) the most difficult to say, so staff should expect this and wait. Don't joke and don't suggest that the patient has forgotten their name.

- 1. Don't interrupt, 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 frustrating and humiliating.
- 2. Don't mistake stammering for something else**  
Don't assume a patient who stammers is nervous or dishonest, or that they're stammering because of a medical condition. It's just stammering. If you aren't sure, it's OK to ask someone if they stammer. Better that than make an incorrect diagnosis.
- 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 if it's a prank call, use our suggested 'script for silent calls' later in this guide.
- 4. Don't Rush**  
Time pressure tends to make it harder for callers who stammer. Try and slow down and don't rush when you're speaking to them. 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 says, 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.'

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**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.** Advertise accommodations for patients who stammer on your website and practice newsletters. Tell patients about the availability of assistive technologies, extended time for phone calls or selecting 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](mailto:EmploymentSupport@stamma.org) or via our [helpline or web chat service](#).

Do get in touch if you have any questions at all. We're very happy to provide tailored support for your particular workplace challenges. Contact us at [training@stamma.org](mailto:training@stamma.org)

# SILENT CALLS

Some people who stammer find it very hard to speak, particularly at the beginning of a call. If a call is silent, or if there are sounds but no words, it may be a caller who stammers who is 'blocking' and working incredibly hard to get their words out. To create space for them to speak you can adapt the script below:

**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**