



ASL is our 1st language
English is our 2nd language

Reading and writing in English is
at best
challenging if not overwhelming



Forcing a patient to communicate in English

- increases feelings of inadequacy
- increases anxiety
- inhibits self expression
- diminishes sense of dignity



ASL in the 21st Century

- 3rd most used language
- 2nd most requested interpreter
- *not* recognized by US government
- *not* listed in US Census



Minority health classifications
are by ethnic and racial groups

impact on Deaf population—
Exclusion from

- minority health funding sources
- national health research agenda
- cultural competency training of health professionals



Deaf Hospice Education & Volunteer Program (DHEP)

"Anytime we are able to get health information in our language, we will show up!"

Founding member of DHEP,

Former President of Minnesota Deaf Senior Citizens



In 8 yrs. DHEP developed

- 45 min. video about healthcare directives and hospice care in American Sign Language (ASL)
- User-friendly reference materials for healthcare providers and Deaf patients
- Deaf-friendly Healthcare Directive booklet
- End-of-life care survey research with 130 Deaf senior citizens



Something big is happening
in the Deaf community!

Cultural change
powered by access
to health information.



How are we different from other minority groups?

- 95% all Deaf people have hearing parents and most family members do not sign
- Culture transmitted horizontally
- Impact of residential schools
- Language deprivation unique to Deaf
- No access to incidental information



What happens when the patient is the hospice team's first Deaf patient?

"Health professionals are nervous and unsure how to communicate".



Myths and Misunderstandings

Some think the Deaf can lip read - not true
*only 30% of the English language
is readable on the lips*

Nurse uses pain chart with "smiley faces"
*ASL has grammatically governed
facial expressions that give these
same faces a completely different
meaning.*



How has DHEP made a difference?

Added three people to the hospice team

- Interpreter
- Deaf Community Health Worker
- Deaf Hospice Volunteer



Case Studies

- Cristina, 29 yrs. old, colon cancer
- Brigit, caregiver for her husband
- Lorna, nursing home, hearing family
- Caroline, 93 yrs. old, in nursing home daughter certified interpreter

PAIN

Hospice and palliative care professionals receive special training in pain management. They prescribe medications to make patients more comfortable. Sometime pain that does not go away stops people from being able to live with self-respect and dignity.

? EMERGENCY Do - WHAT? CALL



- Always call the nurse if any of these happen:
- Person is seeing things that are not there. Sometimes people see insects. (Hallucinations)
- Person suddenly is confused.
- Severe trembling, can't stop muscles from shaking, seizures.
- Feet or lower part of legs are numb or tingle.
- Person feels she needs to urinate.
- Person does not have a bowel movement.
- Person feels like she might vomit (nausea).
- Person has itching, skin rash, or swelling.
- Person has ringing or buzzing in the ears.

to caregivers

important that the person on hospice...
 on who has the pain can describe...
 people have had very bad exper...
 els you do not accept what she...
 suffering.

A DEAF PERSON'S WORLDVIEW IS DIFFERENT

For Deaf people the poles of everyday life are the language and ways of the community within the language and ways of others, the English-speaking society of North America.

"From the Cultural to the Bicultural" Carol Padden in Cultural and Language Diversity and the Deaf Experience 1997, Cambridge University Press, Ed. (The Perspectives)

▶ If you ask a Deaf person, "Do you have some hearing?" Do not assume the reply means the same to you as it does to the Deaf person.

- A hearing person who is hard of hearing means... → the person hears a lot with some hearing loss.
- A culturally Deaf person who is Hard of Hearing means... → the person hears only a little with LOTS of hearing loss.
- For many Deaf people (even Deaf people who wear hearing aids) hearing can mean... → the person hears sounds but can not understand speech or, may recognize hard consonants but not soft vowels.

LIP READING

If you ask a Deaf person, "Do you lipread?" and they say, "Some," it usually means what Deaf... this means a person may try to figure out the words by counting how many syllables he saw on...

HEALTHCARE ENCOUNTERING DIFFERENCES IN MEANING

Deaf people talk with their **HANDS** and **FACE**. They listen with their **EYES**. They watch facial expressions. They need good lighting to hear. Deafness is NOT related to intelligence. Access to health information in a language BEST understood by patients will increase their understanding of medical terms. This is true for BOTH deaf people and people whose second language is English.

Deaf people say:

- LOOK at ME not at our interpreter, when speaking to me.
- ALWAYS have a qualified interpreter present.
- DO NOT USE my hearing aid as an interpreter.

Why?

- It is respectful and it helps to build trust.
- It is the ONLY way to ensure accurate CLEAR communication.
- It is unfair to my child. My child is there as a family member not as a trained or qualified interpreter. Would you want your child to interpret for you?
- They do not qualify as interpreters under the Americans with Disabilities Act (ADA), and cannot be expected to remain objective and impartial.

CULTURAL SUGGESTIONS

- A quick harder tap can mean an emergency, and this can be frightening.
- Alert by the intercom system can help remind staff they must go to the room in person.
- If necessary, try to allow room for hands to move, or to putting tape over someone's mouth.
- Leaves vulner...



best practice guidelines are field tested
with hospice organizations in Minnesota.

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They will be available for purchase in
Winter of 2008.

For notification of release please
send contact information to
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