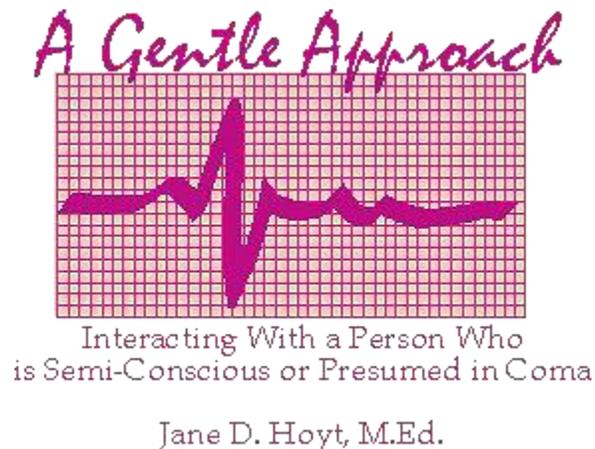


A Gentle Approach



This booklet is not intended as a substitute for consultation with physicians or rehabilitation specialists.

Editorial Preface

Ezra Pound says:

Properly, we should read for power. Man reading should be man intensely alive. The book should be a ball of light in one's hand.

If you ever have a family member or friend who is semiconscious or presumed comatose and are lucky enough to locate a copy of this small book, you will find it a ball of light in your hand.

Here, I speak from experience. Eighteen months ago, my own family found itself in exactly the situation addressed by this booklet. Two distinguished neurologists informed us that the brain injuries a member of our family had sustained precluded the possibility of her ever regaining consciousness. Jane Hoyt kindly gave us an earlier version of the instructions contained here, and those instructions were a precious resource for the family during the months our dear Barbara was consistently scoring in light or deep coma when tested by the medical staff. During those months, the family members at her side and in daily contact with her were treated with unconcealed condescension and impatience by a medical staff convinced that we were sentimentalists clinging to vain hopes. The difficult wait ended with Barbara's finally recovering full consciousness and beginning the long process (still underway) of regaining command over her limbs. As soon as Barbara scored fully conscious on the cognitive assessment test, two things happened: the staff began treating the family with new respect, and they began giving Barbara more attentive care.

The instructions contained here arise out of Jane Hoyt's years of experience working with and helping patients in the dire circumstances addressed by this booklet. On 3 June 1990, the Minneapolis *Star Tribune* published an account of a woman who had been declared irreversibly unconscious by attending physicians but is now, thanks to Jane's remarkable work, a vibrant and active person approaching life with zest and joy.

This little book also helps to illustrate the range projected for the publications that will appear in the Program in Human Rights and Medicine's series, *Working Papers in Law, Medicine, and Philosophy*. The first paper in the series, GEM Anscombe's "Practical Truth," is a searching theoretical investigation in moral philosophy. The present work, by Jane Hoyt, provides practical help of an eminently concrete and down-to-earth sort.

A sister of Barbara who played a central role in her care suggests two instructions that might be added to Jane Hoyt's. First, be prepared to discover that very soon it will seem as though your loved one's ordeal has been lasting *forever*. You may be startled to discover that you can barely remember when the patient was active and well. Second, do not waste time and risk despair by spending hours attempting to imagine how things will be three or five years hence. Tackle the tasks of each day as they arise. Focus on them.

The French have a wonderful saying: "There is no love; there are only deeds of love." This small book teaches its reader how to recognize and perform the deeds that constitute love for an unconscious or semi-conscious patient.

- John M Dolan, Ph.D., Co-Chair
Program in Human Rights & Medicine

Introduction

Over the past twenty years, I have had the privilege and challenge of working with several persons who were presumed to be semi-conscious or in coma. Although days, weeks or even months can go by without clear evidence of response from such a patient, I have personally witnessed or learned about spectacular improvements in certain patients who were wrongly judged "hopeless."

This booklet, based on my experiences and suggestions from others, is intended to help you communicate with an apparently unconscious person. Some patients may not respond as we hope; however, our responses to them continue to matter.

I want to convey my thanks to various persons who assisted me in preparing this booklet for publication: my teaching colleague, David Thofern, who produced the initial electronic version of the text, Rosemarie Dolan, who designed the cover and produced the final text, and Hymie Gordon, MD, James Davies, JD, RN, John M Dolan, PhD, Mary Krumholz, RN, and Mary Senander, who made valuable suggestions that improved the clarity, style, and even the content of the present exposition. (John Dolan proposed four of the rules that appear here.)

You may need to modify the suggestions presented in this booklet to meet the patient's individual needs and preferences. Keep in mind that others may be helped by learning about any successes or insights you achieve.

You may find that caring for or working with a person so totally dependent is emotionally, mentally or physically exhausting. Therefore, I encourage you to find a strong support system for yourself. This will help you remain a source of strength for your family member, friend, or patient.

Jane D Hoyt, M Ed, Chair
Nursing Home Action Group

A Gentle Approach

Interacting With a Person Who
is Semi-Conscious or Presumed in Coma

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1. Above all, talk to the person! Keep encouraging the person to respond, no matter what the apparent extent of her or his disability. Some people who appear unconscious are "locked in" a physical paralysis but actually aware of their surroundings.
2. If you suspect that the person may be in a "locked-in" state, ask the person to move his or her eyes upward. (One of the capacities that can survive damage causing the "locked-in" syndrome is the ability to move one's eyes upward.)
3. Document any signs of consciousness. If the person appears to be in a deep coma, document any signs of movement. This includes sighing, sneezing, coughing, slight finger or toe movements, eye movements during apparent sleep, and so on.
4. If the person moves in any way, try to document what was happening prior to the activity. For example: "John startled and turned to the left when the door to the left slammed shut at 6:15 p.m., 7/12/94." Speculate about what stimulus leads to what response. If possible, repeat a stimulus that appears to produce a response.
5. No matter what the patient does, gently praise that activity. If the person is absolutely still, praise him or her for getting a good rest, but add that perhaps soon he or she will want to move a leg or arm ("like this"--and then gently move the person's limb).
6. Unless the cause of unconsciousness is something horrid (like an assault), gently explain to the person what happened. Do this every day or even more often. Encourage realistic acceptance of the situation as a huge challenge that you are willingly sharing with her or him. Don't try to speculate about the future; rather, encourage facing each hour or day with a positive attitude.
7. Repeatedly remind the person of his or her strengths. For example, "Although right now you can't seem to move yourself much, remember that basically you're in good health, and we're working to help you wake up more," or "Remember you're someone who likes to sing and debate, and those talents may help you regain your speech."
8. Have the person listen to a family member or friend on the telephone. The conversation should last no more than 30 seconds. Then take the phone back and, on behalf of the person, finish the phone call by thanking the friend or family member for calling.
9. Gently and repeatedly remind the person of his or her value to you no matter what the anticipated extent of recovery.
10. Unless you feel hysterical or horribly depressed, share your feelings of sadness, including tears, with the person, but also share your sources of strength. "All of us are very sad about this, but we're working and praying hard with you to help you regain consciousness. You know we'll stick by you through this amazing challenge, no matter what."
11. Wake/sleep cycles of unconscious patients usually are not normal, so do activities with the patient at any time of day or night unless contraindicated by the medical staff or the needs of another resident in the room.
12. If the person seems just to stare, position your face -- or whatever should be the center of attention -- exactly where the person's eyes seem to be looking.

13. In the patient's room, display photographs of her or him prior to hospitalization, but take special care to avoid depressing comparisons. Bring pictures of family and close friends to show the person whenever her or his eyes are open. Hold the picture about one foot from the person's face and slowly move the picture a few inches to each side in case the visual field is impaired.
14. Leave the radio or television on to pleasant programs. Avoid cacophonous or intensely emotional music or subject matter. Check listings in a local newspaper or TV Guide to choose the best station if you will be gone for a long time. (Also consider the possibility that the patient may prefer no radio or television for awhile).
15. If you know the person prefers to be called by a particular nickname or has some other needs that may not be known easily by all staff, put up a neatly lettered sign with the request. Covering it with a "zip-lock" plastic bag will keep it clean.
16. If it feels strange talking to someone presumed to be in coma, tell the person. You might say: "My voice may sound a little strange because I'm still getting used to this challenge we're all facing with you."
17. Use the words, "with you," frequently.
18. When leaving, no matter for how long, *never* say "Good-bye" since that has a ring of finality to it. Instead say, "I'll see you _____" (giving your best guess as to when you'll be back), or "I'm not sure when I can return, but do remember I'll be back with you in thought all the time," or "I'll be back at six ... That's in three hours. Then you and I can watch the news together".
19. If staff members talk about the patient right in front of him or her, gently remark that you would prefer that everyone assume this patient can hear; and, therefore, that the staff please include him or her in the conversation. For example, the doctor might say, "Mary, we've done another test and want to explain the results to you and your family now. I hope that's OK with you. As you may know, we're testing you for any signs that you can hear us...etc."
20. If a doctor or other caregiver focuses only on the patient's weaknesses in a discussion with you, ask what strengths the patient may have. This may be only some vital sign, or the fact that there has been no deterioration in a certain number of days. If the doctor can think of no strengths, help him or her to consider some.
21. If the person makes any sound at all, even just a hiccup or burp, gently tell him or her you're going to guess at what he or she was perhaps trying to say, and then take a good guess: "Maybe you're wondering what's happening right now..."--And then tell the person about recent developments in his or her medical situation (or on the news if you've been listening to it).
22. As you enter the room, knock and reintroduce yourself, even if you left for just moments. "It's just Mary returning from getting a drink in the hall."
23. Whenever you touch the person's body or bump into the bed or drop something, explain what's happening.
24. If you are a close family member or close friend, touch the person frequently on the hand, arm and face. If this friend or relative was not a physically expressive person prior to the current medical condition, say something like, "I'm not sure you can hear me very well, so I'm touching your arm to give you another way to know I'm here close to you".
25. Be sure health caregivers give oral care several times a day to keep stimulating the mouth area. You may want to ask if you can participate in this care.
26. If the person is not ill, that is, if there is no infectious disease, realize this person has a disability and is not sick. Encourage medical staff to think that way too.
27. If the patient is religious, pray with him or her. Tell the person about prayers being said for him or her. Encourage clergy to visit. Ensure that the patient attends chapel if that is physically possible. Be sure that any religious experience is one affirming hope and love and the value of life.
28. If the person has favorite colors, dress in those colors. If she or he may wear personal clothing, bring favorite robes, pajamas and inexpensive jewelry. Fix her or his hair as nicely as possible. If there has been neurosurgery, find some comfortable bonnets or caps for the patient to wear occasionally.

29. If it is medically all right to place a dot of food or drink on the person's tongue, do so with favorite foods. If you are not allowed to do this, be sure the staff knows which flavors the person prefers. Also consider having her or him smell favorite perfumes occasionally. (Remember: If this is done too frequently, the effect will be lost).
30. If the person receives cards, place them in his or her hand(s) as you read them out loud. Display them for staff to notice others' concern for the person. If cards haven't arrived yet, urge people to send them! (Sometimes people do not think of sending a card to an "unconscious" person.)
31. This is usually done by medical staff (whom the patient may not recognize): Gently lift the patient's eyelids while your face is about one foot from the patient's. Explain that you want the person to follow the light of a flashlight in order to check his or her pupils and then slowly move a light from one side to the other about 18 inches from the patient's face. If the patient follows the light, document this and be sure the staff knows, replicates and documents this. If the patient does not respond, tell him or her that the two of you will do this again later since it's an interesting activity.
32. Eat snacks in the patient's room. Tell the person you're hungry and just having a bite to eat. "Perhaps soon I can offer you some, too. Even if you can't chew right now, imagine yourself doing so and who knows, maybe one day you will." Always make such comments with a tone of acceptance about whatever the future may bring.
33. If the person has children, or knows some children, their visiting could be helpful if (and only if) the children would not be scared by the situation. Children who have attended schools have some students with multiple handicaps might handle such a situation well.
34. Gentle animals are often a delight for people with neurological impairments. Always first carefully explain to the patient what he or she is about to experience (perhaps showing pictures of the type of animal to be expected). Of course, permission should be obtained from the nursing staff before animals are brought into a facility.
35. Manicure the person's fingernails, explaining what you are doing. Ask the person to spread out his or her fingers and praise whatever happens, even if you are doing all the work. "Wonderful. Your fingers are nicely relaxed, so we can spread them easily," or "Wonderful. You have your fingers tightly grasping my hand. It's nice that you hold my hand like this, but now I'm going to spread your fingers out so we can give you a nice manicure."
36. Before you use simple items (such as a comb, brush, toothbrush, ribbon, emery board, tweezers, or toenail clippers), place them in the person's hand and mention what you are about to do.
37. If the person has a favorite author, read passages from that author aloud to the person.
38. Be sure the caregivers give "range of motion" therapy several times each day, because neglecting this therapy can lead to severe, permanent contractures. Ask if you can participate in this care. Chat with the patient (and therapist) during therapy.

About the author

Jane Hoyt is Chair of the Nursing Home Action Group, St Paul, Minnesota, which engages in advocacy for the rights of persons with disabilities, primarily through networking with other disability rights organizations, lobbying, and filing amicus briefs in court cases.

Ms. Hoyt helped draft and lobbied for several laws protective of the rights of persons with disabilities including: Vulnerable Adult Protection Act (VAPA), MnStats. 626.557; Revision of the Preamble to the Minnesota Nursing Home Residents Bill of Rights, MnStats. 144.651-144.652; and Amendments to guardianship law, MnStats. 525.539f. She is a former member of the Boards of the United Handicapped Federation and the National Citizens' Coalition for Nursing Home Reform. She served as a member of the Advisory Panel for the Office of Technology Assessment's 1987 project on "Institutional Protocols for Making Decisions about Life-Sustaining Technologies."

For sixteen years (1974 - 1990), Ms. Hoyt was Legal Guardian of her mother, a nursing home resident who had a severe stroke in 1962. She has also been an advocate (1977 - present) for a woman who was for years presumed to be permanently unconscious. In 1990, she was a co-proxy decision maker for a dying elderly nursing home resident.

Since 1968, Ms. Hoyt has been a public school teacher. For the past several years, she has specialized in Health Education. She earned a B.A. degree in psychology at Stanford University and an M.Ed. degree at Harvard University.

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