How Can We Communicate With Our Loved Ones?

This is one of the most frequently asked questions from family members whose loved ones are in the Disorders of Consciousness program. Verbal communication (speaking) often takes much longer to regain, and for some patients, it may never be the same. Our goal is to help families communicate with their loved ones as soon as possible. This is typically done by establishing a nonverbal communication system.

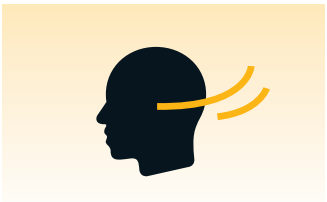
Here is a step-by-step guide on how to establish a nonverbal, yes/no system, either through select motor movements or by shifts in eye gaze:

MOTOR MOVEMENT

Identify a movement your loved one is able to complete fairly consistently. Examples of these movements include: move your left arm, kick your foot, turn your head, show me one finger, etc. It is important to position your loved one in a manner which sets them up for success. This could involve tilting the chair into an upright position to reduce the weight of gravity on their head or supporting their arm in a manner which allows for easier arm movement. If your loved one can complete the movement without your support, then it is often recommended that you do not provide support.

It is important to remember that movements may not always be voluntary and sometimes can happen spontaneously. It is recommended to avoid these movements as a target for communication. For example, if your loved one frequently turns their head to the right, then this would not be a good movement to select, as it may make it harder to determine if they are truly following their given commands.

If you are unsure whether or not the movement you are seeing is intentional and based on your command, try observing your loved one during three different conditions. The first condition is giving your loved one the target command (e.g. move your right arm). The second condition is an opposing command (e.g. hold still). The third condition is a period of observation where nothing is said (i.e. you stay silent and watch for movements). It is best to select a set amount of time to allow them to respond/complete the target movements. The recommended response time is typically 10-15 seconds, and this selected time period would be the same for each of the three conditions. Try to avoid repeating the direction multiple times in order to avoid overstimulation. It is important to make sure you are using the same wording each time for your commands.



Example: You have noted your loved one occasionally turns his/her head to the right.

Target Command (Condition 1): “Turn your head to the right.”
Opposing Command (Condition 2): “Hold still.”
Observation (Condition 3): Quietly observe for a head turn.

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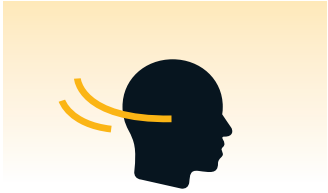
It is recommended you give the three conditions in different orders each time you give them. For example:

Target Command	**Opposing Command**	**Observation**
Observation	**Target Command**	**Opposing Command**
Opposing Command	**Observation**	**Target Command**

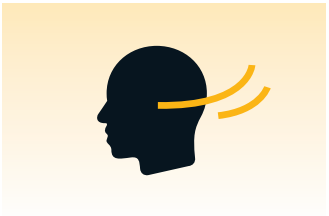
This means, if you give the command three times, then you should also have presented the opposing command three times and observed three times. Complete these trials multiple times throughout the day and/or across several days. Keep a tally of your loved one's responses to identify a pattern. For example:



	Turned Head to the Left	Did NOT Turn Head to the Left
"Turn your head to the left."	I I I	
"Hold Still"	I	I I
Observation		I I I

If you notice your loved one demonstrates the target movement more often to command than during either of the other two conditions (i.e. opposing command and observation), it is more likely that he/she understands what you are asking and is able to voluntarily complete the movement. If this is not the case, then your loved one may not be ready for a communication system yet.

Once you have established two distinct movements, pair one movement with "yes" and the other movement with "no."



Examples of two movement systems:

- Tucks chin down for 'yes' and turns head to the right for 'no'
- Shows one finger for 'yes' and two fingers for 'no'
- Pulls arm in towards their body for 'yes' and pushes arm out for 'no'

Now, have your loved one follow the commands to "show me yes" and "show me no." It is very important that you have two movements, as one cannot communicate effectively if asked to make a movement for 'yes' and hold still for 'no'. Doing so would make it difficult to determine whether or not they are not understanding or if they are just not responding.

It may take several trials to teach them the association between the yes/no movements.

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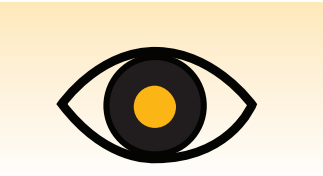

EYE GAZE

Another way your loved one may be able to communicate yes/no is by their eye gazes.

First, identify if your loved one has a preference to looking to one side or the other. (i.e. Do they look more to their right or left? Do you feel like they ignore one side or the other?) Next, you will want to note their eye gaze movements/patterns (i.e. Do they track back and forth; from left to right? Do they track up and down?) Can your loved one control their eyes (i.e. look at the ceiling or look to the left on command)? Based on these observations, you can have them look at yes/no cards. Ensure the cards are spaced enough apart where you are able to clearly see changes in eye gazes/movements.

For example, if you notice your loved one is always looking to the right and can move their eyes up and down, hold the yes/no cards to the right (where they are looking) with the yes card on top and the no card on bottom. Again, make sure the cards are spaced far enough apart to note changes in eye gazes.

We do not recommend using eye blinks, as blinking is a reflexive movement and timing between blinks can vary. If you cannot identify any other movements or eye gazes, then it can be used as a last resort. However, it is important for the yes and/or no to be more than just “a blink.” For example, blink twice for ‘yes’ and hold your eyes closed for ‘no’.

Checking the Accuracy of Yes/No System

It is important to check the accuracy of the established response system. The accuracy of one’s yes/no responses can sometimes be impacted by fatigue, getting “stuck” on a movement (motor perseverations), motor planning (if there is a component of apraxia) and/or understanding of the question (if there is a component of aphasia).

To ensure your loved one’s responses are reliable and/or accurate, it is best to start off by asking your loved one questions you know the answer to and those which are directly related to them and their environment (egocentric).

Example:

Are you a man?
Are you a woman?
Are you married?
Do you have children?
Are you sitting in a chair?

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Once you have established your loved one can answer simple, egocentric questions, then you can move on to questions you may not know the answer to (e.g. 'Are you in pain?'). It is recommended that you ask these questions in a "paired" format. This means these two questions are specifically asked to target the same piece of information. One of the answers should be yes and the other should be no.

Example:

Did you sleep well last night?	Did you sleep poorly last night?
Does your head hurt?	Does your head feel ok?
Do you want to stay in bed?	Do you want to get in the chair?

If your loved one answers yes to both or no to both, try rephrasing the questions and ask again. It is extremely important to use paired questions, especially when the questions are subjective (e.g. related to pain, mood, etc).

If you have any questions, please contact your loved one's speech language pathologist or neuropsychologist for assistance. If you are unsure about anything you are noticing, it is recommended that you videotape what you are noticing to show the doctor.

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Giacino, J. T., Fins, J. J., Laureys, S., & Schiff, N. D. (2014). Disorders of consciousness after acquired brain injury: the state of the science. *Nature Reviews Neurology*, 10(2), 99-114. doi:10.1038/nrneurol.2013.279

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