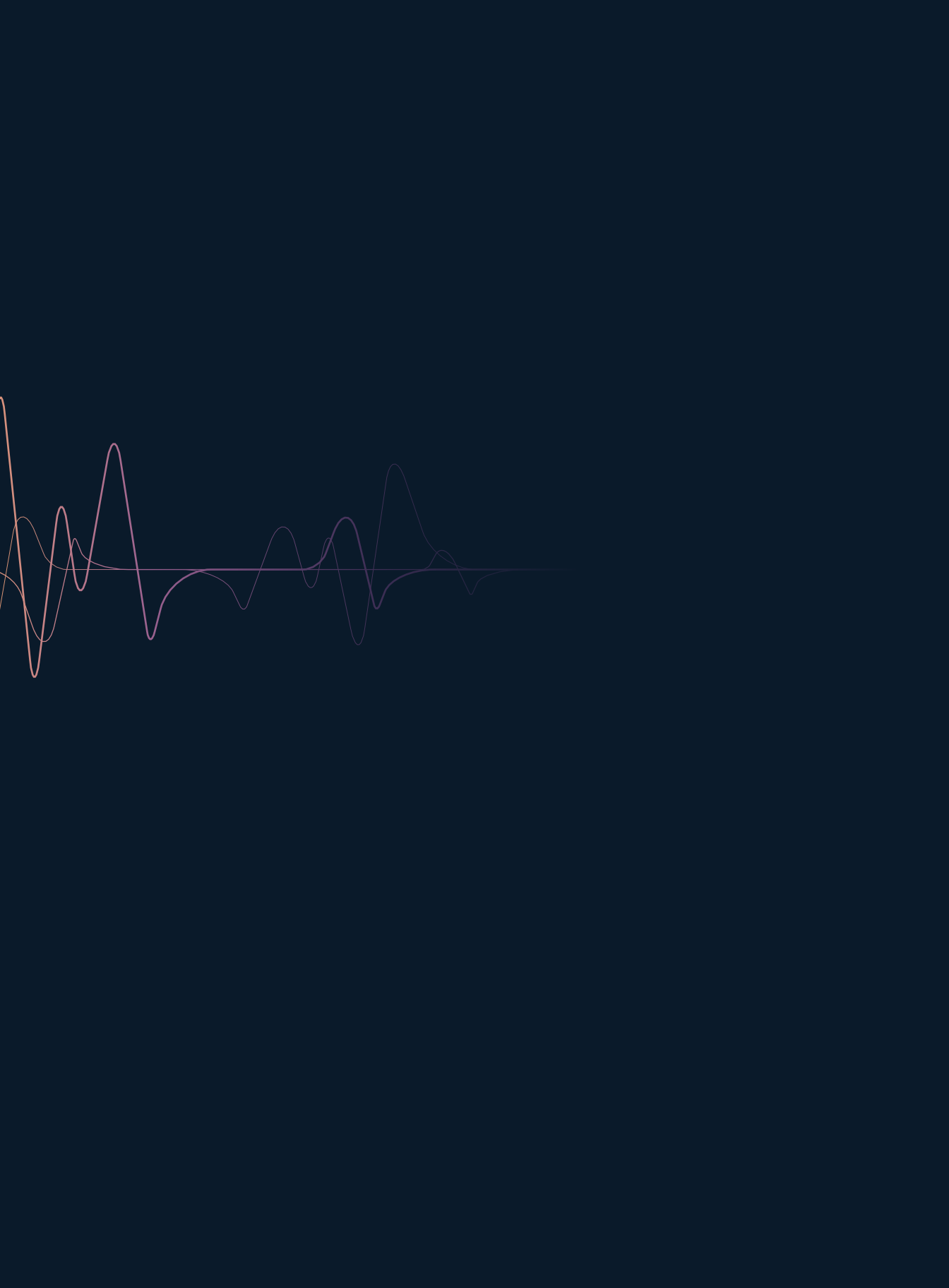


RELAPSING TO  
SILENCE

*A voice for those suffering from selective mutism.*

Written, edited, & designed  
by **Hayley Romansky**



RELAPSING TO

# SILENCE



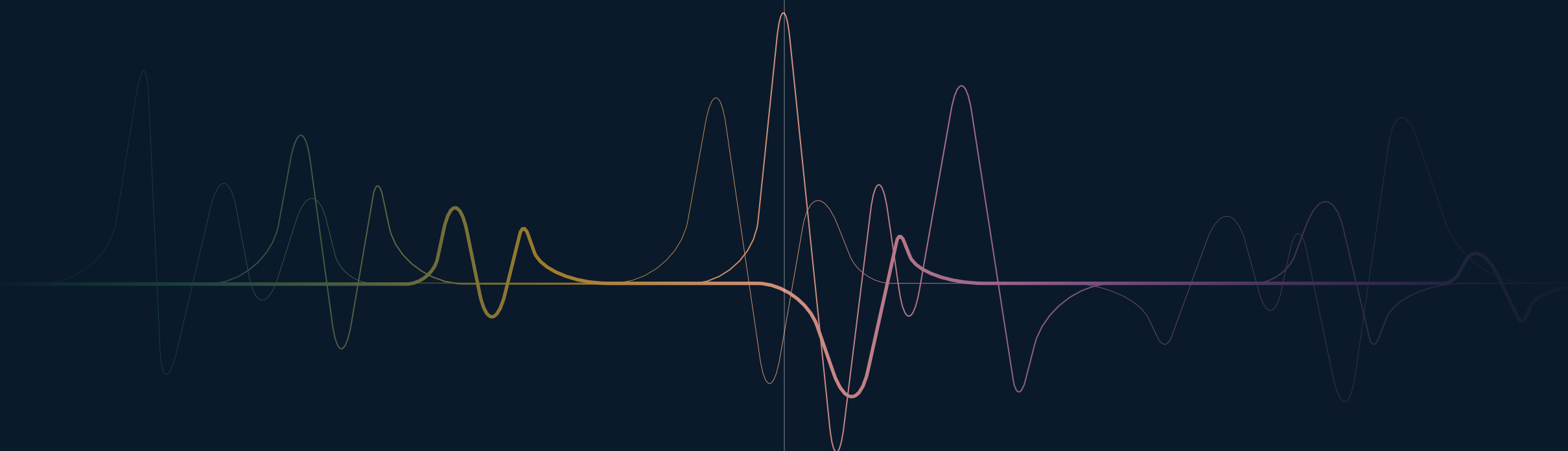
## DEDICATION

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Dedicated to the little girl who never knew why she couldn't speak for herself & everyone who lives in fear of the next time they'll be expected to talk.

Some day our voices will be set free.





# 1 INTRODUCTION

- The importance of this book & why it was created.

# 3 SECTION 1 DEFINING SELECTIVE MUTISM

- What is SM?
- Development
  - Mark
- High & Low Profile
  - Danielle
- Persistence into Adulthood
  - Wendy
- Speech Rules
- Masking
  - The Speech Trap

# 39 SECTION 2 JOURNEY TO RECOVERY

- Sam
- Seeking out Help
- The Process of Overcoming
  - Beth
- Aftermath & Results

# 63 SECTION 3 FINAL THOUGHTS

- Can you cure SM?

# INTRODUCTION



THIS BOOK IS 22 YEARS IN THE MAKING.

It wasn't until the end of 2020 that I found the answer to one of the most troubling questions in my life. Why are there times when I cannot speak? It feels as if there is something physically barring me from letting out any sounds.

The problem \_\_\_\_\_ selective mutism.

At this time, there was no official diagnosis, no reaching out to professionals, nothing but me stumbling upon this topic on my own and delving so far into the research that I was brought to tears.

I cried when I discovered selective mutism not because I was sad, but because for the first time, I felt validated. I had never been able to put a name to the issues I was dealing with on a daily basis, and now it felt possible for me to take control over the parts of my life I had previously thought were unfixable.

In addition to this book standing as documentation of my own journey through selective mutism, this book is for all those who suffer from selective mutism, those who have overcome it, and those who may never get the chance.

\_\_\_\_\_ I hear you.

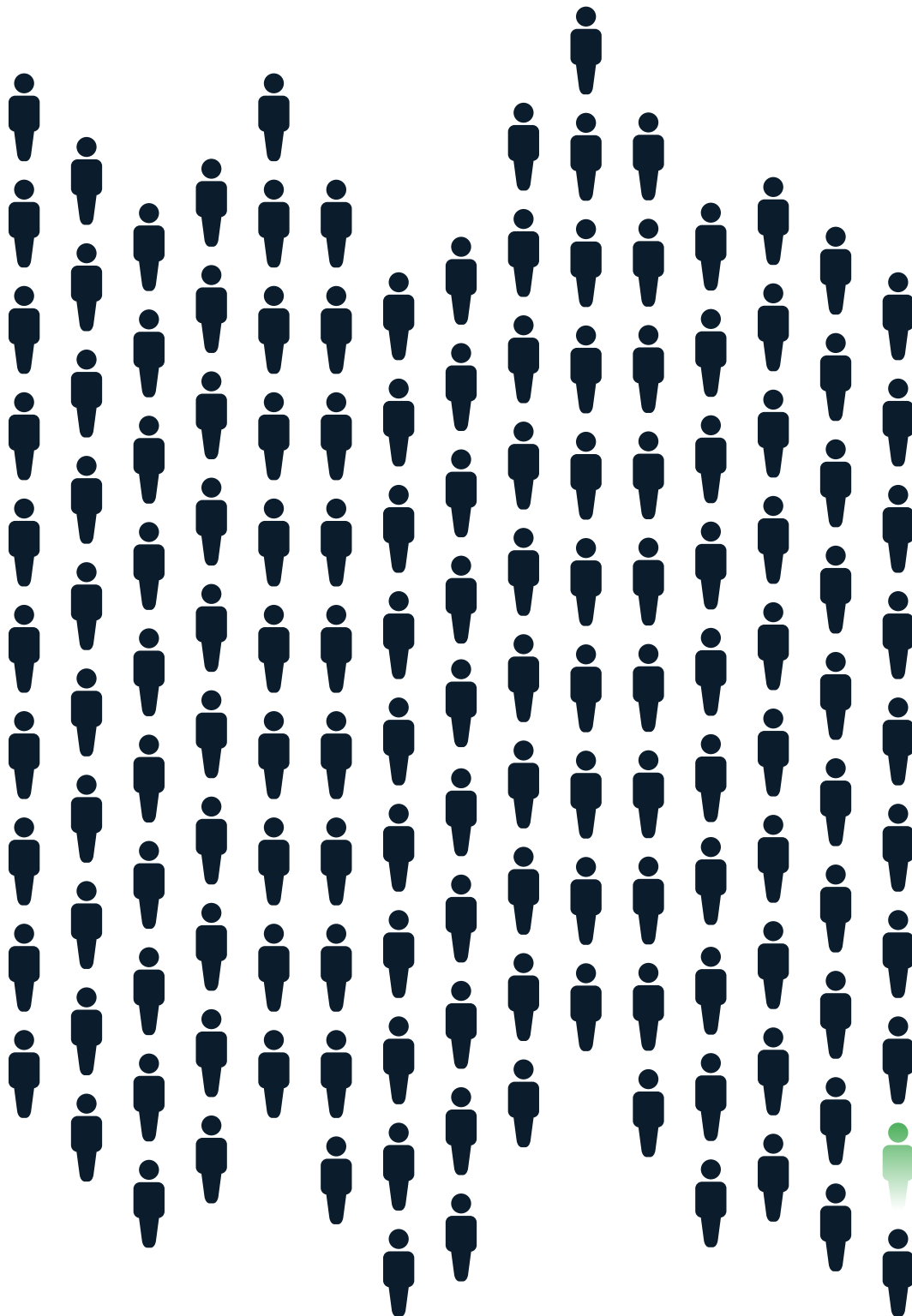
Disclaimer \_\_\_\_\_

This book will not cover everything related to selective mutism. SM varies from person to person and can also be disguised as or comorbid with other disorders. This book will primarily delve into the research and experiences that have helped me through my own journey, and hopefully will further help others as well.



DEFINING

# SELECTIVE MUTISM



## WHAT IS SELECTIVE MUTISM?

### My voice

I first came across the term “selective mutism” while going down a rabbit hole of research surrounding anxiety disorders affecting speech. The first question I, and presumably anybody else, had was what exactly is selective mutism?

Excerpts by Carl Sutton & Cheryl Forrester, Maggie Johnson, and Aaron Walker

Selective mutism (SM) is a **situational anxiety disorder**, characterized by being able to speak in some situations but not others. It is a state of almost constant vigilance; a range of intense emotions and physiological reactions affecting mind and body; a condition which influences, and is influenced by, family dynamics and the behavior of relatives, staff, peers and even complete strangers.

Essential characteristics of SM behaviour as described by DSM-5 and ICD-11:

1. Individuals present a consistent pattern of speaking in *some* situations where speech is expected but not in others.
2. The failure to speak is *persistent*, lasting more than one month, but not including the first month in a new environment such as school.
3. The failure to speak has a *significant* impact on educational or occupational achievement or social communication.
4. Lack of knowledge or comfort with the required spoken language, or a disorder of communication or a condition like social anxiety disorder, may also be present, but is not the cause and does not explain the mutism.

It affects around **1 in 150** younger children, the incidence rate reducing with age to around **1 in 1000** adolescents (NHS, 2015). Furthermore, my own research on SM in adults (Sutton, 2013) estimates that SM affects greater than **1 in 2400** young adults.

Selective mutism affects around

**1 in 150**  
younger children,

**1 in 1000**  
adolescents,

**1 in 2400**  
young adults.

As with most anxiety disorders, females are more likely to experience SM than males.

A person with SM is phobic of initiating speech/being overheard in the proximity of a given trigger person or collection of people.

A person with SM  
may be able to speak  
in one situation

*e.g. at home with close relatives*

but be unable to  
speak — frozen and  
timid — in another

*e.g. at a social event, at school or college, with doctors or dentists, or even in a work meeting.*

While SM may seem like something people choose or elect to do (the old names for this condition used to be *Aphasia Voluntaria* then *Elective Mutism*) this is absolutely not the case.

Muteness/freezing/hiding is triggered by the proximity of specific individuals or groups of people.

Triggers may be generalized: strangers, other students, teachers, shopkeepers, or even work colleagues. Or triggers may be more specific: aunts, uncles, siblings, stepparents, or even parents. Most people with Selective Mutism have a mixture of generalized and specific triggers.

It all boils down to the same thing.

**SM is an anxiety disorder and people with SM have developed a phobia of talking to, or being overheard by, certain people.**

This, odd as it may sound, all reassured me in a sense. It was a term I was unfamiliar with, and yet as I read about the disorder, I understood everything that was being said. The conditions or circumstances described were all situations I had been a part of countless times but could never put a name to or understand why. It makes sense now. Selective mutism isn't that uncommon in children, but it becomes more sparse in adolescents and adults. There's not a surplus of people that even know about the disorder's existence, let alone what it actually is.

**SM is commonly defined as the 'failure to speak in certain social situations'.** However, to me, it is so much more than that. On the surface, it appears as though the sufferer is choosing when and where to speak; however, the truth is that rather than being deliberately silent in certain situations, it feels as though you physically can't talk, like the words will not come out.

## DEVELOPMENT OF SM

When children who have SM do not speak, one of two things is happening: either the prospect of speaking in certain situations fills them with such dread that they are physically unable to speak; or they spare themselves this intensely distressing experience by avoiding the need to speak. **The more they experience either of these scenarios, the more their fear of speaking is reinforced.**

Looking at the cause of SM involves asking how individuals develop a conditioned fear of speaking. In common with other anxiety disorders, there is no single cause; SM arises from a unique interaction of genetic (inherited) and environmental factors.

As with other phobias, there is no single cause of SM but there are elements that contribute to the process of **'fear conditioning'** — the child develops an irrational fear of talking that is triggered by specific people and the expectation to talk.

**It seems that there is no single cause linked to the onset of SM, although there are multiple factors that can cause it to worsen.**

While most anxiety disorders, including Social Anxiety Disorder, begin in adolescence or early adulthood, SM has a very early mean age of onset, as discussed in the introduction. **In fact, many adults with SM would say that they were "born" with the condition** — often because their parents informed them this was the case.

Disruptive life experiences of various kinds—relocation, parental conflict or divorce, parental mental illness, bereavement, bullying, shame, feeling different, and so on—compound mutism in children and adolescents with SM.

THE PROSPECT  
OF SPEAKING  
IN CERTAIN  
SITUATIONS  
FILLS THEM WITH  
SUCH DREAD  
THAT THEY ARE  
PHYSICALLY  
UNABLE  
TO SPEAK.



# MARK

## 35

It's as if something's gone wrong in my brain but at the same time I know that the part that's me is working fine, if that makes sense? **Like I know how to speak and I know what to say, but it just won't... do anything.**

When I was 5 I went to live with my dad's brother and his family. My aunt told me that I was quiet but I don't think it was like now, I remember playing with my cousins and other kids and stuff. I think maybe there was always a feeling that, well not that I didn't belong, but sort of that, I don't know. Maybe that somehow led to having selective mutism in a way. It's not something you notice happening I don't think, you know?

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Sometimes I feel like I don't even know how to talk any more.

I can sit in a room where people are talking about work or what they did last night and there's just nothing I have to say even if I wanted to. Maybe if the conversation was about where you were never even able to talk to people and were living a depressed and lonely life then I'd have something to add.

W  
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## RISK FACTORS

Sensitive child

+

## TRIGGERS

Fear conditioning linked to expectation to speak

+

## MAINTAINING FACTORS

Reactions to mutism reinforce fear of speaking



SELECTIVE  
MUTISM



## HIGH & LOW PROFILE SM

A very important piece of information I discovered was the difference between high profile and low profile selective mutism. While reading about SM, I felt like I wasn't alone. I was being seen, being heard by anyone in those books who also talked about their own experiences. But in hearing about so many experiences, I confronted the reality of how bad selective mutism can get.

I often find I start to invalidate myself. I think "Oh these people have it much worse than me. Maybe they're really the ones who have SM and I'm just overreacting. I can talk sometimes."

But that's what the disorder is. Talking only sometimes and not being able to help it.

Reading about those who couldn't even respond with a head nod or put pen to paper appeared to make my own experiences less valid, less important to fix. But then I reminded myself that just because my SM is low profile, does not make it any less of a problem. The difference between high profile and low profile SM is described as follows:

SM is easy to recognise when children speak to some people, or in some places, but not in others. **However, things are rarely this clear cut because the individual's ability to speak is entirely context-dependent.** Thus a child may be able to speak to a parent, friend or particular staff member, but only when they are sure no one else is listening. Or they may speak freely in front of strangers, but stop as soon as they see a classmate, fearing that they will be expected to talk at school. Despite these apparent variations, a consistent situational pattern can be identified where the child never speaks to certain people; this is described as 'high profile' SM in Anxiety UK's booklet Children and Young People with Anxiety.

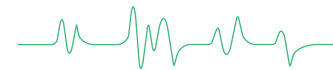
DSM-5 also allows for 'low profile' SM by stating 'Children with this disorder do not initiate or reciprocally respond when spoken to by others'. **In other words, they may respond minimally but not in a reciprocal, conversational manner.** This is a pattern we see in compliant children who are anxious about upsetting authority figures or looking foolish in front of their peers. We also see it in children and young people who are beginning to make progress. They manage to answer straightforward questions and comply with simple verbal routines but it will be clear that this is not without effort; they are tense and speak quietly or in a strained manner.

Children with low profile SM are particularly vulnerable at school because their high anxiety levels may not be recognised. All the time they speak a little, it may not be apparent that they are unable to initiate contact of their own accord, seek help, correct misunderstandings, make friends, or report illness or bullying.

Without appropriate support, many children with low profile SM say less and less until a high profile pattern is apparent or they become adults with low profile SM.

Moments of verbal communication occur more frequently in those with low profile selective mutism in contrast to those with high profile SM.

As with any disorder, degree of severity varies from person to person.



Speech pattern without SM



Low profile SM



High profile SM

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GDANIELLE  
21

For as far back as I can remember, Selective Mutism has been a massive part of my life, from the early years of having to deal with it in its entirety, to taking drastic action in my teens to beat it, to now, battling severe anxiety on a daily basis as a result of it. During my early school years, I was naively unaware that I was different from my classmates. I never struggled in school, always had lots of friends, and had great support from the teachers, despite their lack of knowledge of SM.

Junior school for the most part was a similar story, I had great friends and supportive teachers. My issues really came to a head when I was faced with a supply teacher who appeared to not know about my SM, or at least not know the extent of it. During our first lesson, which was English, we were given a written task to do. To encourage us, the teacher had promised us stickers and so, after we had finished the exercise, we were to go up to her desk and show her the work we had completed. One by one, my friends went up and got their stickers. When it came to my turn, I went up to the teacher to show her my work and, once she'd marked it, she asked me which sticker I'd like. I pointed to one of them but, instead of just giving me the sticker I'd chosen, she insisted that I tell her which animal was on it first. Obviously, that was not going to happen under any circumstances and so I returned to my seat, the only one out of all my friends who did not get a sticker, despite having done the same amount of work as them. As trivial as it may seem now, to a nine-year-old child, this was a massive deal.

It was in this one moment, that I realized how different I was from my friends and classmates.

The supply teacher's campaign to try and make me talk did not end there though, the situation became more severe during a lesson later on in the day. We were given an oral exercise to do, not the best task for a child with SM. However, these exercises were not usually an issue for me as I'd been given a whiteboard by my regular teacher at the beginning of the school year. We were put into pairs and given the task to do. As always, I teamed up with my best friend. We started to complete the exercise with me writing my contribution down on my whiteboard. Within minutes of starting however, the supply teacher came over to us, confiscated my whiteboard, **in doing so taking away my only way of communicating**, and moved my partner to another group, leaving me on my own for the rest of the lesson with nothing to do. Even at this young age, I could feel the anger inside me growing. How could one woman be so ignorant?!

I spent the rest of the day desperately struggling to hold back tears, not knowing how to deal with the anger I felt. As soon as I got home, my parents put in a complaint to the school and, the following day, my headmaster called me out of class and apologized to me for what had happened, informing me that the supply teacher would never work at the school again. For me, the damage had already been done though.

In that one day, any childhood innocence I had had about my SM had been taken away from me, and I began to realize how different I was from my classmates.

This type of incident became all the more common once I'd moved up to comprehensive school, with some of my peers also feeling the need bully me. I had a particularly difficult relationship with my maths teacher when I started year 8. He seemed to feel the need to make me feel isolated, at one point even forcing me into an emergency appointment with a psychiatrist because, no matter what anyone did or said, I physically couldn't leave the house as a result of something that had happened during our previous lesson. At one stage, I was being bullied in between lessons by a girl in my year, bullied during lessons by my maths teacher and, if we had a supply teacher that day, potentially facing bullying from them too. Needless to say that school was the last place that I wanted to be!

Towards the end of my first year in comprehensive school, aged 12, I started having severe panic attacks every day due to the situations that I was constantly being faced with in school, with bullying being particularly prevalent during this time. I missed most of the last term of year 7 because no one knew what to do to help me get into school. By this time, I'd seen seven different psychiatrists, none of them having much, if any, knowledge of SM whatsoever. When I moved into year 8, I had a new head of year who took me under her wing and helped me into school every morning and generally looked out for me. Without her, I doubt that I'd have managed to get through the school gates at all.

By the time I'd got to year 9, I'd been diagnosed with moderate depression, was seeing my tenth psychiatrist, and was on beta blockers and Valium to control my anxiety. I continued to have panic attacks every day and, as the bullying from teachers and pupils alike became more intense, so did my anxiety.

It was after another hellish day that I made the decision, despite being advised not to by my psychiatrist, that I wanted to move schools. My parents and I sat down there and then and searched for schools on the Internet. I quickly ruled out all the state schools in the area as I knew people from my junior school attended them. We managed to find a much smaller independent school that on the outside appeared perfect.

I knew that the only way this plan would work though was if I was able to talk the minute I set foot in the school on my visit.

Somehow I managed to do this and, not long after, I started at the school. **Although my anxiety still affected me severely, the not talking aspect of my SM was well and truly behind me** and I managed to lead a fairly normal school life, despite my on-going battle with severe anxiety and depression.

Within six months of starting at the school, in November 2008 just days before my 15th birthday, I was contacted by a producer from the BBC, asking me if I'd like to take part in a documentary about SM. Even though I hadn't long got over it myself, I jumped at the chance of sharing my experiences in order to help others. The filming of 'My Child Won't Speak' was a long and, at times, very difficult process. Although in the final cut of the documentary, my story got about 20 minutes of air time, we actually filmed around 150 hours' worth of footage, between March and August 2009.

The hardest session of filming for me was undoubtedly the session that we filmed in the shop, with me attempting to buy a chocolate bar. What wasn't shown in the final cut was that for a couple of hours before the filming took place, I was working with a psychologist who had been taking my heart rate at various points during the day. I was also wearing a heart rate monitor during the filming. This only added to the stress I was going through and that, coupled with the fact that I was being followed around by a massive camera and sound equipment, was too much for me. I became incredibly angry, partly at myself for not being able to complete the task, but also at the producer for putting me in a situation where I felt vulnerable.

In the documentary, you can see me refuse to answer any of the questions I was asked and eventually walk away from the camera. At this point, the psychologist, who had travelled from Bristol for the day just to film with us, called me into her car and started talking to me about my heart rate, showing me diagrams mapping the increase and decrease as the situation in the shop intensified. She managed to calm me down enough to carry on with the filming shortly afterwards.

The main thing that kept me going through these difficult periods of filming was the thought that what I was doing could potentially help other people.

For me, that was the only motivation I needed to carry on with the filming.

I've continued to try and raise the awareness of SM over the past few years by sharing my story. I've written a few blogs for various different mental health related websites, one of them being published in a local newspaper and, in early January 2015, recorded 'Finding Your Voice,' a documentary about SM for BBC Radio 4. Helen Keen, who was the presenter of the documentary, is a massive inspiration for me and so I was really honoured to be able to record an interview with her. **I intend to continue talking about SM in the hope that one day, SM will be common knowledge amongst everyone.**



## PERSISTENCE INTO ADULTHOOD

SM is not, by any means, a pleasant experience. While many children with SM may recover in childhood, for those whose SM persists it can become an egregious experience.

While reading up on selective mutism, I found far more information about child sufferers rather than adults. I grew curious. Statistics show that the disorder is more common in children than adults, but why is that? Is it more easily diagnosed in children? Is SM easier to treat in children? Can children grow out of SM without treatment?

A diagnosis of SM is generally made when a child is between 5 and 8 years old (Wong, 2010), hence children with SM may often have experienced the condition for a number of years, their condition markedly worsening in that time, before receiving help.

Adults with SM are significantly less likely to have received diagnoses or help as children; however, diagnosis and intervention rates are improving (Sutton, 2013).

While SM may seem to be a relatively innocuous behaviour in young childhood, by late adolescence and adulthood, should SM persist for that long, there can be serious mental health repercussions —

such as depression, social anxiety disorder (SAD), generalized anxiety disorder (GAD), agoraphobia, and so on.

Additionally, there can be serious social ramifications to the persistence of SM, such as young adults with SM being unable to leave the house unless accompanied, being unable to work, being entirely reliant on aging parents, and so on.

**My own research demonstrates that for those whose SM continues into adulthood, peak severity generally occurs during their early 20s**, although some report significant or even undiminished speech and social difficulties all the way into their 50s (after which I have little data).

There are several factors that can aid with SM lingering into adulthood, such as negative reinforcement and brushing aside one's speaking disorder or assuming they are making a choice not to speak.

A compulsion to be silent is ordinary behaviour for many young children, not just those who develop SM, when they experience stranger anxiety (Lesser-Katz, 1988), when they feel vulnerable, or when they are separated from their primary caregiver.

As a young child, there was no thought involved in my reaction of silence to certain people. **It was all trigger (proximity of an overwhelming person) and response (silence).**

Children with SM don't choose to behave in this way. Their fight or flight response compels them to be silent when they feel physically, emotionally or psychologically vulnerable. There is thus a direct link between 'being perceived' (i.e. social exposure) and silence.

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Won't a child with SM grow out of it?

Do children outgrow their fear of the dark? It may seem like this but, in fact, it is sympathetic handling and appropriate support that allows them to work through it. If they were repeatedly shut in a dark room despite their fear, they would grow up with a deep dread of darkness and losing control. However, as SM is generally not well understood, many children are repeatedly put in situations where they are encouraged to talk, followed by disappointment or disapproval when they do not.

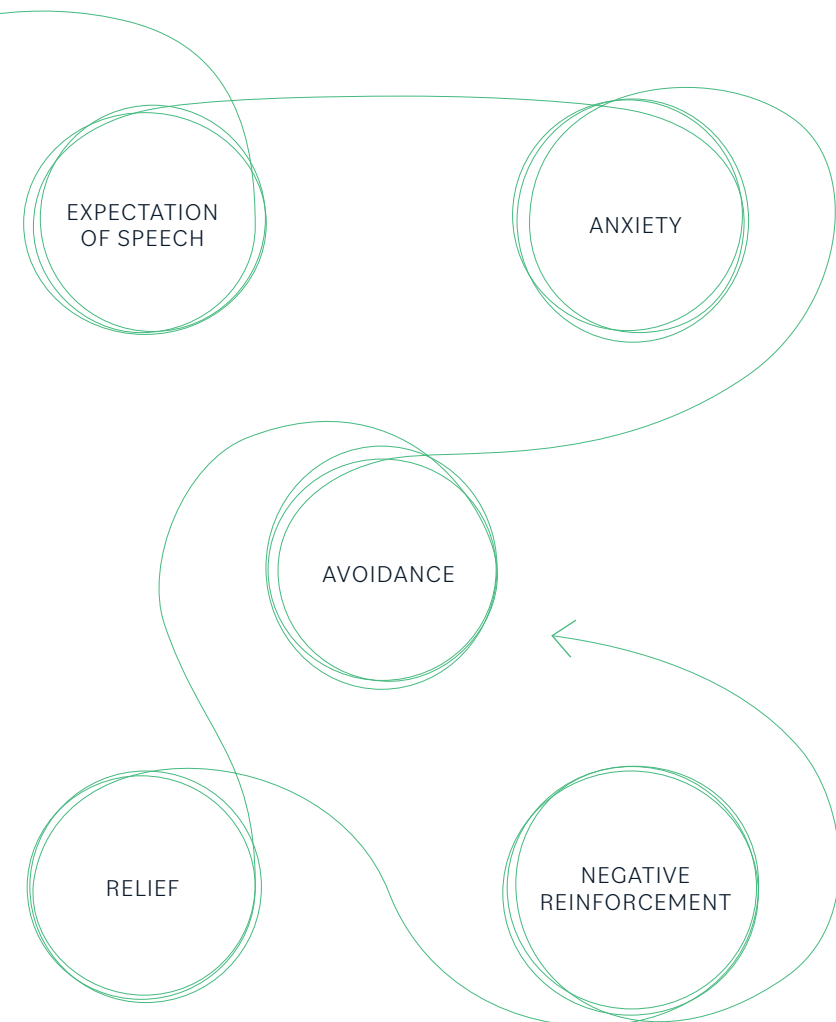
There are two blatant factors in extending the severity of SM:

1) negative reinforcement: acknowledging the sufferer cannot speak in situations and having someone take over for them. This allows them to prolong the ideation that there is a way out without having to speak themselves.

2) harsh criticism and reprimanding of sufferers for their inability to speak rather than being met with support or an attempt for a solution. After years or even decades of this conditioning, it is extremely difficult to break these habits.

For these reasons, it is best to tackle SM as soon as possible. Having said that, it is never too late.

BERGMAN'S  
BEHAVIORAL MODEL OF  
SELECTIVE MUTISM, 2013



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Most parents speak for their children when they are young, whether the child has SM or not, but my mother spoke for me for much longer than is usual. When I needed a spokesperson, it was nearly always my mother who did the talking for me.

I didn't have much interaction with my peers either in or out of school, so I didn't really have a friend to speak for me. I never wanted to seek out social interaction with anybody, so I didn't want a spokesperson to help me socialize; I was more than happy to just be left alone.

Problems arose for me when other people tried to initiate social interaction with me. Far from finding this enjoyable, it felt more like a threat. It put a spotlight on my biggest problem and I felt put on the spot and under pressure to do the one thing I was least able to do – respond. I think in these situations my mother spoke for me purely out of embarrassment.

I didn't like the sound of my own name and never could bring myself to say it, so I especially hated being asked my name. Sometimes on these occasions another child would 'help out' by answering for me. One time, soon after I had started school, a teacher who didn't know me yet asked me my name and a little boy answered for me and told her my name and a little boy answered for me and told her my name to which the teacher replied, 'She's got a tongue, she can talk!'

But of course  
I couldn't  
answer her.

The times when I felt I needed a spokesperson would be if I needed to communicate information to somebody. This was usually when there was a problem that I felt totally overwhelmed by, and it would often mean a potentially difficult interaction with somebody who I saw as an authority figure, for example a doctor, a teacher or even a head teacher. This kind of interaction would be difficult for most young people, but for me it felt so impossible to deal with that I just wanted my mother to take care of the situation for me while I stayed far away.

I didn't feel that I could even cope with being present while my mother spoke to these people on my behalf.

When I was 17 and in the sixth form at school, I had got behind with the work and everything had just got so on top of me that I felt I just couldn't face going to school any more. I was legally old enough to leave school, but knew that my decision to leave half way through the sixth form would not sit well with the headmistress. I made plenty of noise about

it at home, lots of tears and hysterical tantrums, which my parents bore the brunt of on a daily basis. But discussing the problem and how I felt about it with the head teacher, or with the doctor, felt absolutely impossible; like running through fire, or like doing something that is dangerous to my life.

I felt I needed  
my mother  
to speak for me  
like I needed air  
to breathe.

One time when I was younger, my mother took me to see the family doctor and the doctor asked me what the problem was, rather than asking my mother. I just stared blankly. It wasn't because I didn't know what the problem was, **but the idea of speaking for myself — well it had never occurred to me that I even could.**

Speaking felt alien to me and it also felt unsafe. It felt as if there was a physical barrier within myself preventing me from speaking; other people who have SM might understand.

I found it harder to speak to outsiders if my mother was there, or if somebody else was listening. I felt as if I was being assessed on my social performance and on my ability (or not) to speak; rather like being asked or expected to perform on stage in front of a critical audience. I'm not saying this was my mother's fault, or that she is very critical; I don't think she is. But due to my SM, and because so much fuss had been made about my not speaking, that was how it felt for me.

By the time I was a teenager, I think it had become fairly automatic for my mother to answer when somebody spoke to me. When I was 16, I went to an interview for a Saturday job in a small supermarket. My mother came along with me and, out of habit, started to answer questions that the shop manager was putting to me. He said to my mother, 'She has to stand on her own two feet!' and after that I did make some effort to answer his questions. I may not have done brilliantly, but I was able to answer for myself.

All the time somebody was willing to speak for me, I was only too willing to let them.

My mother said afterwards that when I was asked a question I used to look to her to answer. That shop manager offered me a Saturday job. I hated it though. I stuck at that job for a year until, as with school, I felt I could take no more of it. But of course I wasn't able to go to the manager and give him my notice; my mother had to deal with that for me.

I had no  
confidence  
to even try to  
advocate  
for myself.

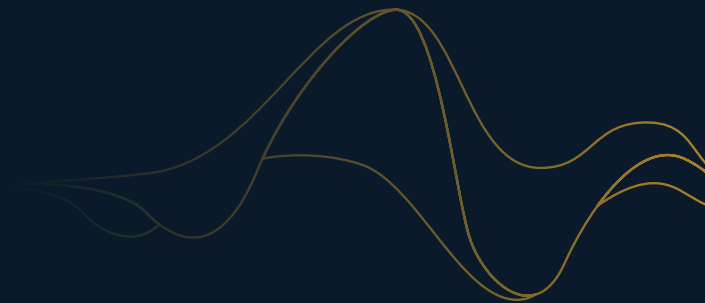
My being on the autism spectrum means that being verbally articulate does not come naturally to me, and I just hadn't had any practice. So as a young adult I was very disabled socially. As a parent myself, I depended very much on my children

to speak for me. This was especially the case if I needed to get someone's attention, for example a waiter in a restaurant. In that way our roles were reversed, my children became the caretakers and I was like the child (the one who needed looking after).

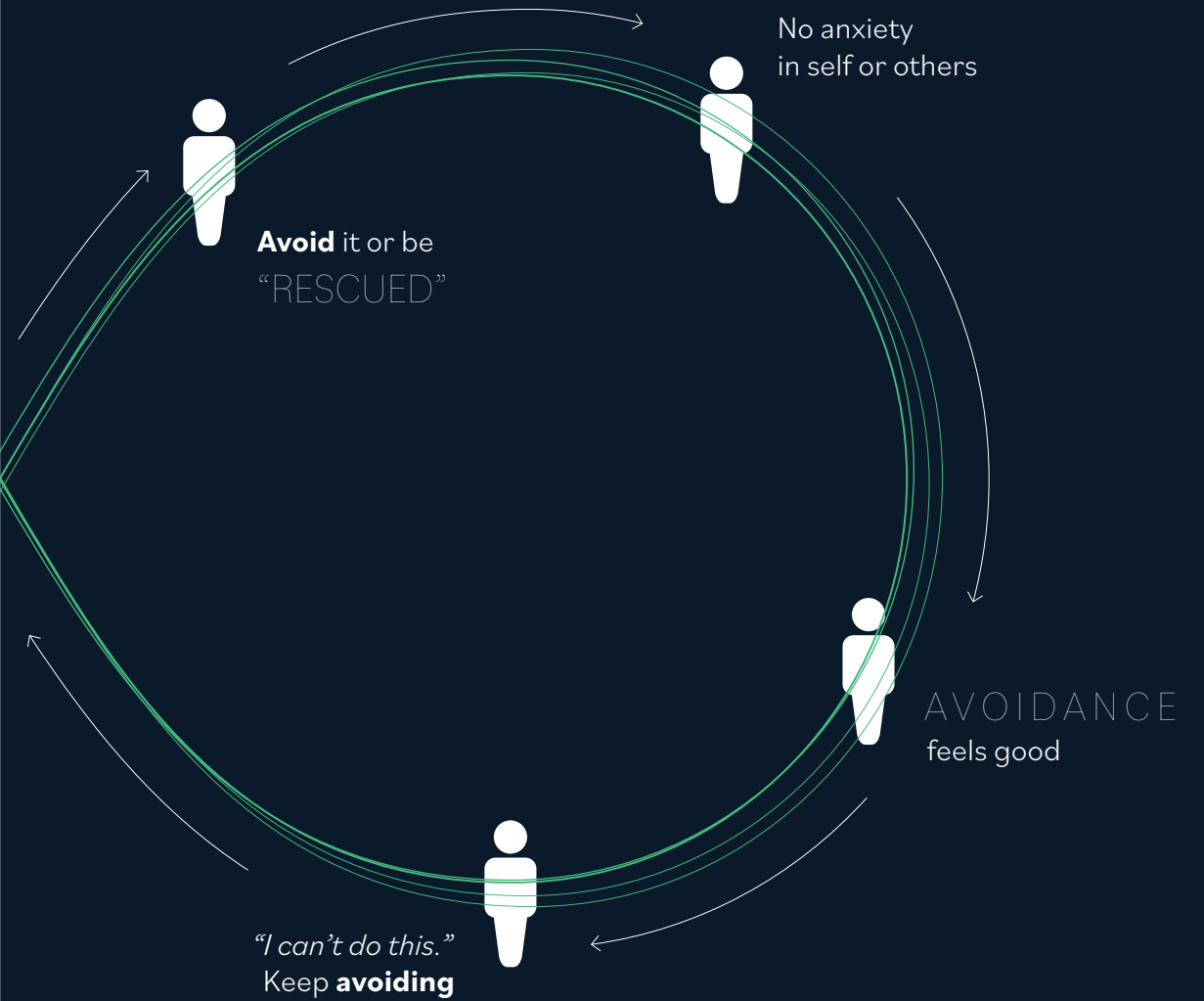
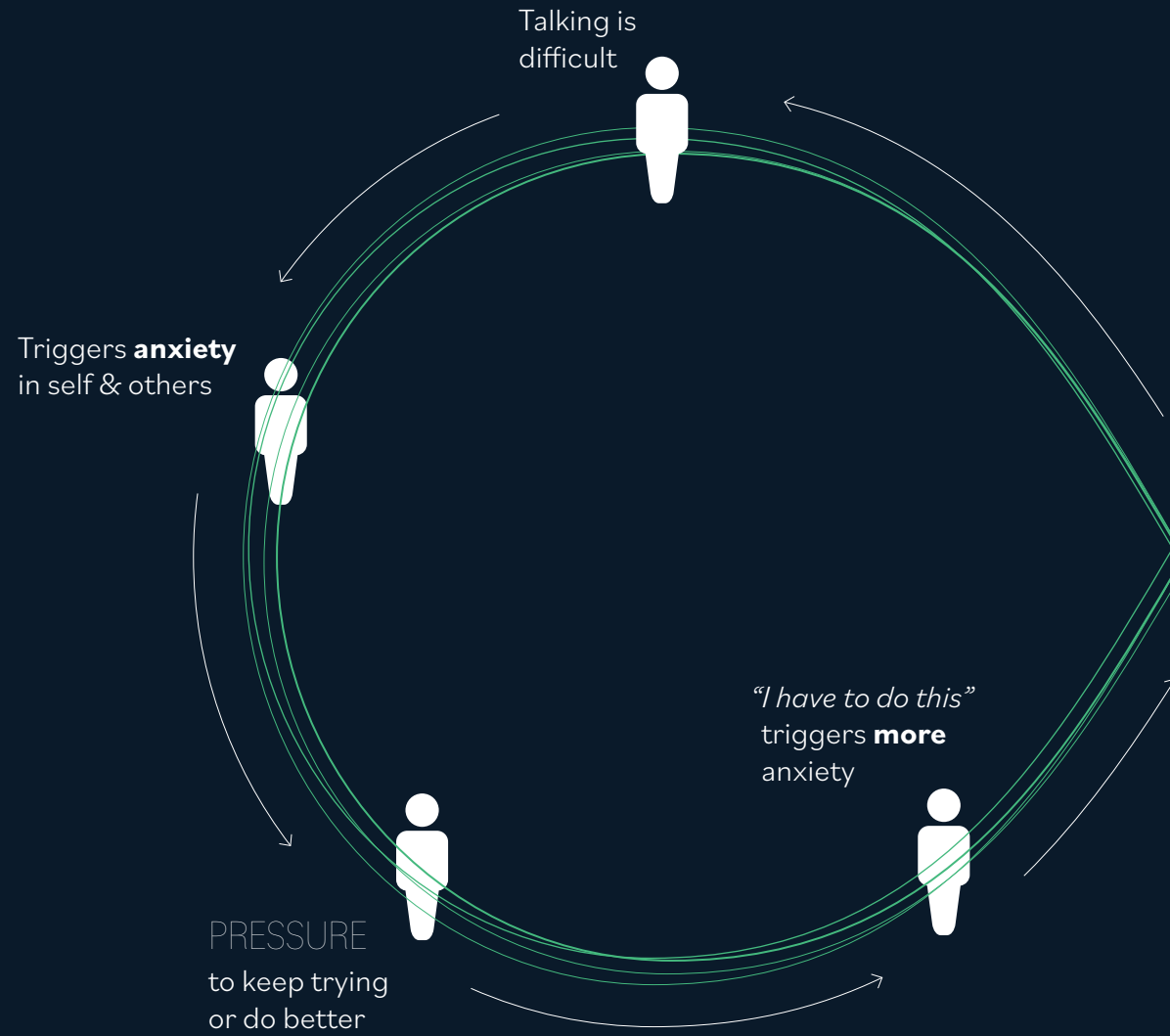
I wish very much that instead of being spoken for, I could have been helped somehow (I'm not quite sure how) to find the confidence and the courage to learn a way of advocating for myself that works for me. The real problem arose for me when I still needed a spokesperson in middle age. At times I needed service providers to intervene to deal with difficult social situations for me. I realized then how undignified and how unhelpful it really was for me to still have people speaking for me. It is undignified because it makes me look like a very disabled person, genuinely unable to advocate for myself.

I realized that being spoken for meant that I could never really grow up, I'd always feel helpless, powerless and I'd always be like a child.

I decided then that the time had come when I needed to either find a way of advocating for myself or accept the consequences of not doing so. Now though, I think perhaps the worst consequence for me would be to suffer the indignity of being spoken for.



# NEGATIVE REINFORCEMENT





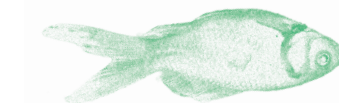
## S P E E C H R U L E S

Something I found especially surprising was that typically, those with SM develop an unconscious set of speech rules. It seems absurd at first, an unwritten list of who you can and cannot speak around. But the more I thought about it, the more I realized that these speech rules are real, and while they vary for everyone, an excellent example of these rules are laid out by Carl Sutton:

## RULE 1

With certain people I was compelled to be mute every single time I encountered them.

*The instinct to be mute.*



When mute, this was my instinct or compulsion not choice. I would liken SM to being a fish circling around its bowl which automatically 'plays dead' every time a gigantic human eye peers in at it. Muteness is both a physiological and psychological reaction to vulnerability and feeling over-perceived by others, silence being an intrinsic part of the fight or flight response. In my own case I have explained that this was, in a large part, based on childhood attachment fears - even as an adult when the fears ought not apply.

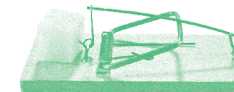
Walker (2014) suggests that the fight or flight response has four main behavioural components: **Fight, Flight, Freeze** and **Fawn** (the so-called 4Fs).

Being silent is a means of 'fleeing' which rouses less unwelcome attention than physically fleeing. I would also 'freeze' physically sometimes, find myself feeling stiff and uncomfortable moving. I would remain in an unpleasant situation rather than remove myself from it. Regarding 'fawning', when I was mute I was entirely unable to be disagreeable. I would agree to almost any question, regardless of how contradictory my chain of 'yeses' (i.e. nods) happened to be.

## RULE 2

Those who had never heard me speak would never hear me speak, even if I had known them for years.

*The speech trap.*



Selective Mutism has a memory of its own. In my own experience it had its own way of making very consistent associations and rules regarding those I could and could not speak to. If I encountered someone I had been mute with before, I would find myself unable to change my behaviour because doing so would also make me feel very uncomfortable.

Frankly, it was too frightening to try to speak having developed a pattern of muteness. If I spoke I would also be stepping out into the unknown. I would potentially rouse the overwhelming attention of a person who I had originally found overwhelming. I would also be afraid of how I might feel to hear my own voice again in a circumstance where I'd become unaccustomed to hearing it. I believed I hated my voice, and that it was strange.

This trap can last for months, years, decades, or a lifetime in situations, and with people, where a pattern of muteness has already developed. The trap can, sometimes, be successfully broken by switching environments and making a fresh start.

## RULE 3

With a few exceptions, anyone related or associated with anyone who I couldn't speak to couldn't be spoken to either.

*I could only rationalize being mute with one person if I was mute with all their associates too.*

## RULE 4

Those who didn't know I was mute in other situations could never be allowed to find out about my muteness.

*My inability to speak had to be my secret from those I could speak to.*

## RULE 5

Those who only knew me as mute couldn't discover I could speak in other situations.

*My ability to speak had to be my secret from those I couldn't speak to.*

The final three rules (Rules **3**, **4** and **5**) are each derived to avoid every possible future eventuality that could result in an expectation of speaking to someone I couldn't speak to. These rules are as much to do with avoidance of humiliation as avoidance of speech. Together they tautologically cover every possibility of being placed in a position where speech is expected. SM can become very 'watertight' and very difficult indeed to escape from—or break into, if you are a parent, therapist or teacher.

While these communication rules relate to my own experience, many other people with SM report similar rule-making. As such, given all these kinds of communication rules, children and adults with SM live in a precarious space where almost everything they try to do or achieve can feel impossible.

Speech rules can clash, placing multiple conflicting speech demands at the same time on a child or adult with SM and resulting in horrid emotional stress. For this reason children and adults with SM tend to live a double life – switching from one life and personality to another on a daily basis.

As an example of conflicting speech demands: consider a little girl with SM who enjoys dance classes after school. She is relatively comfortable in that environment and, though reticent, speaks a little. She has even made a couple of friends. One day a classmate from school, who has only ever seen her mute, shows up at the dance class. Immediately, she has the conflicting demands of hiding her muteness from all the other children in the dance class, particularly her friends and, at the same time, hiding her ability to speak from the girl from school. This is extremely stressful for her, and in all likelihood she will never be able to go the dance class again. Her parents will never be able to understand why this happened or why their daughter is distraught.



## M A S K I N G

No one with SM wants to be known for having SM. The idea of others knowing could result in 1) the lack of expectation of speech which, while calming, only reinforces the issue, or 2) a disbelief that said person is actually suffering from the disorder. It's ashaming to not be able to speak for yourself.

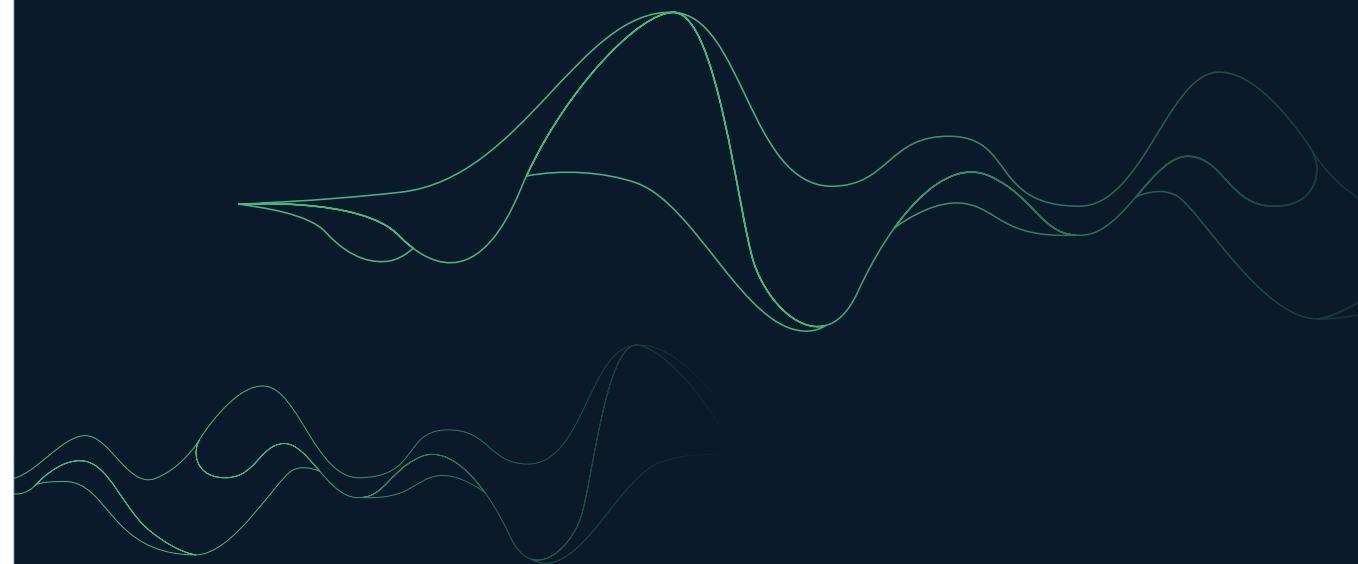
To combat this, sufferers may develop strategies that can assist them in masking or coping with their severe uncomfortable state.

When I'm in a situation where all eyes are on me and speaking is absolutely necessary, I start to uncontrollably shake, my voice gets broken up and raspy, and my gaze flies around the room. I've found that I go through these motions in order to distract myself or channel my nervous energy somewhere else so that I'm not worrying about speaking so much. After all, overthinking this anxiety only tends to make the mutism worse. Over the years I have learned how I can isolate most of my shaking into one of my legs or hands. This tactic has proved especially effective as we shifted to remote classes during the COVID-19 pandemic. I'm still unsure how to combat the instinctual way I alter my voice when speaking.

I think of this action as self-sabotage. My mind recognizes that I cannot speak normally in most situations and I feel inferior because of it. In order to gain control over my otherwise out of my control disorder, I further push myself to failure by subconsciously distressing my voice, proving to myself and others that I should not even attempt to speak.

## I T ' S A

# GRADUAL PROCESS



# THE FEELING OF S M

## THE TRAP

For a child (or adult) with SM, speaking can feel like a very intimate, unnerving, embarrassing, threatening act. Children with SM are generally risk-averse, and it often feels much safer to keep shtum. So much so that speaking at all, in a trigger situation, can be unfeasible. In my own experience, saying one word would have felt as if I was giving others the key to the whole of my private inner world — my thoughts, feelings, wants, desires and needs. These were things I felt very uncomfortable sharing at all.

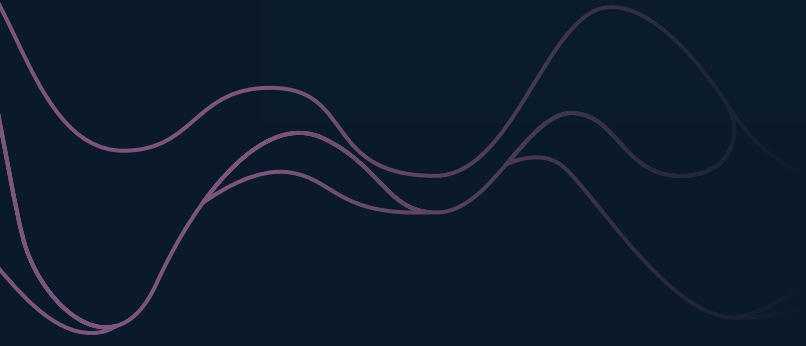
Even if I did eventually begin to feel comfortable with someone, I would still remain unable to speak to them. While I would usually have dearly loved to speak, challenging my inability felt impossible. As a child the maintaining factor (what kept me silent) felt unfathomable. I did not understand why I could not speak. In retrospect, however, it seems to have principally been the fear of re-inviting the attention of someone who I originally found overwhelming. I was safe if I did not speak. If I spoke I would be overwhelmed, more so than ever. I was certainly very change-averse, particularly when such change would encourage personal attention or scrutiny.

After being silent for a while, there becomes little expectation on a child or adult with SM to speak. As such **the fear of initiating speech** (i.e. the speech trap) is deepened due to other people ceasing to expect anything but silence.

This makes the thought of speaking even more difficult. Speaking, when all expectation has gone, would feel like being a jack-in-the-box and hollering ‘surprise’ to everyone whose presence triggered muteness in the first place.

One, perhaps, would have to personally experience SM to understand how distressing it can be to be trapped in such a way. Compounding that distress, however, is that SM can engender very little sympathy or support because it is wrongly perceived to be a choice — namely a ‘refusal to talk’ — when in fact nothing could be further from the truth.

This trap can last for months, years, decades, or a lifetime in situations, and with people, where a pattern of muteness has already developed. The trap can, sometimes, be successfully broken by switching environments and making a fresh start.



JOURNEY TO **RECOVERY**

BECAUSE  
OF ITS  
NATURE AND  
INVISIBILITY,  
ADULT SM IS  
BELOW THE  
RADAR.

Now that there is a sense for how to identify SM, what's the next step? If someone discovers they have it, how do they go about overcoming it, especially in adulthood?

There is no clear model for how SM in adults should be managed or by whom. Because of its nature and invisibility, adult SM is below the radar.

I'm actually a little shocked at how much harder it is to find case studies on adults with SM. I had assumed that silence in adults would be more noticeable because it's more statistically uncommon. But—as experienced by myself firsthand—even adults may be labeled as people who “just don't talk.”

Lack of public awareness means that adults may not even be aware that they have SM. In the absence of a rational explanation, many feel ashamed and try to camouflage their difficulty talking, rather than consider seeking help. For those who do suspect SM, difficulty coming forward and communicating their needs is part of the condition, so it is not always easy to seek help or support.



# SAM 27

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It's hard to see people living life normally because you realise how weird your life is. Even something like seeing a group of people talking, like, everything just collapses and there I am alone and... well that's it, I'm alone.

It's like in the pit of your stomach you feel it you want to shout for help but you can't. Even if you could what could anyone do.

I used to sleep a lot, it's like fast forward for life, I mean what was I gonna miss? Being alone and depressed. Sometimes I'd dream I had a life and had friends and that was better than being awake. But then sometimes I'd wake up and it'd sort of hit me that my life isn't like that so it didn't always help.

You feel like you're going crazy. I remember having weird thoughts like I'd probably be happier in prison, I could deal with that, it wouldn't even be a punishment because that's really no different from my life now, I'd at least be around people. Then you sort of catch yourself thinking these things and the sane part of your brain reminds you that's insane.



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I know it's awkward for people, I know they look at me and think I'm shy and a bit weird, you know people say "there's Sam, he doesn't say a lot" and straight away I know that sets me up as shy and quiet. Well of course I seem quiet,

## I can't talk but it doesn't mean I don't want to.

I think everyone gets it sometimes you think oh I wish I'd said this but it's too late. **Imagine that all the time, you wish you'd said anything but you couldn't.** I just want to do something but there's nothing that helps.

I tried going to college, it was something we tried to sort of build up to when I was going there [therapy] every week, but it wasn't a nice experience at all. I said a few things on the first day but it's not enough, you know, it's not normal, I don't think people really give you a chance. I understand it but it's not helpful for someone who's trying to get through something like SM. I was a lot younger then but it still sort of leaves you thinking you know... what's the point.

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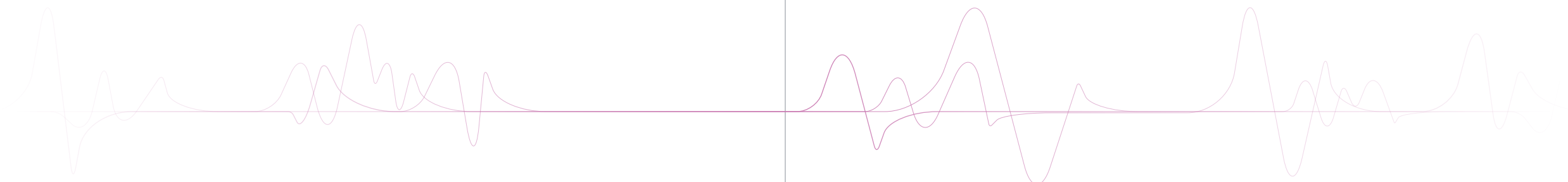
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# SEEKING OUT HELP

What was the tipping point for adults with SM to seek help? No one with SM wants to live with it forever; it's disheartening. However, the nature of the disorder makes any kind of recovery seem hopeless. To actually reach out to a professional, a friend, a family member, or anyone at all and ask for help is nearly impossible. It's not just about building up courage, it's taking a leap of faith over a ravine so wide you don't know whether or not you'll make it across. You're technically safe where you stand on the one side, but on the other awaits a much better life.

The process of seeking help may often cause individuals to confront the painful reality of one's predicament. For some it may be experienced as an admission of failure which itself may result in lowered self-esteem, causing a further sense of powerlessness. For sufferers of SM these difficulties are accompanied by the practical problems encountered when trying to communicate with others and strategies which are employed to overcome the inherent difficulties speaking may similarly be felt as admissions of failure. Even if these fears and difficulties can be overcome there remains the potential for misunderstandings to occur and for any efforts made to appear futile.

What follows are examples of the driving catalysts that lead sufferers to seek help for their SM.





## MARA, 24

“I didn’t really see my family much, sometimes at birthdays, but even then they didn’t really talk to me because they didn’t expect me to say anything back. There’s no good way of dealing with it because if I’m there I feel bad because I can’t talk and if I just avoid those times then I feel bad for missing them. I miss them no matter what I do really. . .

I would prepare for weeks whenever I had an appointment just to end up cancelling it cause it was just too much. When I did go I’d rehearse everything I wanted to say over and over just hoping I’d be able to talk.

The first time I actually went I did say most of the stuff I wanted to but then he said “we’ll you’re talking to me aren’t you”, and it’s like, oh.. well.. what do you say to that..?

I read about SM online when I was trying to work out what was wrong with me. The last time I went to the doctors before getting counselling I actually took in some information I’d printed out and handed that to them. I felt weird doing that because they’re supposed to know these things, I’m not supposed to tell them.”

## SARAH, 25

“When I was 17 my grandma died and other than my dad she was the only person who really talked to me, sometimes we’d just sit in the garden and she’d talk to me about plants or what she’d done that week or watched on tv. I’d just nod and smile but it was nice to be talked to like I was normal again... **I know she wanted me to talk and I wish I’d been able to say something too.** I felt bad about that for a long time and I still do. It’s like... SM takes people away even when they’re there. And it takes me away from them. You can’t really live with SM or it’ll take everyone away from you, I think. It made me realise it wasn’t just going to get better on its own.”

## SAM, 27

“I mean, what do I have to look forward to? Because it never feels like it’s going to get better. Sometimes I think what will it be like in 5 years or 10 years or even longer and what will have changed then? More things I’ve missed out on, just wasted time.

I think they [therapists] just get frustrated and tired of me. I understand it though. I know it’s my fault because only I can make myself talk but I don’t know how. It’s like.. all those years gone because I can’t talk, no friends, no work, no education, no money. . .

**I kind of think of it this way, maybe one day I’ll be better, I’ll be happy and I’ll be able to talk** and then I’ll look back and though it’s still my life it’ll be better because it’ll have gotten me to where I am, if that makes sense. I still really hope that will happen.

It’s hard because it makes you feel so pathetic, I could write it down or I could have asked my sister or someone to help but then that makes you feel like you can’t do anything. I guess that’s true... but you sort of don’t want to know it or face it so you just manage and get by. Till you just can’t keep going.”

## ROSE, 28

“It was hard for a long time looking back at my life and the things I’d missed.

It gets to the point where you just can’t keep going like that and you just have to do something, going to the doctors and saying “I can’t talk, help” (or writing it) is hard to do but the alternative of doing nothing is even worse.

It was good to know that what I had had a name, but selective mutism is just a really bad description of it. I’ve told people in the past that I had selective mutism and how that was why I couldn’t always talk to them and more than once people have said “well just stop being so selective then” and then you have to try and explain that you can’t control it. I always thought it should be called involuntary mutism or something because that’s how it feels.”

## MARK, 35

“It’s like you don’t want to think about it and all the things that you haven’t done or been able to do because of SM... It’s only now that I’ve tried getting help because I can’t go on like this, so I have to do something... .

It’s like, you start to realise it’s eating up your whole life. **If I knew what I was supposed to do or how I could have done it then I would have by now.** Actually getting help is another problem because that seemed impossible too, in the end I wrote a note saying everything I wanted to say and took that with me to my doctor. It felt silly to do, but I think it let them understand how bad my problems were.

Knowing that someone has figured out what was wrong I think was important.

After my therapist mentioned it I looked it up and things that other people had said. It’s like yeah this is it, they sounded just like me.

For so long I didn’t even know I had anything that had a real name or that other people had the same thing and if doctors can’t even tell you what’s wrong then you really don’t expect them to be able to help a lot.

When I was about 13 or 14 I was sent to a sort of group therapy place. At that time they hadn’t said I had SM, they didn’t really say it was anything but all the other children there had types of autism. I didn’t fit in there at all, obviously I couldn’t say anything though. I think people assume that if you can’t talk then you can’t think properly either, not that kids with autism can’t think properly but you know, it’s more unchangeable sort of I think? Even with SM I could talk to my family so clearly I wasn’t limited in that sense, if you know what I mean. **That really put me off trying to get help for a long time because people just didn’t understand.”**

## HAYLEY, 22

For me, the final straw was entering my senior year of college—in other words now, as I write this book. The looming threat of entering the work force was becoming all too real, and while I wasn’t necessarily scared of taking on a real job, I was terrified of what might prevent me from getting one. I have high ambitions for myself and I want to do amazing things in the future, but to try and accomplish this without being able to hold even a simple conversation? I knew I would never be able to compete in my field.

This is what essentially drove me to create this book in the first place. I knew I wanted to create a project surrounding my speaking difficulties, but even at the start of my senior year I didn’t know what to refer to it as beyond bad anxiety. My hope is that the information from this book will lead people to their own discoveries of what might possibly be SM, and for this project to be the catalyst that drives them to get the help they need. The first step in any recovery process is acknowledging the problem at hand.

# THE PROCESS OF OVERCOMING

## WHO & WHAT HELPED AND HOW

### KATIE, 26

“Positive attitudes from other people make all the difference.

Even if it didn't make me start talking, having people be nice to me and include me made me feel a lot happier and more comfortable around them. I'm not sure if there were any particular strategies that worked; I think it might have been different if I had been 'diagnosed' when I was younger but, by the point I knew what was wrong, it felt a bit too late.

It was very isolating and confusing not knowing what was wrong with me and not knowing how to fix it. I had never met anyone who was suffering from the same thing and there was nobody that I could relate to until I came across SMIRA. **For the first time, I felt like I fitted in and was part of some kind of club.**

People wanted to know me, include me and hear about my experiences, and I felt useful and accepted for once. SMIRA introduced me to different techniques I could use to make speaking easier and also to people that were going through the same thing. I wasn't ashamed any more and didn't feel like a failure. Even though I wasn't 'cured' of my SM by finding SMIRA, **it made me feel like it was going to be OK which, in turn, probably helped me get over it.** It also helped my family and the school understand more about my situation too.”

### CARL, 45

“I believed that the only way I could break selective mutism was to make myself suffer so much that I could not tolerate it any longer, and I had to speak.

I started my PhD in another city again, deliberately having isolated myself from everyone, so that I could (one way or another) speak. After abject suffering, I had a nervous breakdown. **I was helped just by the existence, rather than in practical terms, of a wonderful psychiatrist** who prescribed an SSRI (paroxetine) that had very recently come on the market.

I did then speak to my mother and, in fact, it was she who invented the strategy to help me.

I started to whisper the words from a book to her, prompted by her to do so (the book was *Our John Willie* by Catherine Cookson) and, after a day or so, managed to increase my volume. A few days later, I spoke to my stepfather for the first time. A few weeks after that, I joined an amateur dramatic society and appeared on stage in a play (*The Sound of Music!*), just to prove to myself that it was over.

After being so unwell, I continued and completed my PhD. It was a huge emotional, less so academic, achievement.”

## SARAH-JANE, 50

“Firstly, acknowledgement and an understanding that I had suffered from SM and that I was not alone.

This was a platform to start working from and included making others around me aware of SM and how it can affect someone’s life.

Secondly, having a safe place to start speaking within —

in my case, this was with my therapist who I had already been seeing for approximately one year prior to my realisation that I had been an SM sufferer. One main quality of my therapist that helped specifically with SM was developing trust and not fearing that she would judge my silences and difficulty to speak out and possibly reject me.

Specific strategies that helped included EFT (emotional freedom technique) which uses tapping on specific meridian points in the body; and a movement programme developed by the Institute of Neuro-Physiological Psychology (INPP) to overcome the physiological effects of my retained Moro reflex. As a result, I felt able for the first time to take a deep breath, down to my stomach; less constricted by body tension; more able to use eye contact and show my teeth when smiling; and a general diminishing of the terror when speaking.

Thirdly, my personal experiences of recovery have taught me that if my stomach ‘churns’, I now recognise this as a sign that I want to say something and I am holding back.

Once I have recognised this feeling, I am usually able to consciously overcome any anxiety I have about speaking. As I practice this more and more, my speech has become more automatic.

I would also add that a temporary solution in my life was learning a foreign language. I went to Mexico as a teen and felt a real sense of rest, with no expectations to speak their language, for six months. When I did start to speak Spanish, I definitely didn’t experience as much anxiety as when I spoke English.”

## STRATEGIES THAT DID NOT HELP

### KATIE, 26

“Bribery or putting any kind of pressure on me did not help.

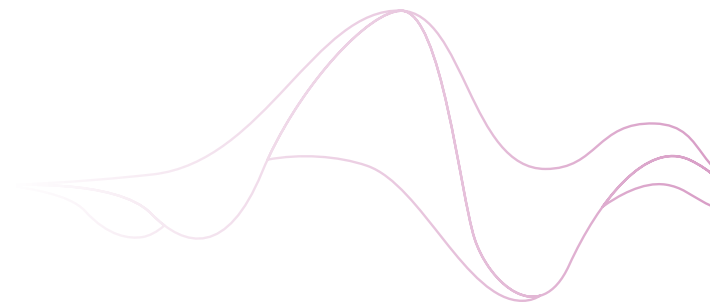
**If I felt like people were trying to force me to speak, I just felt even more isolated, upset and misunderstood.**

In a way it made me not want to speak at all. A lot of people seemed to underestimate how hard it was for me to speak and kept saying things like ‘just speak’ which was very frustrating.”

### SARAH-JANE, 50

“Being around anyone who would try and force me to speak or expect me to speak.

Others’ assumptions about my silence, such as defiant, rude, spoilt, etc, that would often be followed with some kind of disciplinary measure. This seemed to be because **most people struggle to understand why you cannot speak** if you have no physical damage that can be ‘seen.’”



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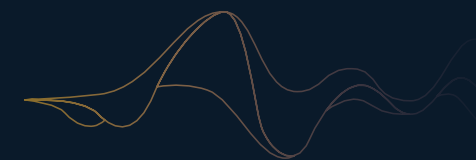
I suffered from SM right back in my earliest memories — being afraid to speak, watching the world as if through a pane of glass, not knowing how to connect with other children.

I don't think any one factor caused it — possibly a combination of an introverted, very independent personality, and being a middle child. I had a great-uncle who remained voluntarily mute throughout his adult life, so perhaps some genetics were involved too. I grew up in a wonderful, loving family, and suffered no identifiable trauma.

During my first few years at school I very rarely spoke, and subsequently had no friends. **I found it virtually impossible to express my feelings, although I could usually answer a direct question if asked.**

I remember sitting at the dinner table desperately wanting to know what day we were going on holiday, hoping one of my brothers would ask my parents, as I couldn't get the words out. I tried to avoid drawing any attention to myself, and spent a lot of time wanting to be invisible.

I suffered from recurrent ear infections as a child. My mum knew to ask if my ear hurt when I hovered about in the kitchen instead of hiding in my room. I never spoke to my lovely grandparents, or wider family, unless in response to a direct question. Growing up I found social situations incredibly difficult.



When I started junior school, a new girl moved onto my street, and becoming best friends with her transformed my childhood. With my friend, I was confident, sometimes loud and often mischievous — though, even as a teenager, she commented that I sometimes came round to her house, hung out for a while, and left again without saying anything!

Throughout my school life, basic things like answering my name in the register left me nauseous and anxious.

I would leave a shop rather than have to address the shopkeeper and found most social situations terrifying. I did, through my friend, develop a small group of other friends with whom I could mostly be myself. I had a lot of fun with them. However, I never wore clothing with a label or wording on



it; I never listened to music without headphones; and I tried to keep any aspect of my life that could be open to judgement as hidden as possible. I also found noise and crowds distressing.

I dropped a grade in two of my GCSEs because, during the exams, my pen ran out, and I couldn't put my hand up and ask for another one.

In the year I graduated from university I moved to a new city, started work as a research scientist, married and had a baby. This was my toughest time. My old friends were travelling, or out partying, enjoying the usual life of twenty-somethings. I loved my job, and my new family, but felt extremely lonely.

At that point I still didn't know what it was that prevented me from connecting with people, or why I had times when I simply couldn't speak.

After moving nearer to my hometown, when pregnant with my second child, things improved, although the fears were still there. Health professionals and new friends thought I suffered from depression, as I seemed so quiet and rarely smiled, no matter how I felt inside. I often came across as standoffish, weird, grumpy or uninterested until people got to know me. It's only in recent years I realized my struggle with friendships was because I closed myself off through fear.

Basic tasks like getting the attention of a waiter or phoning a plumber were major challenges for me, causing a lot of stress. I know my children missed out when they were younger as I couldn't approach other parents at the school gates, so they had a very limited number of friends invited round to play. If a stranger spoke to me in the street, I would freeze, unable to answer. Going to the hairdresser was a nightmare.

If I saw someone I knew out and about — even someone I would class as a good friend — I would hide, unable to cope with the possibility of passing the time of day.

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The road out of SM was a long slog, and one I haven't finished yet. The central factor in overcoming my fear of being noticed and judged was my Christian faith. I can remember a light bulb moment as I walked to my local shops, one of my children in a pushchair, hoping not to see anyone I knew. Suddenly I had a revelation – I believe God loves me, he knows me better than anyone and made me 'me' on purpose – so, if other people, who don't know me as well, don't like me or think I'm any good, they must be wrong!

I would repeat this to myself over and over as I faced social situations: 'I don't have to be ashamed of who I am or what I say'. I also worked on not calling myself a 'freak' or saying 'I hate being me!' when I failed to talk, or when I did and then worried about what I'd said. I replaced it with positive words instead: 'I may have said something stupid, but that's okay. I don't have to be perfect.'

I also had some fantastic counselling in my mid-20s after

my problems  
began to  
affect my voice  
physically —  
it became  
so weak

I struggled to use the phone, causing problems in my job as an antenatal teacher.

The counselling helped me consider how much our words – and the way we say them – are part of our identity; and to address some self-esteem issues.

I began to set myself daily challenges. The fact that fear controlled huge parts of my life grew increasingly frustrating and upsetting. **Every day I did something that scared me:** I made a phone call, drove on a busy roundabout, said hello to a mum in the school playground. And gradually, put together, these things began to work. I even dealt with a chronic spider phobia to the amazement of my family! Eventually I made a decision never to say no to anything simply because I felt afraid.

I started public speaking in my early 30s, and to my surprise found not only did I enjoy it, I was actually quite good! It was chatting to people afterwards that I initially found difficult. I now speak in a wide variety of situations: at conferences, on local radio, and even on a stage at our town carnival.

Around four years ago, I had a real break-through moment, when, for the first time, I initiated a conversation with a stranger. Up until that point, I had only addressed someone I didn't know if I really needed to (like a receptionist at the doctors). I had never started small talk or made a passing remark. On this occasion, I made a comment to a cleaner in a campsite toilet – a nothing, everyday occurrence to her, but a huge deal to me! I walked out of that toilet ten feet tall! It still surprises me when I find myself chatting with people I don't know.

I am still facing challenges – one of the biggest of which is my facial expressions.

When I taught myself to smile a few years ago, I was amazed at the positive reactions I got. I have received a lot of hurtful comments over the years about this issue, and nowadays I probably find smiling appropriately more tiring than talking. I have some catching up to do because I missed out on learning the normal rules and social nuances that others develop as children. I still find crowds can make me very anxious.

But my life is unrecognizable from how it used to be. The biggest message of my story is that

change is  
possible,

and it thrills me to be able to stand up in front of other people and share that truth with them.

# AFTERMATH & RESULTS

## REMISSION

### KATIE, 26

“As soon as I started college at 18, I was able to speak freely, but was still very shy.

**I think I was ready to start talking before then but, as I had spent so long not speaking at school, it was so hard to break out of it.**

I was fine at uni but, a few months later, when I had started my first proper job, I began to feel panicky and dreaded going to work. I felt extremely anxious, shy and self-conscious all the time and it reminded me of how I felt when I was at school. I went to the doctor’s who gave me some beta-blockers and I also saw a cognitive hypnotherapist.

**I think the effects of having SM for so much of my childhood, and the way people have treated me, may have affected my confidence.** However, I am a lot more confident and less anxious now and feel like I am getting more confident as I get older. I am naturally quite introverted and think that being shy and quiet is perhaps part of my personality, rather than a side effect of having SM. I don’t feel like I have been too affected by it.”

### CARL, 45

“For a number of years after I started speaking to my mother and stepfather, I believed I was over SM.

However, I continued to feel the effects of stress, after my experience at university and what I’d had to do to myself to speak again — isolating myself and purposefully making myself unwell. Although not diagnosed, it is clear to me that was I was suffering from PTSD.

Unfortunately, I still have the same triggers and I still become mute — particularly around partners and other relatives. I still have rules (as I always did) about who I can speak to and who I can’t. **Because there is no tailored therapeutic support out there for adults with SM, it will be something I will have for the rest of my life.**”

## SARAH-JANE, 50

“I would say that my significant recovery from SM happened after approximately two years of therapy and one year after realising that SM existed.

**It was still then a further couple of years until speaking became almost automatic.** I shock myself now, as at times I feel like I have verbal diarrhoea and my voice seems louder — something that those around me have also positively commented on.

However, to be absolutely clear, from my experience, I feel one never does totally get rid of early damage (programming) but one can recognise it and can take immediate steps to override it. Sometimes I still freeze. When this happens, I don't panic — I stop and acknowledge that it is just a reminder of my SM, take a breath (including time out) and start again. I still see my therapist as the consequences of suffering SM for decades left me with a lot of 'work' to do, particularly in the areas of relationships and self-esteem.

**Interestingly, as I write these words, I can see that my ability to write freely and express myself was also hindered by SM and this has only developed as I now speak freely.**

Although regaining my voice has been hard work, it has definitely been worth it because, for me, speaking freely is so very linked to my identity and who I really am — something that I had never been in touch with before.”

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FINAL

**THOUGHTS**



# CAN YOU CURE SELECTIVE MUTISM?

## MY CONCLUSION

After reading the experiences of those who took steps to overcoming their SM, it appears that there are numerous variables that can affect the success rate of recovery. What appears to matter are factors such as length of suffering, degree of negative reinforcement, ability to have a fresh start or allow SM to subside on its own, comorbid disorders, etc. However, one thing seems common throughout all these experiences of recovery: no matter how much you've gotten your selective mutism to recede, sometimes it will come back. Of course, it can come back with varying levels of aggressiveness and frequency, but even those who have "overcome" SM do seem to slip into episodes every now and then.

Surprisingly, this realization doesn't scare me like I thought it might. The certainty that SM will always be around is just that — it's certain. A guarantee for a disorder where there are no guarantees. I know it will always linger within me, but just the same I know that I have the chance to lessen it greatly.

Sometimes, or at least to a certain degree.

Ultimately, my own personal therapy has been the process of researching the ins and outs of SM. I've never felt more secure about knowing what I am dealing with. I've discovered my "speech rules" that have effectively been keeping my SM at its peak, and I've realized certain motions that I go through when trying to cope with SM. I think trying to dismantle these unconscious rules as well as aiding the proficiency of my coping will benefit me greatly in my next steps. At last, I'm beginning to see the beginning signs of my own recovery, or at the very least a chance at it.

It's a long road ahead, and a seemingly endless one at that, but I've learned what I'm dealing with and it's time to figure out the right way for me to tackle it.

But the most crucial thing that I've learned through these months of research—

I'm not alone.

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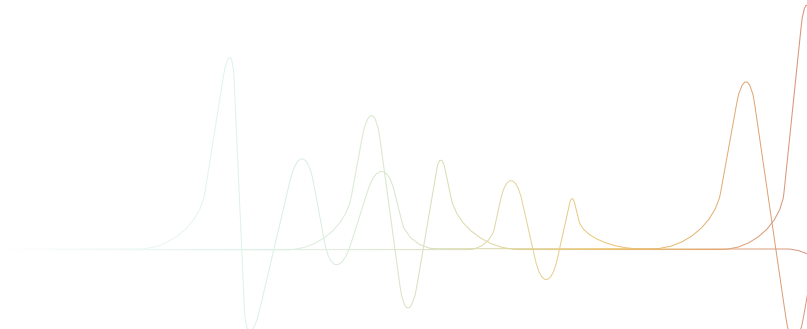
The creation of this book and discovery of my selective mutism would not have been possible without the guidance of my thesis instructor, writing & design consultants, fellow peers & critics, as well as support from my friends & family on this long, long journey.

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Most of all, thank you for always giving me a comfortable place to speak. I can't wait to see what incredible things you all do in the future.

Onward.



# COLOPHON

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## **Bilo**

designed by Pieter van Rosmalen from Bold Monday, 2018.

Some grotesques are a little more grotesque than others. Born of an attempt at a serifless Bodoni, Bilo's organic shapes lend the nine-weight family a strong personality. Faint references to vintage sans serifs from the late 1800s can be toned down thanks to stylistic sets; an alternate single-storey 'a' gives Bilo the appearance of a geometric sans.

## **Rooney**

designed by Jan Fromm, 2011.

The idea behind Rooney was to create a rounded typeface without it becoming too playful or trivial. Based mainly on old-style serif construction principles, such as a subtle angle of stress, open letterforms and a gentle contrast, Rooney feels serious yet its rounded shapes and soft curves make for an overall impression of warmth and smoothness. By combining the familiar, readable qualities of a serif face with distinctive and original letterforms, Rooney is a modern and versatile text typeface.

Written, edited, & designed by  
**Hayley Romansky**

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