

Communication during Casual Interaction (COCAIN)

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Presentation

Let me first say a few words about my own situation. I was diagnosed with ALS four and a half years ago at the age of 35.

Unfortunately, I have to say that my ALS has developed quite a lot.

Today, my whole body is essentially paralysed, although I can still move my head slightly. Moreover, I can neither eat nor drink.

And maybe you have already noticed that my lips, just like in the Cillit Bang commercials on tv, are not completely synchronised with my speech. This is because of the fact that I can not speak. And this is why I speak here today....

An important thing is that I can still breathe. So I do not need a ventilator yet.

I live alone in a small apartment. But I am never alone, of course; I cannot be. 24 hours a day, I have one of my eight young blonde female personal assistants around me.

Despite my serious handicap, I still hold my position at the university. This is possible because of, among other things, some high-tech communication systems. But I will come back to that.

The Spelling System

A good safe choice for communication is the spelling system. As you can see, the alphabet is inserted into a 5 x 6 matrix. The system works in the following way:

A	B	C	D	E	F
G	H	I	J	K	L
M	N	O	P	Q	R
S	T	U	V	W	X
Y	Z	Æ	Ø	Å	

My personal assistant counts the rows one, two, three... until I lift an eyebrow. She then reads the letters in the appropriate row, until I again lift an eyebrow. This gives us the first letter in the first word of what I want to say, and the process is then repeated for the next letter, etc.

Anyone can learn the spelling system and be able to communicate at some speed.

The advantage of the spelling system is that it always works. It works inside and outside. It works in the car, it works in the shower, it works in the bed.

The disadvantage is that it takes a long time to say very long sentences.

If I for instance want to say something complicated and intelligent, then it soon becomes very tedious using the spelling system. Unless, of course, if the personal assistant can more or less guess what I am saying. But then it cannot be very complicated and intelligent....

Personally I use the spelling system mainly for small-talk, and to give direct orders to my personal assistants when I want my basic needs to be fulfilled. Then I spell for instance (in alphabetical order): beer, food, sex, tv....
And so on.

On the other hand, if you want to do poetry or philosophy or theoretical physics, then the spelling system is not really adequate. Then you need something better.

The Computer

I have not been able to use an ordinary keyboard for three and a half year. I therefore use an on-screen keyboard.

I have three ways of controlling my computers. I use a scanner, a headmouse or an eye tracker. In this way, I can do exactly the same as anyone else with the computer. Except to turn it on....

Let me say a few words about each.

The scanner is essentially just a switch which is connected to the computer. When the switch is activated, something happens on the screen. I am actually giving this talk using the scanner. Each time I turn my head, the computer reads the next sentence. With the appropriate software, one can do everything with the scanner; that is: Open and close documents, surfe the internet, write emails and so on. It is my experience, however, that the scanner is extremely slow to use for most things.

A headmouse, on the other hand, is extremely efficient. If you can control the head, you can do everything on the computer very fast, except of course to turn it on. Actually, one year ago, I could no longer use the headmouse. Within three months, I lost most of my neck muscles, so my head was just hanging down on my left shoulder, and I had no external use of it. But then I got a new neck support and then I could use the headmouse again, at least for certain things. I can still open and close documents, surfe the internet, read the newspaper, read my emails and so on. I can even write short messages using the Gazetalk program, which does not require much precision.

For any serious writing, I use an eye tracker. I got the new quick glance eye tracker last summer. I was lucky to be already familiar with the Gazetalk program so I could start writing almost immediately. The Gazetalk program is, in my opinion, superior to most other programs when it comes to writing using eye tracking. Unfortunately, I have the eye tracker only on my stationary computer at home. I would like to have it also on my laptop, so that I could take it anywhere I go. This is of course already possible, but for it to be really useful, the technology needs to be improved. One problem is the sensitivity to sunlight, and other lights in general. Another problem is the time consuming act of calibrating the system.

Conclusive Remarks

Even if you can not speak and is almost completely paralysed, there are ways to communicate. With or without a computer.

Personally, I use the computer as much as possible. If I have a friend visiting me, I prefer to dismiss the personal assistant to the kitchen and to use the computer instead. It is just more relaxed that way.

For me, it is also of psychological importance that the computer can speak. Even if it is not my own voice. A voice is after all just waves in the air, so there is no reason to be religious about it. I use ViTal speech synthesis with the English voice, Roger.

I have only been talking about communication for people who can not speak and who are at least paralysed below the neck. If you can use your hands, there are of course many much simpler ways to communicate. For instance using sign language or paper and pen. So this is considered as cheating....