AFFIDAVIT

STATE OF FLORIDA
COUNTY OF DUVAL

Before me this day personally appeared William Polk Cheshire, Jr., M.D. who, being duly sworn, deposes and says:

I, William Polk Cheshire, Jr., M.D., have personal knowledge of the facts stated in this declaration and, if called as a witness, I could and would testify competently thereto under oath. I declare as follows:

I am a neurologist practicing in the State of Florida and am certified by the American Board of Psychiatry and Neurology. In regard to my educational background, I received an A.B. in biochemical sciences from Princeton University, an M.A. in bioethics from Trinity International University, and an M.D. from West Virginia University. I completed an internship in internal medicine at West Virginia University, a residency in neurology and a pain fellowship at the University of North Carolina.

I am also an appointed volunteer with the Florida statewide Adult Protective Services team, in which capacity I was called on March 1, 2005, to provide an independent and objective medical review of allegations of possible abuse, neglect, or exploitation of Ms. Theresa Marie Schiavo.

Although no one from the Department of Children and Families has inquired about my personal views about treatment decisions in cases of persistent vegetative state (PVS), I would like to disclose that I came into this case with the belief that it can be ethically permissible to discontinue artificially provided nutrition and hydration for persons in a permanent vegetative state. Having now reviewed the relevant facts, having met and observed Ms. Schiavo in person, and having reflected deeply on the moral and ethical issues, I would like to explain why I have changed my mind in regard to this particular case.

In my daily conversations with colleages, I have been interested to hear what others have thought about the issues surrounding this case. I have heard from neurologists, other physicians, nurses, other paramedical professionals, attorneys, ethicists, clergy, geriatricians, teachers, the elderly and the young. I have heard from people of many faiths, Roman Catholic, Protestant, Jewish, and people without a particular faith commitment. Generally, I have found that many people who have thought seriously about this case say that they have been unable to reach a judgment. They acknowledge valid principles on both sides of the arguments, and they recognize the difficulty of ascertaining from the media accurate and complete facts needed to reach a trustworthy conclusion. All agree that this is an extraordinarily difficult case and that the family members on both sides must be suffering greatly.

There is, at the heart of this case, uncertainty regarding the neurologic diagnosis on which treatment decisions have rested. The courts have ruled, on the basis of credible expert testimony, that Terri is permanently in a persistent vegetative state (PVS), which is a

specific neurologic diagnosis meaning wakefulness without awareness. Patients in a persistent vegetative state lack integrated function of the cerebral cortex while retaining involuntary brain stem reflexes that regulate heart rate, digestive, circulatory, sleep and other involuntary bodily functions. Their behaviors are automatic, nonpurposeful, uninhibited reflexes no longer under voluntary control by higher brain centers.

On the other hand, there have been repeated claims that Terri at times seems more responsive, even intentional and interactive. Such observations, if true, would be inconsistent with a diagnosis of PVS, the diagnosis upon which medical and legal decisions have been based. The question thus arises, whether Terri might be in what neurologist call a "minimally conscious state." This question is important, for in making decisions that affect the life and welfare of Terri, one would like to know whether she is aware of her environment, aware of others, aware of her own bodily discomfort, or has thoughts that we would regard as human even if she cannot communicate them to us. As my charge is to investigate the possibility of abuse or neglect, it matters whether Terri would be able to recognize and feel the consequences of abuse or neglect. Some actions might even be unintentionally neglectful if performed by persons unaware of Terri's level of awareness.

There are many behaviors typical for patients in PVS that someone without neurological training could easily mistake as voluntary. The non-neurologist seldom has experience in observing how the brainstem and basal ganglia behave when deprived of input from the cerebral cortex where consciousness is believed to reside. It is quite common for dedicated and caring family members, hoping desperately for a sign from their loved one, to misinterpret these reflexes as evidence of communication. Such behaviors can include involuntary arousal, eye opening, random eye movements (nystagmus and horizontal scanning), brief eye contact, reflexive withdrawal from a noxious stimulus, movement of the lips or mouth or turning of the head in response to oral stimulation (suck and rooting reflexes which also occur in newborn infants), spontaneous grimmacing or smiling or displays of emotion (affective release, usually a momentary gesture), and certain other nonsustained behaviors usually not seen in healthy adults. Some of the video clips of Terri Schiavo that have been presented in the media display such involuntary behaviors. It is the responsibility of neurologists in cases like this to educate family members so that they will not develop a false hope of recovery.

Where is the neurologist in this case at this time? It is my understanding that nearly three years have passed since Terri has had the benefit of neurologic consultation. How, then, are we to be certain about her current neurologic status? There remain, in fact, huge uncertainties in regard to Terri's true neurologic status. Although exploring such questions may be uncomfortable, I believe that medicine has an obligation to ascertain the neurological facts to the highest possible degree of certainty.

Some studies have indicated, upon follow-up over time, a high rate of false initial diagnosis of PVS.[1,2] Furthermore, the diagnosis of minimally conscious state had not yet

[1] Andrews K, Murphy L, Munday R, et al. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. British Medical Journal 1996; 313: 13-16.

become standard parlance in the field of neurology at the time of Terri's initial diagnosis. The minimally conscious state has emerged as a distinct diagnostic entity only within the last few years.[3,4]

Although Terri has undergone structural imaging studies of her brain (such as the CT scan which I have reviewed), she has not, to my knowledge, undergone functional imaging studies, such as positron emission tomography (PET) or functional magnetic resonance imaging (fMRI). The structural studies have shown substantial loss of cerebral cortex which was deprived of blood supply for more than 40 minutes in 1990, but there does remain some cerebral cortex.

New facts have come to light in the last few years that should be weighed in the neurologic assessment of Terri Schiavo. Significant strides have been made in the scientific understanding of PVS and minimally conscious states since Terri last underwent neurologic evaluation. As usually happens in science, the newest evidence is prompting the medical community to think about this field in new ways. With new evidence comes fresh appreciation for what is actually happening in the brains of persons with profound cognitive impairment. And there is a great deal more to be learned.

Of particular interest was the fMRI study published just this year by Schiff and colleagues of two patients at Cornell University. When these patients, who had been diagnosed as being in a minimally conscious state, listened to narratives read by a familiar person, large areas of the cerebral cortex normally involved in language recognition and processing lit up. The presence of metabolic activity in those brain cells was far more than expected given their inability to follow simple instructions reliably or otherwise demonstrate at the bedside evidence of comprehension or communication.[5] From this study one may conclude that there is still a great deal we do not know about what previously unsuspected cerebral cortex functions may yet be occurring in the minds of persons who have sustained profound brain damage and are no longer able to communicate outwardly what their thoughts may be.

Based on my review of extensive medical records documenting Terri's care over the years, on my personal observations of Terri, and on my observations of Terri's responses in the many hours of videotapes taken in 2002, she demonstrates a number of behaviors that I believe cast a reasonable doubt on the prior diagnosis of PVS. These include:

1. Her behavior is frequently context-specific. For example, her facial expression brightens and she smiles in reponse to the voice of familiar persons such as her parents or

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[2] Childs NL, Mercer WN, Childs HW. Accuracy of diagnosis of persistent vegetative state. Neurology 1993; 43: 1465-1467.

[3] Giacino JT, Ashwal S, Childs N, Cranford R, Jennett B, Katz DI, Kelly JP, Rosenberg JH, Whyte J, Zafonte RD, Zasler ND. The minimally conscious state: definition and diagnostic criteria. Neurology 2002; 58: 349-353.

[4] Laureys S, Owen AM, Schiff ND. Brain function in coma, vegetative state, and related disorders. Lancet Neurology 2004; 3: 537-546.

[5] Schiff ND, Rodriguez-Moreno D, Kamal A, Kim KHS, Giacino JT, Plum F, Hirsch J. fMRI reveals large-scale network activation in minimally conscious patients. Neurology 2004; 64: 514-523.

her nurse. Her agitation subsides and her facial demeanor softens when quiet music is played. When jubilant piano music is played, her face brightens, she lifts her eyebrows, smiles, and even laughs. Her lateral gaze toward the tape player is sustained for many minutes. Several times I witnessed Terri briefly, albeit inconsistently, laugh in response to a humorous comment someone in the room had made. I did not see her laugh in the absence of someone else's laughter.

2. Although she does not seem to track or follow visual objects consistently or for long periods of time, she does fixate her gaze on colorful objects or human faces for some 15 seconds at a time and occasionally follows with her eyes at least briefly as these objects move from side to side. When I first walked into her room, she immediately turned her head toward me and looked directly at my face. There was a look of curiosity or expectation in her expression, and she maintained eye contact for about half a minute. Later, when she again looked at me, she brought her lips together as if to pronounce the letter "O," and although for a moment it appeared that she might be making an intentional effort to speak, her face then fell blank, and no words came out.

3. Although I did not hear Terri utter distinct words, she demonstrates emotional expressivity by her use of single syllable vocalizations such as "ah," making cooing sounds, or by expressing gutteral sounds of annoyance or moaning appropriate to the context of the situation. The context-specific range and variability of her vocalizations suggests at least a reasonable probability of the processing of emotional thought within her brain. There have been reports of Terri rarely using actual words specific to her situational context. The July 25, 2003 affidavit of speech pathologist Sara Green Mele, MS, on page 6, reads, "The records of Mediplex reflect the fact that she has said 'stop' in apparent response to a medical procedure being done to her." The Adult Protective Services team has been unable to retrieve those original medical records in this instance.

4. Although Terri has not consistently followed commands, there appear to be some notable exceptions. In the taped examination by Dr. Hammesfahr from 2002, when asked to close her eyes she began to blink repeatedly. Although it was unclear whether she squeezed her grip when asked, she did appear to raise her right leg four times in succession each time she was asked to do so. Rehabilitation notes from 1991 indicated that she tracked inconsistently, and although did not develop a yes/no communication system, did follow some commands inconsistently and demonstrated good eye contact to family members.

5. There is a remarkable moment in the videotape of the September 3, 2002 examination by Dr. Hammesfahr that seemed to go unnoticed at the time. At 2:44 p.m., Dr. Hammesfahr had just turned Terri onto her right side to examine her back with a painful sharp stimulus (a sharp piece of wood), to which Terri had responded with signs of discomfort. Well after he ceased applying the stimulus and had returned Terri to a comfortable position, he says to her parents, "So, we're going to have to roll her over...." Immediately Terri cries. She vocalizes a crying sound, "Ugh, ha, ha, ha," presses her eyebrows together, and sadly grimmaces. It is important to note that, at that moment, no one is touching Terri or causing actual pain. Rather, she appears to comprehend the

meaning of Dr. Hammesfahr's comment and signals her *anticipation* of pain. This response suggests some degree of language processing and interpretation at the level of the cerebral cortex. It also suggests that she may be aware of pain beyond what could be explained by simple reflex withdrawal.

6. According to the definition of PVS published by the American Academy of Neurology, "persistent vegetative state patients do not have the capacity to experience pain or suffering. Pain and suffering are attributes of consciousness requiring cerebral cortical functioning, and patients who are permanently and completely unconscious cannot experience these symptoms."[6] And yet, in my review of Terri's medical records, pain issues keep surfacing. The nurses at Woodside Hospice told us that she often has pain with menstrual cramps. Menstrual flow is associated with agitation, repeated or sustained moaning, facial grimmacing, limb posturing, and facial flushing, all of which subside once she is given ibuprofen. Some of the records document moaning, crying, and other painful behavior in the setting of urinary tract infections.

The neurologic literature has traditionally distinguished between, on one hand, the patterned reflex responses resulting from mere activation of spinal and brain stem pain circuits in PVS and, on the other hand, conscious awareness of pain which requires participation by the cerebral cortex, including interpretation, felt emotional awareness, and volitional avoidance behavior that would not be expected to occur in PVS. Recent studies suggest, however, that such a distinction may not be the clear bright line previously imagined. Laureys and colleagues demonstrated, for example, neuronal processing activity in the primary somatosensory area of the cerebral cortex in response to noxious stimuli in patients with PVS.[7]

Regardless of what objective measures may be available, the conscious experience of pain remains a phenomenon directly discernable only through introspective awareness, which means that one cannot directly know with certainty the pain another person experiences. If, as the authors of a consensus statement on PVS wrote in 1994, there are some cases in which "the absence of a response cannot be taken as proof of the absence of consciousness,"[8] then should not the clear presence of pain be given serious consideration as possibly indicating conscious awareness in Terri Schiavo? The fact that Terri's responses to pain have been context-specific, sustained, and, in the taped example I cited, in response to a spoken sentence, all suggest the possibility that she may be at some level consciously aware of pain.

Terri has received analgesic medication as treatment for her pain behavior. This seems to be appropriate medical treatment if one cannot know with certainty whether her behavior indicates conscious awareness of pain. If a patient behaves as if in pain, then the

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[6] http://www.aan.com/about/ethics/109556.pdf

[7] Laureys S, Faymonville ME, Peigneux P, Damas P, Lambermont B, Del Fiore G, Degueldre C, Aerts J, Luxen A, Franck G, Lamy M, Moonen G, Maquet P. Cortical processing of noxious somatosensory stimuli in the persistent vegetative state. Neuroimage 2002; 17: 732-741.

[8] Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state – second of two parts. New England Journal of Medicine 1994; 330: 1572-1579.

clinically prudent and compassionate response, when in doubt, is to treat the pain. If a patient behaves at times as though there may be some remnant of conscious awareness, then the clinically prudent and compassionate response, when in doubt, is to treat that patient with respect and care. If Terri is consciously aware of pain, and therefore is capable of suffering, then her diagnosis of PVS may be tragically mistaken.

7. To enter the room of Terri Schiavo is nothing like entering the room of a patient who is comatose or brain-dead or in some neurological sense no longer there. Although Terri did not demonstrate during our 90 minute visit compelling evidence of verbalization, conscious awareness, or volitional behavior, yet the visitor has the distinct sense of the presence of a living human being who seems at some level to be aware of some things around her.

As I looked at Terri, and she gazed directly back at me, I asked myself whether, if I were her attending physician, I could in good conscience withdraw her feeding and hydration. No, I could not. I could not withdraw life support if I were asked. I could not withhold life-sustaining nutrition and hydration from this beautiful lady whose face brightens in the presence of others.

The neurologic signs are in many ways ambiguous. There is no guarantee that more sophisticated testing would definitively resolve that ambiguity to everyone's satisfaction. There would be value, I think, in obtaining a functional MRI scan if that is possible.

This situation differs fundamentally from end-of-life scenarios where it is appropriate to withdraw life-sustaining medical interventions that no longer benefit or are burdensome to patients in the terminal stages of illness. Terri's feeding tube is not a burden to her. It is not painful, is not infected, is not eroding her stomach lining or causing any medical complications. But for the decision to withdraw her feeding tube, Terri cannot be considered medically terminal. But for the withdrawal of food and water, she would not die.

In summary, Terri Schiavo demonstrates behaviors in a variety of cognitive domains that call into question the previous neurologic diagnosis of persistent vegetative state. Specifically, she has demonstrated behaviors that are context-specific, sustained, and indicative of cerebral cortical processing that, upon careful neurologic consideration, would not be expected in a persistent vegetative state.

Based on this evidence, I believe that, within a reasonable degree of medical certainty, there is a greater likelihood that Terri is in a minimally conscious state than a persistent vegetative state. This distinction makes an enormous difference in making ethical decisions on Terri's behalf. If Terri is sufficiently aware of her surroundings that she can feel pleasure and suffer, if she is capable of understanding to some degree how she is being treated, then in my judgment it would be wrong to bring about her death by withdrawing food and water.

At the time of this writing, Terri Schiavo, as the result of decisions based on what I have argued to be a faulty diagnosis of persistent vegetative state, has been without food or water for 5 days. She is thus at risk of death or serious injury unless the provision of food and water can be restored. Terri Schiavo lacks the capacity to consent to emergency protective services and must trust others to act on her behalf. If she were to be transferred to another facility, it would be medically necessary first to initiate hydration and ensure that her serum electrolytes are within normal values.

How medicine and society choose to think about Terri Schiavo will influence what kind of people we will be as we evaluate and respond to the needs of the most vulnerable people among us. When serious doubts exist as to whether a cognitively impaired person is or is not consciously aware, even if these doubts cannot be conclusively resolved, it is better to err on the side of protecting vulnerable life.

Respectfully submitted,

William Polk Cheshire, Jr., M.D., M.A., F.A.A.N.

William P. Cheshire Jr.

Sworn to (or affirmed) and subscribed before me this 23 day of March, 2005, by William Polk Cheshire Jr. M.D.

Personally known ✓ OR
Produced Identification _____
Type of Identification Produced _____

Christine A. Lent

CHRISTINE A. LENT
MY COMMISSION # DD 055758
EXPIRES: September 22, 2007
Bonded Thru Budget Notary Services