STAMMERING & PATIENT CONTACT

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.







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

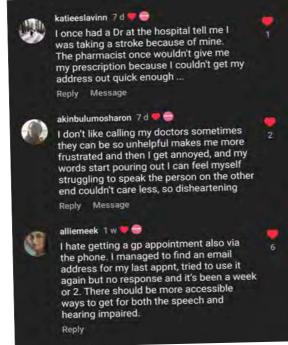














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At least 1% of adults stammer. Some chose to and are able to swap words or avoid situations to mask their stammer. So, while you may not pick up on those pauses, swapped words, and the exhausting preparation involved in sounding fluent, the person 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 a considerable number of patients who potentially face real difficulties reaching you when they need help.

INTRODUCTION

STAMMA conducted a survey with members about their experiences of making GP appointments and seeing a GP. We heard about extra hurdles experienced by those who stammer, summarised below. You can read the full, anonymised accounts here.

1. Mental Distress

If the phone is the only channel to making an appointment, many will 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.

2. Blocking & Getting Disconnected

Some will get through on a call and 'block' before speaking, where no sounds come out. Pressurised receptionists 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.

3. Lack of Training

Receptionists 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 particularly common when a caller takes longer to say their own name

4. Providing Patient Details

Words that can't be swapped, such as name, address, date of birth, can be the hardest to say for those who stammer. If the patient has disclosed a stammer and it is flagged on their record, then the receptionist would be in a position to support the caller.

5. 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.

6. Explaining the Symptoms

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

7. Misapprehensions

We've come across calls with GP practices and pharmacies where stammering has been taken as the effects of drugs or mental impairment. This can have significant consequences for that patient's treatment.

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



Everyone pictured in this guide stammers or is shown with a family member who stammers.

ABOUT STAMMERING

Stammering is different to the occasional repetition or hesitation that everybody experiences. It's when someone repeats, prolongs, or has silent blocks when trying to say sounds or words. There might be signs of visible tension as the person works hard to get the word out, and they may look away to avoid seeing people's negative reactions.

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. Stammering is the way some people talk. That's all.

- About 8% of children will stammer at some point.
- At least 1% of adults stammer.*
- Stammering can run in families. Around 60% of those who stammer have a relative who stammers or used to stammer.
- We say 'stammer' in the UK, other countries use 'stutter', the terms are interchangeable.
- Ethnicity does not affect stammering.
- People do not stammer because they are less intelligent or have a nervous personality.
- Patterns of stammering vary from person to person.
- Stammering fluctuates. It often varies from situation to situation as well as over time. That's normal for stammering.
- You may not know that a person stammers. Some people will mask their stammer, and swap and avoid words and speaking situations to sound fluent.
- It can be exhausting and stressful for a person who stammers to try to speak fluently.

*A poll of 3,000+ representative sample of UK adults conducted by Peekator showed that 1.5% said that they stammer. Previous polling with YouGov showed even higher percentages. Until the stigma around stammering is removed it's going to be hard to know how big this audience is.

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YOUR PATIENT JOURNEY

If you want to ensure that your surgery is accessible to everyone, then look at the way in which patients will be in contact with you, whether in person or online or via the phone.

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 do 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.

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PATIENT CONTACT

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 for stammering.

Here are some do's and don'ts when talking to a patient by phone or in person.

DON'T

1. 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-intentioned, but people who stammer often find it rude, humiliating and unhelpful.

2. 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. 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.

DO

1. 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.

2. Focus on the content

Focus on what your patient is saying, not how they say it.

3. Make space for stammering

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 what they're saying 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.'



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 use a script similar to the following:

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

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."

Silent or occasional sounds.

You After another 30 seconds...

"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...

"I'm not sure if you're there and need to talk to me. I'm going to finish the call now, but you're very welcome to call 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."

End the call.





ADDITIONAL 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 webchat service.

ABOUT 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 business more inclusive and improve your customer experiences with tailored staff training and guidance. Contact us at EmploymentSupport@stamma.org.

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STAMMA

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IT'S HOW WE TALK