

COMMUNICATING WITH PATIENTS EXPERIENCING LOCK-IN SYNDROME

Hi there,

A close friend's father was severely paralyzed after a stroke in Nov 04. It happened suddenly. Fainting spells a couple of days before the stroke and on that faithful day, he just couldn't walk all of a sudden and was slurring. He was sent to a hospital and there, he fell into a coma. Things weren't looking good and his family was told he may not survive the next day. He did survive but upon waking, he was found to be completely paralyzed. he had to be fed through a feeding tube and the only movement he could make was just to blink.

As a friend, there was nothing I could do but pray for a miracle. At the same time, I was doing a lot of reading up on the Internet. One day, the idea of using Morse code to help severely paralyzed patients communicate struck me. Severely paralyzed patients can be said to be experiencing the "lock-in" syndrome. Since he can only blink, perhaps he can blink out a code. I searched through the Internet and realized that there is a little research on helping lock-in patients communicate. However, it usually involves expensive gadgets. I did more research and chanced upon communication boards being used to help patients who cannot speak (but can move their limbs) communicate. I combined the two and came up with communication boards that will help lock-in patients communicate. The Morse code though fast, may be a bit difficult to pick up, so I also designed a colour-coded alphanumeric table and 2 other boards for patients to communicate basic needs and health conditions. Most of these will require the patient to be able to read English.

The communication boards will not benefit many people if it stays with me, so I'm posting it on the internet to be shared with all who have family and friends plagued by the lock-in syndrome.

I believe it's a great deal for such patients to be able to communicate their needs and wishes to their caregivers. But do not be too hopeful when using these boards. The lock-in patients may be experiencing depression and may not respond as expected. My advice is to go slow, be encouraging and never fail to love. As a healthy person, you can never fully understand what it means to lose so much in a short time.

The communication boards require at least one helper to facilitate communication. I've got an idea of a gadget that will allow words to be spelt using the eye gaze method. There is no need for any helper to assist in communication. It's a combination of several technology widely available commercially now. Gadgets performing similar functions currently (those that read brain waves or use a camera to capture eye movement) are costly, complex and hard to learn. My idea's a little simpler but I have no idea how it can be constructed yet. If I ever do find out, I wish I can manufacture these gadgets cheaply, so every hospital can buy plenty of them for all lock-in patients, and caregivers can easily afford to buy it for their loved ones.

Okie. That's it for now. If any of you have rehabilitation success stories to share or feedback on these communication boards, please email me at

INSTRUCTIONS FOR COMMUNICATING WITH COLOUR-CODED ALPHABET TABLE

1. The columns are colored-coded to speed up the communication process.
2. First ask the patient if the alphabet he's looking for is in any of the sets of color-coded column. For example, say, "Blink if the letter is in the BLUE COLUMN". If he does not respond, try the PINK COLUMN, and then the GREEN and YELLOW column.
3. If he blinks, then ask him to narrow his selection down to one column. For example, say "Blink if the letter is in the FIRST BLUE COLUMN".
4. Once he selects the right column, say "Now, I will be moving my finger down this column slowly. Blink once I reach the letter". Proceed to slide your finger down the column slowly.
5. When he blinks, stop and say "Are you looking for the letter B?" Blink if YES.

Notes:

- Have a whiteboard and marker ready to write down each word he picks. This way, he will be able to keep track of what he has spelt so far by looking at the board.
- Give him a lot of encouragement when he gets the letter right. It really means a great deal to be able to communicate with his family.

INSTRUCTIONS FOR COMMUNICATING WITH MORSE CODE

1. Present the entire table to the patient. Explain that he should blink once to represent a dot and look to the side (the side opposite where you will be sitting) to represent a dash. (He can also do a long blink, but that may be more tiring)
2. Each time he blinks, reaffirm by saying aloud "Ok, that's a dot." And write the response on a whiteboard. Same goes for a dash.
3. When complete, ask him if the set is complete and blink for yes.
4. Decipher the word and ask him "Were you spelling the letter A?" Blink for yes.
5. Write the alphabet on the whiteboard and continue.

Notes:

- It is faster to use the morse code to communicate, but it requires the patient to have some level of alertness and clarity. It may take some getting used to and the learning curve is slightly steeper than that of the colour-coded table. It is best to introduce this to the patient when he gets better.

ALPHABET USAGE FREQUENCY

1. E	2. T	3. A	4. O	5. NI	6. S	7. R	8. H	9. L	10. D	11. C
12. U	13. P	14. F	15. M	16. W	17. Y	18. BG	19. V	20. K	21. QX	22. JZ

INTERNATIONAL MORSE CODE TABLE (Alphabets)

A	• —	I	• •	Q	— — • —	Y	— • — —
B	— • • •	J	• — — —	R	• — •	Z	— — • •
C	— • — •	K	— • —	S	• • •	,	— — • • — —
D	— • •	L	• — • •	T	—	.	• — • — • —
E	•	M	— —	U	• • —	?	• • — — • •
F	• • — •	N	— •	V	• • • —		
G	— — •	O	— — —	W	• — —		
H	• • • •	P	• — — •	X	— • • —		

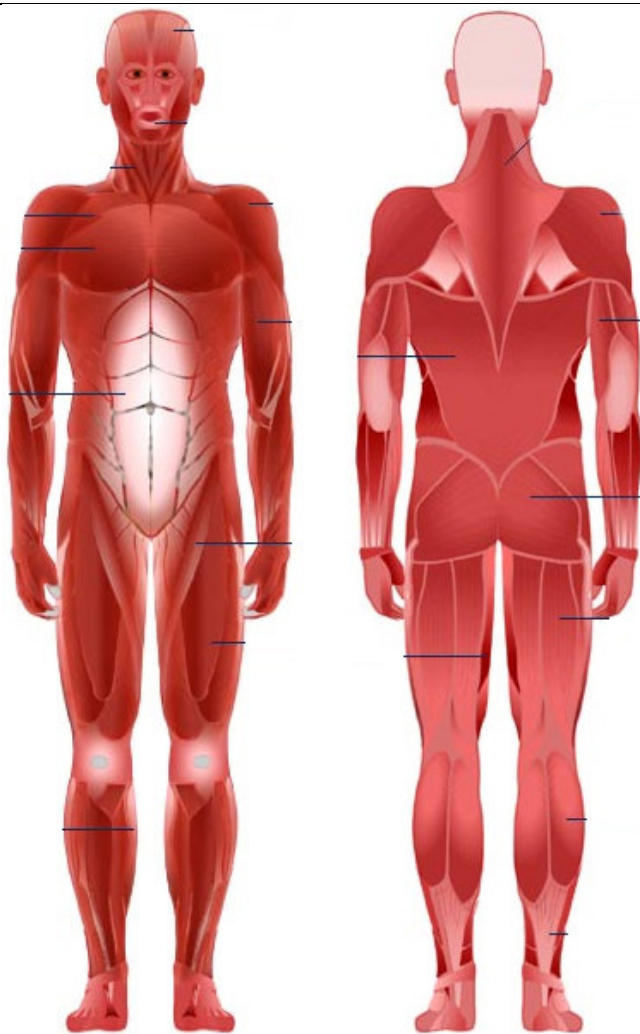
INTERNATIONAL MORSE CODE TABLE (Numerals)

1	• — — — —	6	— • • • •				
2	• • — — —	7	— — • • •				
3	• • • — —	8	— — — • •				
4	• • • • —	9	— — — — •				
5	• • • • •	0	— — — — —				

A	F	K	P	U	&	1	6
B	G	L	Q	V	,	2	7
C	H	M	R	W	.	3	8
D	I	N	S	X	?	4	9
E	J	O	T	Y	!	5	0
				Z			

Colour-coded Alphanumeric Communication Table (ordered by alphabets)

I AM...		I WANT...	
Choking	Anxious	To be suctioned	Massage
Hot	Cold	To sit up	TV
Thirsty	Hungry	To lie down	Radio
Better	Worse	To sleep	Family
Wet	Drowsy	Blanket	Exercise
Tired	Angry	Pillow	Doctor
Nauseous	In Pain	Socks	Nurse
Frustrated	Afraid	To Spell	Thank You ☺
Disappointed	Giddy		
Unsure (of what is happening)		Turn my body 	Turn Lights 



This part of my body...

Itches

Aches

Stings

Burns

Hurts

Throbs

Cramps

Is tender

Is numb

The pain is...

Constant

Throbbing

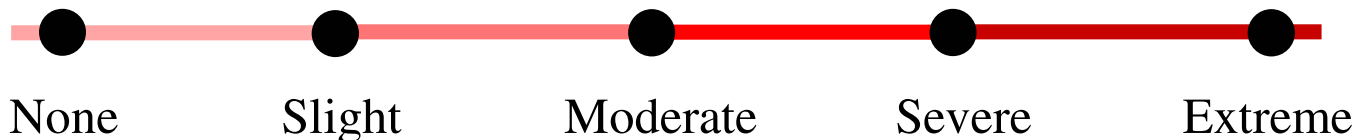
Intermittent

Dull

Radiating

Sharp

Level of pain...



I want pain medicine.

3	4	4	5	5	6	6	7
4	5	5	6	6	7	7	8
5	6	6	7	7	8	8	9
6	7	7	8	8	9	9	10
7	8	8	9	9	10	10	11
8	9	9	10	10	11	11	12

Number of steps it takes to reach each box.

E	A	O	R	H	F	0	5
T	I	S	U	P	V	1	6
N	D	C	B	G	,	2	7
L	W	Y	J	Z	.	3	8
M	Q	X	-	@	?	4	9
K	&			\$!	%	#

Colour-coded Alphanumeric Communication Table (ordered by alphabet usage frequency)