

Achieving Success

Parents experiences with Cued Speech



The right to language

The achievements of a **boy with no hearing until he was 2 ½** and then very poor hearing through his cochlear implant, who, despite this, went on to develop advanced literacy, good speech and good listening skills.

His parents' aims were to give him the advantages of learning both English - fully, as a toddler and as a first language - and BSL.

They wrote this because they believe that it's the right of all deaf children to have full access to language and education and that parents shouldn't have to struggle, as they did, to achieve this.

The diagnosis

“ Our son is now 14 years old, and was diagnosed profoundly deaf at 9 months. Hearing aids didn't seem to help and MRI scans revealed that he had no auditory nerve on one side, and very little, if any, on the other. With lengthy assessment for a cochlear implant (CI) underway with no guarantees of the likely outcome, we faced the very difficult challenge of how to support his language and communication skills through his vision alone.

We start to learn to sign

We were lucky to be living in an area with a hearing support service that was very positive about British Sign Language (BSL). Our Teacher of the Deaf was Level 2 / 3 in BSL himself and signed fairly fluently with our son during his home visits, and he arranged straight away for us to have weekly sessions with a profoundly deaf inclusion worker who used BSL as her first language. We also took advantage of local Level 1 BSL classes.

But will signing meet our son's need for language?

We started using some basic signing with our son as soon as we could and he was beginning to sign back with a few words, but our signing wasn't anywhere good enough to provide an adequate language model. I knew from studying papers in psychology and child development at university that he only had a very short window of two to three years when his

brain was hard-wired for language learning, after which his ability to learn a first language would decline dramatically and language-learning would become much, much harder for him – and in a few years it would be too late. Despite our best efforts we were just learning BSL too slowly! We were very worried that if we just carried on like this, he was going to miss out on the chance to properly acquire a full first language while he could.

Lacking the ability to sign properly in BSL, it was tempting to drift into sign supported English, and yet we knew that he couldn't hear the spoken English. While subconsciously it felt to us like we were communicating fully, we knew, in fact, that what he was receiving was a very poor substitute for a signed language: all that he could perceive was a limited range of single words and fragments of phrases signed badly with no grammar. It was certainly nothing that one could really describe as a language.

Although this very basic level of signing was useful to enable some two-way communication early on, we knew language.

Although this very basic level of signing was useful to enable some two-way communication early on, we knew that this wasn't getting him anywhere near to acquiring a first full language, and we felt like time was rapidly running out for him. We knew that communication and language, although closely related, aren't one and the same thing. While communication is all about interpersonal interaction, language acquisition is a distinct and (as regards a first language) time-limited process of establishing complex cognitive structures and



>> pathways in the developing brain that are crucial to a child's future intellectual capacities and development.

We fully embraced the prospect that he would need and want sign language to communicate face-to-face with us and others, at least while he had no useful aided hearing, and we accepted that he might never have enough aided hearing to ever develop intelligible speech - hence our determination to learn and expose him to as much sign language as we could. But from our early attempts to learn BSL, we also knew that we didn't have any hope of quickly attaining the fluency and command of BSL needed to use it effectively and consistently at home. Whatever our best intentions, as neither of us is a natural linguist, we also knew that there was no real prospect of us ever switching from spoken English to BSL as our family language. We feared that if sign were to be his only language, our son would end up being marginalised from our family life to an extent that, for us, was unacceptable.

So we felt totally baffled when professionals and almost everyone we met at that time seemed to assume that sign language would be the straightforward answer, as though this was an easy, natural and obvious thing to do. We couldn't understand how they could expect us to suddenly start parenting our son in a completely foreign language that we had absolutely no competence in. This seemed equivalent to assuming that we could switch overnight to speaking Japanese or Russian, without any access to suitable language classes. We could only think that they assumed that because he was very profoundly deaf, he only needed a very basic level of language and that a low level of communication would be enough for him.

We felt, to the contrary, that his need for language was all the greater precisely because of his deafness, as his life-chances would be so disastrously compromised without a strong command of a first language and the literacy and numeracy skills that it supports. No one advocating sign language as the only route for him seemed to realise, or dared to mention, that by choosing BSL as (apparently) his only option without access to a suitable language model at home, we might be choosing for him to struggle with literacy, choosing to limit his choices in future employment, and choosing to limit his ability to enjoy literature, film, TV and everything else in

mainstream culture that most of us take for granted. The promise that sign language would enable him to be socially integrated with the Deaf Community didn't reassure us, as we couldn't see how this could be a positive choice for him if it was his only choice, forced on him by the lack of alternative life-choices.

Finding out about Cued Speech

Given the apparent lack of options advised by our local professionals, we will always be thankful that our son's auditory neuropathy (AN) diagnosis led us to discover that USA-based experts were recommending (and still do) that all parents of children with AN should consider using Cued Speech (CS) to make sure their children can fully and reliably access spoken language in the home, regardless of whether they can hear it clearly or at all.

We discovered that CS is a lipreading-based system that combines a few simple hand movements close to the mouth with normal speech to make visually clear every sound a person is saying as they say it. It provides a simple visual alternative to hearing aids and cochlear implants by enabling a deaf child to see visually all the sounds of natural speech.

Just like hearing aids and CIs, it serves as a tool to enable the deaf child / person to perceive spoken language through a means that compensates for their lack of perception through their natural hearing. Whereas hearing aids and CIs enhance a deaf person's aural perception of speech, CS can enhance the visual perception of speech for those who are completely deaf. And just as a young hearing child can subconsciously make sense of the speech sounds that it hears and begin to understand spoken language through auditory perception, so a young deaf child with no access to sound can subconsciously make sense of the speech sounds that it can see through visual perception, as long as these sounds are consistently transformed into visual information in real time with CS.

Although spoken English can only be partially perceived through lip reading alone, CS enhances the visual clarity of speech to a level comparable with normal auditory perception. Although young deaf children cannot acquire spoken language through lip reading alone, the complete and unambiguous visual information that is perceptible when connected speech is combined with the





hand movements of CS makes it possible for a young deaf baby or child to acquire and access spoken language in a way that is fully analogous and (if used consistently) at a similar or equal rate to a hearing child's acquisition of spoken language, even without being able to hear a single sound of it.

To benefit from CS to acquire and access spoken language, deaf children don't themselves need to learn how to cue back, just as hearing aids don't speak and aided children don't need to put hearing aids on their hearing parents to communicate with them; it is the deaf child (/person) who needs the help of hearing aids or CS to access another person's speech. To access and acquire spoken language receptively, they simply need to have their visual access to speech around them enhanced by their primary carers consistently using CS in natural everyday conversation and communication.

The English language through CS

On reading the auditory neuropathy advice, we realised immediately that, without being able to benefit fully from hearing aid or CI technology, CS provided the only way that our son could have a chance to acquire English as a first language during his critical years of language acquisition. We knew that he needed sign to communicate, at least at that stage when he wasn't able to make good use of his implant. But, on reading the advice from the USA, it was clear that, with CS, he could also acquire English. In fact, it was obvious to us that it would be a lot easier for him to learn English as a first full language than to learn BSL, as we could immediately provide a perfect and complete language model and a natural communication environment in cued/spoken English in a way that would probably never be possible for us in BSL. We knew that he might never be able to speak English to communicate verbally, which is why he needed to be bilingual, but we felt confident that learning English through CS didn't mean that he couldn't also learn and use BSL, and vice-versa.

Thus, for us, CS wasn't a choice; it was a necessity if he was to have the chance to acquire a first full language and fully access our family life. It was the only way that we could avoid him becoming

permanently language disabled later in life, the only way that we could enable him to gain the language necessary to support literacy and numeracy when he got to school. We believed that acquiring a complete first language directly and naturally from us as his primary carers was his right, as it would be assumed to be for any hearing child. Without a full first language, we felt that his other fundamental rights would be seriously compromised – his right to family life, his right to literacy and education, his future right to access employment, etc. – and that his social and emotional development and wellbeing would be seriously at risk. We also believed that he had a right to acquire his 'mother tongue' in the real sense of the word – to learn the language that we naturally use to communicate as his parents and as a family – and that we, as parents, had a right to try to use our mother tongue with him. While the main focus was rightly on his needs as a deaf child, we felt that we also had rights and needs as his parents, including our parental language rights and our right to a family life with our son.

Learning to cue: swift, easy and free of charge

Given the general lack of knowledge and interest in CS among most of the professionals supporting us at the time, we had to seek guidance from experts in the USA, Belgium and France, and from the Cued Speech Association in the UK (CSAUK). We were relieved to discover that we could learn the entire system in less than a week as there are only 44 sounds of spoken English to learn to cue, and that the CSAUK could train me and my husband straight away and free of charge in our own home.

Much like learning to touch-type (for which the position of the 26 letters of the English alphabet must be learnt rather than the 44 sounds of spoken English), we were advised that it would take several weeks of practice to get up to normal speech speed. After only the first week of training, however, we would both be able to say to our son anything at all that wished in the English language (just as we would be able to type it) and he would be able to fully access this, regardless of the fact that he couldn't hear a single sound of it. His vision was fine, he didn't seem to have a learning disability, and he was still very young, so they reassured us



that there was no reason to think that he wouldn't start to pick up spoken English as easily as a hearing child would, so long as we were consistent about adding the cues to everything that we said to him and made sure that we had his visual attention when speaking to him.

It seemed unbelievable and miraculous to us that we could cue to him nonsense words, silly sounds, nursery rhymes, read stories to him, chat to him, to say to him whatever we liked in English with every bit of syntax, grammar and vocabulary fully, simply and easily represented as though speaking normally. In fact, after only one week of CS training, we were capable of cueing perfectly and accurately every single one of the 30,000 or so words in our own vocabulary and any word or phrase ever published or spoken in the English language – something that wouldn't be even remotely possible for us in BSL even after a lifetime of immersion in sign language.

Looking back, the enormity of what CS gave him is very obvious but initially we were also delighted to just have unambiguous and clear communication. He was around one year old when we started to use CS and not long afterwards I wrote:

'Cued Speech has allowed our son to understand English fully, despite having no hearing. It has been hard work, but being able to stop him having a tantrum by explaining to him, in English, that he can go and play in the sand after we've found his buggy and changed his nappy, so why doesn't he come and help me find his buggy? ... Or that he will be able to have his biscuit as soon as I have put the shopping in the car and got him in his car seat ... is worth everything!'

The discovery of CS and what it could do for our son and for us as a family was truly and profoundly life-changing, and continues to be thirteen years down the line.

Bilingualism - the best of both worlds

We found out that in France and Belgium CS is used to give access to more than one spoken language – as well as sign language – and that many deaf children there have high achievements, even with no hearing at all.

For the first time, we realised that we could have

similar aspirations for our own son. Our approach to bilingualism was distinct from the more dominant 'Sign Bilingual' approach that seemed popular among many deaf educationalists in the UK at that time: whereas Sign Bilingualism promotes BSL first and the later introduction of English – primarily written English - as a second language, we were committed to our son acquiring English early as a first language with, as far as possible, the simultaneous acquisition of BSL. Guided and encouraged by the obvious success of this alternative CS & BSL-based bilingual approach used in Belgium and elsewhere, we started using CS as well as our best efforts to sign with our son as soon as we were trained up.

Within a couple of months of our initial CS training, we were able to cue quite fluently and say anything that we liked to him in spoken English. For the next few years, we sandwiched everything that we said to him with the two languages, often saying and repeating things three times using CS, sign and, following his implant, speech without CS or lipreading. He continued to sign to us, but within a few months he also had a receptive English vocabulary of around 100 words and began spontaneously translating what we said in spoken English/CS into sign. With the two languages going, communication became quite easy.

Because of our use of CS his acquisition of English from his first birthday until starting school was astonishing: in those few years, he closed the receptive language gap between him and his hearing peers, and by the time he started school, he had age-appropriate understanding of English.

Cochlear Implantation - a 'failure'

Eventually video evidence of him turning to a loud bang on a drum at home provided confirmation of a functioning nerve and he was approved for an implant, at age two and a half. For the first six months or so following his switch-on, we were hopeful that his implant was working and that he would be able to use it like the other implanted deaf children that we knew. But when the audiologists started to programme his implant they found that, for various reasons, only half of the electrodes could be used. The quality of his hearing was further compromised by the underdevelopment of his auditory nerve. The outcome was that he could detect sounds



>> quite well, but he couldn't easily discriminate them, and so he couldn't identify many single speech sounds or words, or follow any connected speech.

Following his implant, we had placed him in a state of the art aural/oral nursery for deaf children in central London (where all communication is through speech), with highly specialised and experienced Teachers of the Deaf (ToDs), Speech and Language Therapists (SALTs) and (Occupational Therapists) OTs and a teacher to child ratio of 1:4. It was soon apparent, however, that he wasn't accessing spoken language aurally in the way that his peers were and wasn't making the 'expected' progress. We were made to feel that this was some kind of failing on his part, but we knew that the basic problem was that his implant wasn't working as well as other children's, and that this specialist centre for deaf children simply wasn't equipped for helping deaf children who couldn't hear.

We were desperate to do anything that we could that might make a positive difference. We hoped that Auditory Verbal Therapy (AVT) might help, and we drove all the way to Oxford and paid the expensive fees for our son to have one-to-one sessions with the leading AVT therapist at the time. Yet when it became obvious to her that our son couldn't hear well with his implant, she made us feel foolish for being there at all. She was quickly frustrated with his failure to perform the listening tasks, and after a few sessions she told us that she didn't think there was much that could be done for him. Her advice was that we should revert to signing with him. We were made to feel again that he and we had failed and that we should scale down our expectations of what he could achieve.

We were getting the same message from his consultant and team in the cochlear implant programme. In his annual post-implant assessment reports, they made it clear that they considered his to be a failed implant as he couldn't differentiate the Ling sounds [these are six phonemes which give an easy way to assess if a child had access to the entire speech spectrum in English] without lip reading, he couldn't follow their speech, and the intelligibility of his own speech was very poor. We dreaded having to attend the assessment appointments and cope with the pained and disappointed looks on the faces of the ToDs and SALTs as they advised us that signing would be the only fair option for him. Two members of

the implant team subsequently travelled 200 miles to observe him at school, and following this visit, they told us bluntly that, in their view, he couldn't be educated in a mainstream school and that it was unrealistic to expect him to access education through English. They felt that by placing him in mainstream education, we were setting him up for failure. We were taken aback by how forcefully they expressed this view, and how unwilling they were to listen to our own assessment of his progress and prospects.

The principle of 'informed choice' didn't seem to mean anything for us. Confronted daily with the many choices open to other parents of profoundly deaf children – choices in schooling, technology, how to boost listening and language – we felt stranded and hopeless. We had no real support to cope with the discovery that he wasn't like most other deaf children and couldn't benefit from the same opportunities open to them. For a long time, we found it extremely upsetting to be around other parents of deaf children. Although deaf, their children could be enabled to hear, whereas our son couldn't. We couldn't take part in their chat about implants and other technology and their options for boosting their children's listening and speech. None of their discussions seemed to have any relevance to our situation and we were always left feeling miserable and alone in the knowledge that we were in a different place from them and there was little we could do about that, however much we wished that things could be different.

Why didn't UK professionals tell us about CS?

We couldn't understand why we hadn't received any information about CS from NDCS or from our local professionals or the implant team. As the only alternative to accessing spoken language with technology, we couldn't fathom why it hadn't been the first thing mentioned to us when it had become obvious that our son had no aided hearing and might not be able to benefit from an implant.

This seemed all the more puzzling when we discovered that it is a tried, tested and robustly researched tool for supporting profoundly deaf children in Spain and in Europe's French-speaking countries, where it is often used in conjunction with sign language to enable deaf children to be fully bilingual. This was our aspiration for our

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son. We couldn't understand why, in the UK, all the focus seems to be on enabling deaf children to access spoken language through technology, totally ignoring the only means by which the deafest children who are unable to benefit from technology can be given an equal opportunity to fully access spoken language. Many deaf children without useful aided hearing may never be able to speak, but this needn't mean that they can't have equal access to spoken language visually, and hence, later, also be able to read it and write it and benefit from all the opportunities that it brings. We felt that something must have gone very wrong in the UK if the deafest children aren't given the same chances to acquire and access spoken language and become fully literate in the way that they are in other countries.

We were astonished to discover that our ToD and SALT had never heard of CS before. Worst of all, our SALT openly mocked us for trying to use something that she considered inappropriate to use with a young deaf child. She turned her back on me and pretended to lecture our son with a wagging finger about how misguided we were to think that he could access English through a phonics-based system when he was still a baby. I pointed out to her that natural spoken English is a phonics-based system that is usually assumed to be quite easily accessible to hearing babies, but she didn't get the point.

Our ToD was more positive and provided great moral support; it made all the difference working with a professional who was willing to try something that was new to him. He appreciated the importance of our son acquiring a first full language, and having recently started his own Level 3 BSL training after years of learning to sign, he understood how impossible it would be for us to provide a proper language model of BSL for our son in the short time necessary. His open-minded approach seemed a rare and valuable attribute compared to most professionals that we were in contact with at the time.

Access to Education

We tried a variety of pre-school options including a sign-bilingual placement. The most successful was a mainstream nursery with one-to-one inclusion support where he could access everything receptively through CS. We subsequently opted for a small mainstream village school with full-time CS and BSL

communication / inclusion support.

As CS can be learned within a relatively short period of time, and since it is no problem to cue slowly with a young deaf child while building up speed through practice (they, after all, are subconsciously developing their receptive 'cue reading' skills at the same time as the person cueing to them may be perfecting their own cueing skills) it was very straightforward to recruit the inclusion / communication support worker who had the right temperament and commitment to supporting our son and then train her up in CS once she was in post. Within a few weeks, she was able to cue slowly to our son every word and phrase that the teacher or other children said, so long as everyone wasn't speaking at once. She could cue whole story books to him, all the separate sounds in phonics, and in group play situations or in the playground, she could pick out and cue to him certain things that people said or 'cue over' the background noise in the classroom. The fact that he already had age-appropriate understanding of spoken English meant that he was able to keep pace with his hearing peers in every area of the curriculum, including maths, and in some areas, including reading, he began to overtake many of them.

Having all classroom communication cued to him by his CS communication support worker consistently and completely throughout the school day meant that he was able to access everything directly and simultaneously in English, including phonics for literacy. There was no worry about the quality of the language input he was accessing in the classroom, as his Communication Support Worker (CSW) was able to cue every word and phrase exactly without any need for translation into a different language. Her job was a very demanding one, nevertheless, and became more so as he progressed through school and needed more rapid CS transliteration to follow classroom teaching and discussion, but she was able to keep pace with the increasing demands and continue to develop her cueing skills while he continued to improve his cue-reading skills. This process continued into secondary school. She can now cue at a phenomenal rate while memorising and chunking verbal information when his attention is distracted to other visual input, while his cue-reading skills have also continued to develop. His CSW is also an expert and highly experienced inclusion worker who has ensured that he has





had maximum access to every aspect of learning at school and has also worked hard to support his developing play and other social skills. She has always been his advocate in the classroom, but also trained and supported him to become more confident in advocating for himself and to become an increasingly independent learner. She has always ensured that his teachers see themselves as his teachers, rather than her substituting in any way, with her role strictly to facilitate his access and inclusion.

Literacy and educational Achievement

He took easily very to reading and writing – more easily than many of his hearing peers – perhaps helped by already having a visual phonic ‘map’ in his head from his early exposure to CS. By Year 2/3, he was using spoken English as his first language; by age 6 he had a reading age of 10; he achieved Level 4/5s in his English SATs in Year 6; and now, at 14, he has a reading age of 16+.

He is thriving in a small mainstream secondary school, still with CS-based communication support. In Year 8, he came fifth among his year-group of hearing children in the average grade across all subjects in his end-of-year exams. In his last four or five years’ school reports commenting on his academic progress, not a single teacher has had any reason to make any reference to his hearing loss. In his most recent language assessment undertaken by the ToD, he scored above the maximum possible score at the final level of the British Picture Vocabulary Scale (BPVS) vocabulary test. The test is designed for hearing children between the ages of 3 and 16, so it is quite an achievement for a deaf child to score the maximum at 14 years old.

His lip reading and listening skills develop

We and all the professionals supporting him had previously assumed that he wouldn’t ever be able to follow speech without lipreading. But a listening assessment at the Ear Foundation shortly before he started secondary school indicated that he can follow connected speech quite accurately without lipreading if speech is slowed down a bit. When asked how he could do this, he said that he uses his language

knowledge to guess and predict what’s being said when he can’t distinguish it with his hearing alone.

We now hardly use CS at home as he is fine with two-way communication in spoken English if people slow down and make sure they are facing him to enable him to lip read. He is now able to follow the speech of some of his teachers at school without having to rely entirely on his communication support worker, and he is also beginning to use lip-speaking and simultaneous speech-to-text palantyping (remote subtitling) in addition to CS to follow spoken communication in class.

The huge and unexpected improvement in his listening skills over recent years challenges the assumption that developing and supporting listening depends on prioritising auditory over visual input. Our experience suggests that for children whose aided hearing is very poor, early, continuing and full acquisition of English visually through CS could be a key to developing good listening and oral skills later.

Developing Speech, English language skills, BSL and communication

His education authority agreed to arrange BSL tuition throughout his school career, but in practice this has proved very difficult as the local hearing support service has had problems providing a suitably qualified and reliable BSL tutor to visit our son regularly during the school day. Together, we are looking at other ways to build his BSL skills and build on the links he already has with the D-deaf community.

He started choosing to speak instead of sign when communicating with hearing people from the age of 6 or 7. Although his expressive spoken language was some way behind his receptive comprehension for a couple of years, however, with help from a SLT and a voice coach, it rapidly caught up, and he is now a fully fluent and competent English speaker. Despite not being able to hear all the sounds of English clearly, he has used his receptive language knowledge to develop his speech. He is now intelligible to most people and converses quite easily with his (hearing) brothers and best friend (none of whom cue with him). He is now very happily integrated and confident with his friends at his mainstream





school. He still has to work very hard to use his lip reading and listening skills to join in but he will now confidently ask his friends to repeat things that he has missed. He has a strong sense of humour and particularly likes to crack jokes that involve a play on words. He is very keen to pick up jargon and phrases that his peers like to use with one another.

He has recently been discharged by his current local SALT as her assessments indicate that he has reached all expected targets in communication skills for a child of his age and doesn't need any further support from her.

Future opportunities and life-chances

Most importantly, perhaps, is the fact that he now has a whole world of options open to him in his future life that simply wouldn't have been possible if he hadn't had the chance to acquire English as a first language during his preschool years. Without that, he would have struggled with his social integration within the family, and almost certainly struggled with literacy, numeracy and everything else that is connected with a child's normal linguistic and social development. For him, there was no technological solution that could ensure his access to spoken language, and so Cued Speech was the only option. As his parents, we will always feel relieved that we recognised the importance of his primary language acquisition before it was too late, and, almost by chance, that we found out about the only tool that could make this a possibility for him.

A recent piece of writing shows his confidence and sense of aspiration, and sums up where he has got to on his journey.

He wrote: **"To be deaf is to be different, but then nobody is the same, not even identical twins. One day, I hope to be a medical doctor, graduated from Cambridge. I suppose my hopes are quite ambitious!!!"** It may be, in fact, that the General Medical Council wouldn't allow a profoundly deaf person to train or practice as a doctor, but any barriers to him achieving this or any other ambition

won't be due to a language deficit of any kind. He will face the usual barriers that any young person of his age might encounter, such as the need to work very hard to get the grades that he wants. But he knows that, as long as he steers clear of choosing opera singing as a career, he has as much potential and as many opportunities in his future life as his hearing peers.

In the end, 'informed choice' meant for us something quite different from what it is usually assumed to mean. It meant being informed early on about his fundamental language needs and associated rights, including his right to family life, and the paramount importance of addressing these effectively during his critical years of language acquisition. It meant informing ourselves beyond and despite the information being given to us by professionals. It meant looking further afield for expert information and advice that seemed to be lacking in the UK. It meant taking responsibility for informing his teachers and CSWs about how to support his access and inclusion effectively at school. It meant being informed to recognise good evidence-based practice and research that could guide our decisions, irrespective of whether this came from the UK or abroad. It meant talking to other parents who had faced similar challenges, and learning everything we could from their experience. The outcome for our son is a level of linguistic, social and academic competence and confidence that was unimaginable to us at the point of his diagnosis.

For a system that is so well-researched, so well-established and so well-recognised in other European countries, and one that has proven so incredibly successful for our son and others with no hearing who have used it in the past, it is imperative that questions are asked about why it is not be used and supported more widely in the UK with deaf children who do not have useful aided hearing. It is the only alternative to technology for those children if they have hearing parents and are to have a chance to fully acquire their family's spoken language (English or other) during their critical early years of language acquisition.



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