



STEVE'S EMERGENCY COMMUNICATION TO-GO "The Communication Doodle"

Contents

- 1. Purpose of device**
- 2. The base product**
- 3. Building the device**
- 4. About symbols and letter order**
- 5. Physical and mental requirements**
- 6. Using the device**
- 7. Acknowledgments**

1. Purpose of device

This is a tool for basic or emergency communication. It is *not* a replacement for an electronic communications device (i.e. Tobii). But when a more robust device is unavailable or inconvenient, it can be a useful alternative. My wife and caregiver use it quite effectively with me in a variety of situations such as in theaters, sports arenas, and at home when I am wearing a BiPAP mask, or anytime I'm outside without my Tobii. It has the potential to be useful in interactions with emergency or medical personnel. More on this in the "How to use device" section below.

Know that there are many different solutions to this need for a low-tech, easy-to-use communication tool. This one will not meet everyone's needs. It is a portable, inexpensive option that may work for many, I believe.

2. The base product

The product I have adapted is the **Fisher-Price DoodlePro, Clip-on**. Its advertised dimensions are 9.6 x 1.4 x 8 inches, and it weighs 5.5 ounces. The writing surface is 4.4 x 2.8 inches, which sounds small, but we have found it adequate for our needs. A magnetic stylus comes attached with a short cable, and there is a hole behind the screen in which the stylus is stored. The unit includes a "carabiner-style" clip that may or may not be useful to you. It can be removed.

The price of this toy is \$9.00 on Amazon today. A shortened link to it on Amazon.com is <https://amzn.to/2LeHZNd>

Larger magnetic doodle toys (see "Acknowledgments" about toy name) are available and would work for those for whom portability is not a chief concern. However, the weight of larger units may be an issue for caregivers. Also, similar products are sold on Amazon and elsewhere. I haven't seen big savings on these products, and cannot attest to their suitability for this use. *Caveat emptor*.

3. Building the device

This section describes the process used to build my device. This consists of *recommendations only* and describes how *my* device was built. Users and caregivers should make adaptations that make sense for them.

- Use address labels; trim as needed.
- Print letters in block caps with a medium-width black Sharpie.
- Make colored dots as shown.
- Use a letter-frequency order (more on this later).
- Take care that bottom row of labels is affixed carefully, as wrinkles or bubbling may cause sliding eraser to jam.

At the top of this document is the image I created as a guide for the caregiver who built my device. At bottom, see a photo of the device she built.

4. About symbols and letter order

The mock-up I created shows five groups of letters, each accompanied by an identifying symbol (colored dots).

I strongly suggest using a letter order other than strict alphabetic. My order was inspired by the score sheet I used in competitive Scrabble play. What I settled on is slightly different than my mock-up. Here it is:

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

This order shows vowels, followed by the five most frequently used consonants in English (viewers of Wheel of Fortune will recognize these), the rest of the alphabet in order, and is followed by a number sign (hashtag).

Notice there are no punctuation marks and no "space" character depicted. More on this in "How to use device." First, a brief discussion of physical and mental requirements: this is mostly directed at the user/patient, but also the caregiver.

5. Physical and mental requirements

I am a person with with amyotrophic lateral sclerosis, better known as ALS or Lou Gehrig's disease in the U.S. (motor neurone disease in the U.K. and elsewhere). I am a PALS (person with ALS), and it is my compatriots whom I feel may benefit from this device. There may be others who might use it, but here I will address PALS specifically. The information may or may not be more generally useful.

(Throughout this document, I use the terms "user" and "PALS" interchangeably, and "caregiver" for the person holding the device and interpreting the user's message.)

It is assumed that the PALS cannot speak or, at least, has a poor quality of speech that can be difficult to understand. All that is really required of the PALS using this device is the ability to indicate "yes" and "no." What I do is arch my eyebrows for "yes" and shake my head (just slightly) for "no." I do not nod my head for "yes," because like most PALS having difficulty with speech, this is hard for me to do. Every PALS has different capabilities and should settle on yes/no and other indicators that are non-taxing, easy to understand, and unambiguous for the caregiver.

We have found two more indicators useful. I sweep my head to my right to indicate the end of a word. This is seldom necessary, but in some cases it is. An example is N-O-T. The caregiver may assume a longer word is coming (nothing? notice? Nottingham??), and the user can indicate end-of-word to move things along.

Lastly, a symbol for “we’re on the wrong track” is useful. I close my eyes with exaggerated tightness until caregiver notices. This may mean “the last letter or word is wrong,” or “go back to previous group,” or “let’s start over.” Usually it will be clear from the context which it is. If not, the caregiver can ask and the user can indicate “yes” when appropriate.

The PALS should have eyesight good enough to see letters and symbols on device during silent communication, and/or hearing adequate to understand caregiver’s cues when using a verbal method.

The caregiver must be familiar with the user’s yes and no indicators, and must be able to call out or point to colors and letters while watching for these. This may sound easier than it is, or it may sound harder than it is. In our experience it is neither easy or hard. It takes a little bit of practice and a little bit of patience.

The device is quite light. Caregivers who stand when using it must be able to hold it in one hand while writing on it with the other.

6. Using the device

Caregiver stands beside user and calls out the color of first group of letters. In my case, “red” for the group of five vowels. If the user has no reaction (“no” is unnecessary here), caregiver calls out the next color, “blue.” If user signals “yes” (an arch of eyebrows for me), caregiver starts reading letters in that group – L, N, R, S, T – until user indicates “yes.” Caregiver writes chosen letter on doodle surface, then starts again with first color (letter group) and repeats this process until word or phrase is revealed. *The caregiver should not hesitate to guess at what the user is trying to say*; doing so can save a lot of time.

In a public setting where silence is preferred, the caregiver can use the attached stylus to point at colors and letters.

It may be useful to print instructions for using the device and to keep it with the device. This would be invaluable in an emergency when an unfamiliar person may need to assist the user. See next page for an example.

Caregiver instructions:

Hold unit in front of you, below user's eye level with letters facing you (user will read them upside-down).

Begin by calling out colors, "red, blue, green, yellow, black." User will indicate "yes" by raising his eyebrows when color corresponding to letter desired is called.

Alternatively, point to dots instead of saying names aloud. Especially in a loud room or anywhere where silence is preferred.

After color of letter group is identified, point to each letter until user indicates "yes."

IMPORTANT: Do NOT be afraid guess at a word. Do so early and often—this can save a lot of time.

User will skip niceties like "please" and "thank you" and "would you." He will skip articles (the, a, etc) or conjunctions (and, etc) and other small words (my, is, etc) when he can. The sentence "Would you please wipe my face" becomes "wipe face," which gets the job done.

Punctuation not included. Spaces between words must be inferred by caregiver.

The hashtag indicates numerals, carer speaks "1, 2, ... 9, 0" until "yes" is given.

WRITE letters on screen, don't try to remember them.

If confusion occurs, show user what is written, and ask "correct so far?" If he indicates "no," it may be necessary to erase and begin again.

Exercise patience and DON'T be discouraged!

7. Acknowledgments

Magna Doodle© is the copyrighted name for Cra-Z-Art's product. It may work as well as the Fisher-Price DoodlePro©. I don't know. Reviewers on Amazon.com tend to prefer the Fisher-Price product.

Thanks go to my speech therapist Beau B for his help and encouragement at each change in my communication abilities, to my caregiver Julie B for building my device and for her continuing wonderful care and friendship, and to my wife Joann P for her help using this device and, always, for her patience and awesome loving support!

The device as built

