

## Palliative Dementia Care

Even though verbal communication may be lost, there are techniques that can be employed when caring for residents in coma or end-stage dementia.

By Irene Barnes and Stan Tomandl

# Coma Care in End Stage Dementia

Being with someone in Coma is about love and connection and a belief that as long as there is breath there is consciousness. Those of us drawn to be with people in these times, seek a deeper way of communicating with people in far away places. These techniques may sound at times dry, but they can open up worlds between you and the one you love and care for. They can bring relief and excitement to a relationship that has seemed one sided, and give comfort to someone who is normally left in what may appear to be a "peaceful" state with medications to quiet the pain. Please join us in the study of coma and end of life dementia care and development of connection in one of our most crucial times of yearning to be understood and loved - near death. Thank you.

Many caregivers have difficulty understanding or providing care for persons no longer able to communicate verbally. The following ideas can be applied to working with people in coma, the dying process, or in end stage dementia. Helping bring awareness is about love and care of those in remote states of consciousness.

Stan Tomandl in his work with people in coma and/or palliative situations finds:

Helping people complete communications, no matter how small, assists them to complete their lives near death. We as helpers do not need to know the content of their communication. Our task is to help the *other* person become aware of their own content and then complete their process as far as possible. (Tomandl, 1991, pg.25)

He goes on to state the following:

- Everything can be understood as information at one level.
- People are persistent in communicating information and will continue to send messages until those messages get received. Hence perseverations continue until communication is complete.

*A man lies in coma with his left hand slightly curled, for days. I wonder about this small cue. His curled fingers attempt to send a message. I put my fingers on his left palm. He bends his fingers lightly around mine. This is positive feedback. I squeeze slightly in return. He squeezes harder. I squeeze back. He now hangs on for dear life. I say, "You're squeezing with your left hand, go ahead as long as you want." He hangs on for two minutes. As he begins to relax, I relax also, and report to him what he is doing. I remove my hand. He no longer curls his fingers. He has completed a communication with himself, even though I do not know about the content of his communication.* (Tomandl, 1991, pg. 24)

- Blank access interventions are statements without content. They support clients without projecting onto them.

*Someone may presume a person is sad when they are crying. They may be sad, angry, frustrated, happy, or touched. A blank access intervention, a non-judgmental statement, would be "Water is coming from your eyes." These types of statements are useful because they can increase clients' awareness by reflecting and amplifying their experience without confusing them by attempting to guess what they feel. Blank access interventions can bring immense relief to those who are only partially conscious.* (Tomandl, 1991, page 26-27)

- Declarative statements or phrases work better than questions. Your clients can digest a declaration more quickly than a question. Questions usually take clients away from their immediate experiences and send them on a roundabout thought trail that slows their awareness.

Generic Blank Access Statements:

*"Notice what you are experiencing / seeing / hearing / feeling / moving." (Tomandl, 1991, page 27)*

- People in comatose states have left their normal states of awareness and cannot communicate by "normal" means. As helpers, we can temporarily aid patients to gain more awareness of what is happening by commenting on the cues we are observing.  
Cues are small or seemingly insignificant bits of information. These include twitches, jerks, scratching, clutching, gurgles, wheezes, sighs, coughs, swallows, eye movements, tears, etc. Parents do this all the time with babies. Work with the strongest cue that you notice in the moment.
- Channels through which clients communicate are
  - \* Visual Cues: upper chest breathing, looking up; turning their head and/or trying to focus; reaching for something; fluttering of eyelids; rubbing their eyes.
  - \* Hearing Cues: eyes looking sideways or eyes moving back and forth in large slow movements; head cocked to one side; mid-chest breathing. They may be hearing internal or external voices or sounds.  
*Please assume comatose folks can hear what you say.*
  - \* Sound Cues: mouth, jaw, lip and throat movements; groans; grunts; snoring; babbling; screams; gurgles; etc. As an awareness helper, repeat their sounds back to them, longer and louder, this intervention encourages your client to try and form words.
  - \* Body Sensation Cues: lower stomach breathing; looking down towards their feet; rapid eye movement (REM); rubbing scratching, stroking; patient's hands placed on their own body.
  - \* Touch: People in coma states are very sensitive. They can be surprised and scared easily by outside stimuli, even if they show little outer reaction. Approach respectfully, for instance, tell the person that, "In two breaths I am going to put my hand on your left forearm. Here it comes." (Tomandl, 1991, page 38-39)
  - \* Relationship Indications: When patients make eye contact, or turn their heads, even minutely towards you when you speak.
  - \* Couple Communication Channels: As with most of us in normal states of consciousness, people in altered consciousness often perceive and communicate in two or more channels at once. If someone's eye lids are flickering and they are breathing into their lower stomach, you might say, "Go ahead and see what you are feeling," or "Feel what you are seeing."

◆ *Positive Feedback and Negative Feedback:*

*Stan goes on to say: An increase or decrease in number or intensity of cues shows positive feedback. No change in cues indicates negative feedback. Try different interventions to search for positive feedback. (Tomandl, 1991, page 32)*

Leaving:

*When you feel you are tired or need to leave, end the visit with telling the person when you will return, and if you feel comfortable doing so a hug, kiss, or an extra touch might be appropriate, especially if you feel you may not see the person again. (Tomandl, 1991, page 43)*

References:

- Tomandl, Stan (1991) *COMA WORK AND PALLIATIVE CARE: An Introductory Communication Skills Manual for Supporting People Living in Coma Near Death*. Victoria, B.C.: [www.comacommunication.com](http://www.comacommunication.com)
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Stan Tomandl, MA, PWD, forms one half of a partnership with his wife Ann Jacob in Coma Communication and Process Oriented Facilitation in Victoria, BC. They teach caregivers and family members, and work with people in coma/delirium/dementia states, locally, across North America, and around the world by telephone and video Skype conference. ~ Coma Communication and Process Oriented Facilitation  
Phone 250-383-5677 ~ [annstan@comacommunication.com](mailto:annstan@comacommunication.com) ~ [www.comacommunication.com](http://www.comacommunication.com)

Irene Barnes, RN, BSN, has over 20 years experience as a dementia caregiver. She currently works as a community nurse to long term facilities in the Greater Victoria's Outreach Team, focusing on mental health issues for seniors. Irene is an instructor in the Continuing Care Department, Camosun College, Victoria, BC.