



# Vital Voices 2019

Celebrating the Voices of AAC Users

AAC Users tell their stories!

The Scottish Government introduced legislation on 19 March 2018-Part 4 of the Health (Tobacco,Nicotine etc. and Care) (Scotland) Act 2016. This legislation is to ensure communication equipment and support to use the equipment are provided to people of all ages in Scotland.

To celebrate the one year anniversary of this landmark legislation, we have produced this booklet to celebrate the many voices of people who use Augmentative and Alternative Communication systems.

These are the **V**ital **V**oices of AAC!

*There are more ways to communicate than you think!*

**What some AAC Users have to say about the importance of having a communication aid:**

**I like it when  
people listen to  
me!**

Having a  
communication aid  
makes people pay  
attention to me.

**I can tell people  
jokes and make  
them laugh!**

**Speech is the most important  
thing we have. It makes us a  
person not a thing. No  
person should ever be a  
thing**

**I like being  
involved in  
meetings about  
my future.**

**You use different  
communication  
when you meet up  
with people socially.**

## **AAC Awareness 2019**

### **Patient Story**

Lesley is a long term user of a communication aid. She self manages her system but relies on support from the NHS Lothian Regional Communication Aid Centre for repairs and upgrades.

My name is Lesley. I am 44 years of age and was diagnosed with Primary Progressive MS in 1999.

I agree to my story being used as part of a general AAC Awareness Campaign in Scotland . If you need the document signed, my Mum could do it on my behalf, as she has POA and I have the legal documents to hand.

At this point in time I could not live without my eye gaze. Yes it has enabled me to get my points across but there is so much more to it! It has given me my life back. This enables my Mum to happily go out occasionally knowing that I am busy on the Eye Gaze as it enables me to do all of the things which I used to take for granted such as putting the TV on and changing channels ( if I am not watching catch-up online on the Eye Gaze) or reading a book on the Eye Gaze ( either on the Kindle App or through Audible ).

I often think back to how life must have been for my Gran who was very disabled with rheumatoid arthritis and had only the radio and TV to keep her company. With the Eye Gaze I can text, email or phone anyone in an emergency which fortunately I have never had to do but it is a huge comfort knowing that I could if I had to. I also make good use of Amazon Prime by listening to music or watching movies. All this of course after I have read the daily newspapers online and caught up on what's happening in the world either through Twitter or other online apps.

All this became possible I feel almost by accident! As I became involved with an OT who specialised in technology as I could no longer effectively use my hands to operate my iPad and she introduced me to the possibilities of a Tecla Shield. Technology was very important to me as I had retired, something I never dreamt I would do as I was previously so busy including taking a lot of exams both whilst I was training over 3 years to be a Chartered Accountant after spending 4 years doing my degree. That was possibly why I went for a part-time role as a Non- Executive on a large Health Board (5 years after diagnosis ). However, with the Tecla Shield I was able to apply for a voluntary role with the Ambulance Service when I retired in 2013.

It then eventually became apparent that my voice could not be heard and understood in Committee Meetings which after chairing meetings for so long I was quite devastated by it, but maybe not completely surprised. I quickly got in touch with the OT again and we tried various things but very fortunately for me she knew of a girl who worked for an external body which Social Services had links with. This of course turned out to be Keycomm. After then trying various apps with them on the iPad she then brought an Eye Gaze on a large stand which I could use internally, with a promise of an Eye Gaze that I would eventually be able to attach to my wheelchair. Suddenly I could speak to friends and family ( but only if they visited me ).

The day finally arrived when I got an Eye Gaze which was attached to my wheelchair ( it probably wasn't that long after getting the trial one, it just felt like an eternity to me )! That day I just happened to have an appointment with my MS Consultant and he was very impressed seeing the direct response from me ( he was watching as I typed ) rather than hearing my Mums version, as she attends appointments with me.

The Eye Gaze also allows me to independently visit friends at their home as I no longer need my Mum to interpret what I say. Now I have lots of questions prepared for them as well as stories about what I have been up to. So from that perspective the Eye Gaze has had a huge impact on not only my life but my Mums, and anyone else that I come in contact with.

Overall, if my motivation hadn't been work and my OT didn't happen to know about the girl from Keycomm, I'm not sure how I or others would acquire their Eye Gaze. I thought that it was something that was only available to millionaires like Stephen Hawking!

The main challenges for the Eye Gaze will be the specific voices which are banked for patients at the Ann Rowling Clinic, to not have a delayed start, as you feel it takes so long to type out your response as it is. So I am happy with the generic Heather voice ( at least it is not American! ) the other problem I have is that the Eye Gaze is not as reliable when I have been in the car and I have inevitably been bounced about, due to bad roads, I end up re-calibrating numerous times after any car journey.

## AAC Awareness 2019

*Zena is living with Motor Neurone Disease and her speech has deteriorated rapidly. She was referred to Speech and Language Therapy prior to her diagnosis and has received ongoing support with her communication. She is currently using an iPad with TouchChat to communicate which has been provided for her personal use. She continues to be supported by NHS Western Isles.*

“It has worked well for me. You (SLT) were very supportive. It was in good time. I did not realise at the time that my speech would deteriorate so quickly. It was so useful having it in advance of the requirement to use it.

I could not do without it. I have lots of people coming to visit and could not communicate without it. It is great on a one-to-one basis but when there are lots of very chatty people it is more difficult. Having said that, some people stop talking until I have said what I want to.



## **My Magical Box**

by Sam A. Chambers

Sam is supported by NHS Forth Valley

**Some people have got magical ways of communicating**

**Like me they have got a magic of communication by the magic of technology using the  
Magical Box I can feel free to say whatever I want by the magical ways of technology it**

**Follow me about wherever I go, it is like my magical friend**

**who helped me to do wonderful things**

**which "Normal people" can do**

**But**

**Sometimes technology is a bit of a trial when it breaks down,**

**I can feel so**

**Frustrated!**

**it's like the voice take away from you.**

**Can you imagine how that feels like without any**

**Voice? You couldn't say what you want.**

**As my magical box give me the power of space**

**I can have the freedom of speech**

**With this magical voice**

**So**

**I can be like " normal people "**

**Thanks to my magical box**

**But**

**Who know what the future will hold for my magical box?**





**My name is Jamie. I am from Stirling and I am 39 years old. I have cerebral palsy and a learning disability. People might look at me and think I cannot communicate or understand. I cannot speak but I can communicate. I like to chat and to have a laugh and make jokes. I can think about what I want and make decisions. People just need to give me a chance. My main ways of communicating**

- **I answer yes/no questions by looking to the left or right.**
- **I have a communication book which works with something called partner assisted scanning (pic). This means that I rely on another person to hold the book and scan the options so that I can navigate through the pages and use words - I don't have the physical ability to point or turn pages. I learnt to use this method of communication when I was a child and have had this book for a very long time. It is very important to me.**
- **I often use Talking Mats to give my views on lots of different topics. Talking Mats is a visually supported way of helping people to communicate about things that matter to them.**
- **I use facial expressions and body language like anyone else.**
- **In the past my Speech and Language Therapist helped me to try a high tech eye gaze system but it wasn't for me. Recently I had help from speech and language therapy to update my book with lots of words that will help me to express more.**

**My communication aids have helped me to say what I think, to chat, to communicate about things that matter to me. I have been able to communicate with my social worker recently about big changes in my life such as where I live, who I want to support me and what I want to do. I experience a lot of pain and would be living with this in silence and unsupported if I could not tell people about it and get their help.**

**People are very important to me as they need to learn how I communicate and how to communicate with me. They need to add words and phrases to my communication book to keep it up to date. They need to give me time to communicate. The hardest part is getting people to take this time and effort for me. Sometimes I am thinking of something and I cannot get the message across easily – this is hard for me. I enjoy life more when I can communicate.**

**Jamie is supported by NHS Forth Valley**



## ***AAC Awareness- My Patient Story***

My name is Ludmila, I have been living in Scotland for 9 years and have been diagnosed with MND since 1998. I am a Russian speaker and I also need an interpreter to communicate apart from communication aid, i.e. my special computer and special program.

We have received all this help from speech and language therapy five years ago and our lives have changed. My husband complains that I speak too much now and he needs his peace and quiet 😊

I became an active user of internet, got back in touch with old friends and gained many new ones. So I don't feel left out any more from the rest of the world.

The only problem we have is that the computer needs to be updated now and again, like any other system, but the professionals who help me are absolutely fantastic! My family and I are very grateful for all this help and support.

***Ludmilla is being supported through NHS Tayside.***

## What some AAC Users have to say: Strengths and Challenges:

Using photos really gets people involved.

In a busy place it is sometimes difficult to be heard

It's important to have the right words.

It can make people pay attention to me.

Sometimes it is hard to communicate with different people. It is frustrating.

People can get a bit freaked out about the equipment.