Why Do We Take Care of Others? In End-of-Life Care.
by Gerard S Brungardt, MD, BeL

We are all persons in need. So then the question for us as health care workers is "Do we recognize this need in the persons we are caring for… and then, do we provide that need?"

I take care of people towards the end-of-life. I have many cases I could use, I do this on a regular basis, but this is a good example. This gentleman had a lymphoma with a tracheo-esophageal fistula – a hole between his breathing pipe and his swallowing tube – which they had stented. It was not controlling things 100%, but there was a stent in there. He was getting PEG tube (gastrostomy tube) with full feeding, he was getting over 2000 calories (2000 cc) per day of feeding. When he came to us he complained of diarrhea, nausea and vomiting, abdominal pain, dyspnea and cough. He was miserable. He was absolutely miserable. And, of course, he and the family were looking to us to make him more comfortable.

I was convinced that the majority of his symptoms were because he was getting too much food and water, he was just getting way too much. Now the trick in this situation is convincing the patient and family (now the patient is usually pretty easy to convince) but the family of the idea of backing off on his food and water. Because it's very common in this situation for several of the doctors in their white coats to have said to the effect "If you ever stop the PEG tube – this food and water – he will die," or something to that effect. So the negotiation point in this case, as is often the case, was "He can have all he wants, we'll put a syringe next to his bedside, and you can shoot it in." He took 300-400 cc/day. So once we did that all of those symptoms resolved in less than 24 hours. He was just getting way too much.

His needs, his true needs were not being recognized. He was just being plugged in to the equation. "Are you full? Who told you?" Only nobody asked him if he was full or not. They just started dumping it in. He got plugged into the equations of so much weight and age and everything else and they got 2200 cc so if we can get it through that PEG tube we're going to get it through.

Recognized Basic Human Needs include food and water, be clean, warm and dry, and finally having clothing and shelter.

A lot of this has really caused me to reflect on basic human needs. What are our basic human needs? For a long time we really haven't had to reflect on that. And one of the things I've done - I've asked different hospitals, Catholic hospital systems and friends around the country "In your documents, in your policies and procedures, where do you say (at St. Mary's Catholic Hospital) 'We will provide these basic needs.'?" Now as near as I can tell I have yet to find where it says that. And I would truly appreciate if somebody could send me if they do. And my general sense is, and as I've talked to people, that's because they are so basic and so elementary that we don't

feel a need to write it down – that we need to do that. In a sense it's too bad we are having to do this but if we return to that it might help provide things.

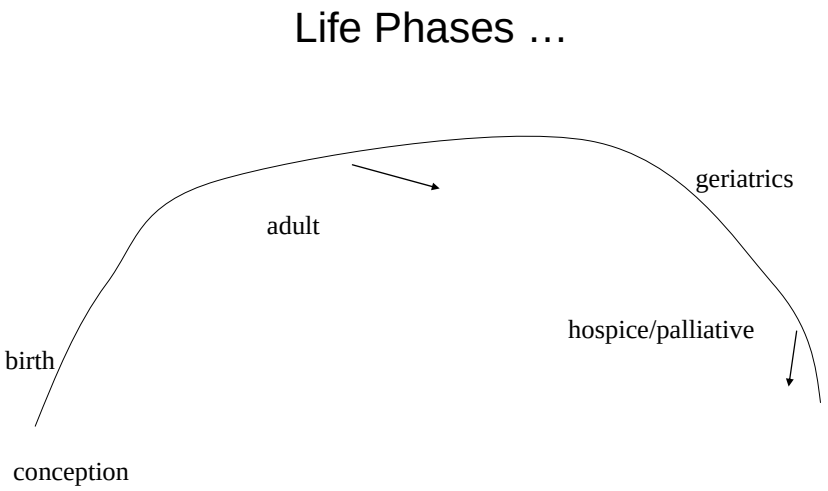
Here some articles from the Geneva Convention in 1950:

Article 25 The premises provided for the use of prisoners of war … shall be entirely protected from dampness and adequately heated and lighted.
Article 26 The basic daily food rations shall be sufficient in quantity, quality and variety … Sufficient drinking water shall be supplied.
Article 27 Clothing, underwear and footwear shall be supplied to prisoners of war.
Article 29 … sanitary measures necessary to ensure the cleanliness and healthfulness … which conform to the rules of hygiene.

This is one of the places I have found this. There was this magic time after World War II (and before the Cold War) when the whole world agreed that we need to write down how we should treat each other and a variety of these incredible documents came out. Mary Ann Glendon has a wonderful book about Eleanor Roosevelt's involvement in human rights and it's a really nice read (1). And in these articles is a place where we have defined how we should treat each other - as a brotherhood of the world - how we're going to treat each other and these basic human needs that we referred to earlier.

A couple of other places I've run into them. Mother Teresa and her rules for the Missionaries of Charity "First get them clean. Tend to their little wants." John Paul II in his allocution on patients in the vegetative state "the sick person still has the right to basic health care" "… nutrition, hydration …" some of these basic needs.

This is another case the internal medicine residents presented to me at a case conference just a few weeks ago. An 84 gentleman with a long history of dementia was progressively declining. He was admitted to the acute care system for work-up of mental status changes. And again at some point somebody did their calculations and plugged him into the formula and decided he needed a couple of thousand calories a day. Well, he wasn't eating that volitionally so they got a Dobhoff tube in. He was fighting that – he had to be restrained – through this whole process he aspirated and died of that.



In the reported figure there is a model I've found helpful in teaching this concept - the idea I'm trying to get across. This is a life phase, a life curve – from conception to the end of life. One of the problems I think is that we all – Internal Medicine, Family Medicine – get trained in the middle part of the curve and we then take what we've learned and apply it - we see an adult and we apply it. Well, the trouble is that if the patients is towards the end of the curve, what we've been taught up here in the middle of the curve doesn't apply and we need to re-adjust, re-think our medical care. We need to recognize what the new reality is – of those patients.

What are the needs of people towards the end of life - the nutrition and hydration needs of people toward the end-of-life? There is a really nice summary for you all from the American Journal of Gastroenterology (2) that summarized 40 some studies on nutrition-hydration and basically did not find that getting 2000 some calories a day into somebody that's dying is helpful.

Approach to eating at end of life should include one food at a time, finger foods, adjusting textures and providing food supplements, working on consistency/texture/position to reduce aspiration and using cold, frozen foods.

What is helpful in end-of-life? Their needs change - food and water requirements - it looks very much like a baby doesn't it? It very much mirrors the beginning of life – and that's one thing I tell patients and families – that's very helpful for them to get an idea. They're not going to eat three square meals a day; they're not going to McDonalds and 'super-size' it. That's not where they're at anymore … in their journey. And it's a lot more like a child.

So gentle hand feeding is how it's referred to in the literature. See the example of "The death of St. Francis who refused "extraordinary" treatment from his doctors and had stopped eating.

However, Lady Jacoba, his friend, had come from Rome with his favorite almond cookies. He ate little bits of these cookies from her hand before he died. Perhaps it was a foretaste of what we are all promised in Christ Jesus."

The best people I know who can do this - truly brilliantly do this - are hospice home health aids - entry level hospice nurse aids. I always - when I'm making rounds and I go in and I know there's a 'hot' nutrition-hydration thing - the yuppies with their internet they want that PEG tube in their dying loved one. I always make sure I have one of our health care aids with me. Because the question always comes "Well what should we do? Are you just going to starve them to death?" No, no … we're going to give them what they need. "Well how do we know what they need?" And that's when I bring the health care aid and "Well Mary here knows really well". She is magic … beautiful … at sensing the patient's need and providing that. And again in much the same way a mom knows when her baby is full. Mom can sense this. I can't sense this.

There are lots of other examples in this theme of basic needs. I've been using nutrition-hydration as an example. Oral care - I'd be curious to take a survey of you all. Our oral care in our community over the past 10-15 years has plummeted. It's shameful. How patients come to us with … they've had no oral care … thick, caked … horrible mouth care. It's no wonder they cannot enjoy what it is they may be able to enjoy. They can't even enjoy it if you give it to them - their mouth is in such horrible shape. And there are a lot of reasons for that. I suspect you all can guess some of those reasons - staffing ratios in the hospital and priorities and other things in the hospital.

And so the key to all this is recognizing these basic needs. Not what we've decided or what power has decided given our necessarily limited models. And like the Good Samaritan recognize the humanity in the person - in their "I" - and provide these basic needs. Once we provide these basic needs - once they are warm, dry, fed, they feel clean - They have this dignity restored to them. They're then free to do the work - the real work they need to do - the relationship work. Balducci has a real nice a beautiful article which discusses more – once those basic needs are met - the importance of the things that are left to do then (3).

A passage from Pope Benedict's talk to physicians last fall (4) serves as a good summary of what I'm trying to say today. Contemporary medicine's focus on curing – fixing "has created a new risk: that of abandoning the patient as soon as the impossibility of obtaining appreciable results becomes apparent." But … "his suffering can be alleviated" … and we can "accompany him on his way".

1. Glendon MA. A world made new: Eleanor Roosevelt and the Universal Declaration of Human Rights, Random House, 2001)
2. Korez RL, Avenell A, Lipman TO, Braunschweig CL, Milne AC. 2007 Does Enteral Nutrition Affect Clinical Outcome? A Systematic Review of the Randomized Trials Am J Gastroenterol;102:412–429
3. Balducci L 2008 And a Time to Die. J of Med and Pers 6(3): 99–103
4. BXVI Address to participants in the National Congress of the Italian Surgery Society, 20 October 2008