



Patient-Provider Relationships: Is the Patient a Better Driver?

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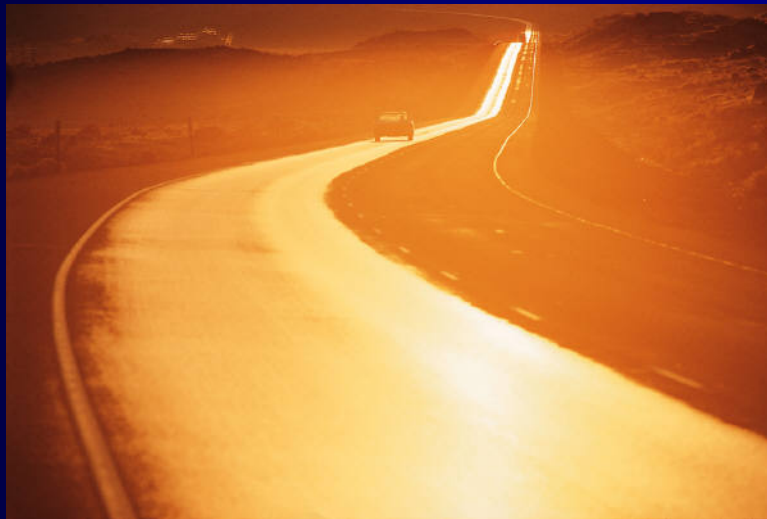
Executive Director, Medical Education Institute

Director, Life Options Rehabilitation Program

Is the Typical Patient a Better Driver?

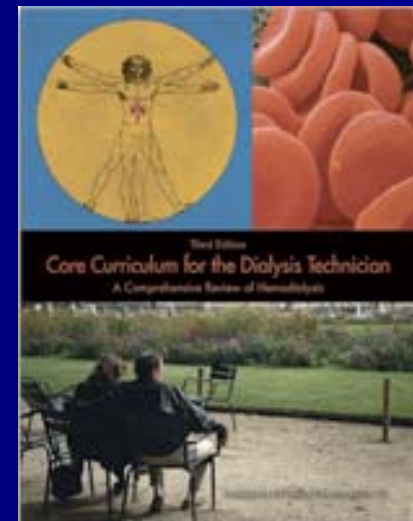
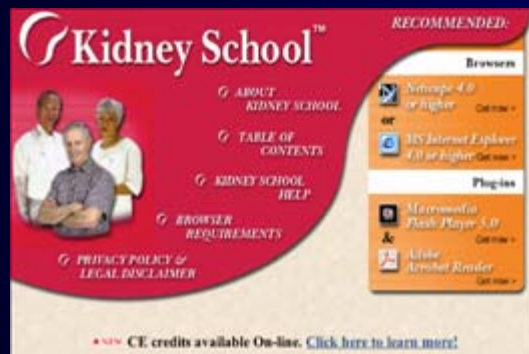
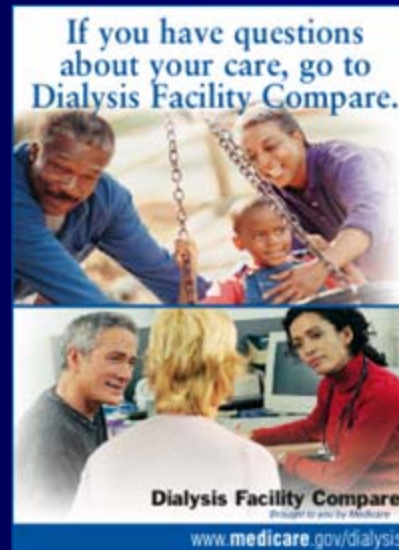
☐ Yes

☐ No



Medical Education Institute

- MEI has developed or worked on:





What We'll Cover

- Expert patients
- Communication & health literacy
- Autonomy
- Educating for Self-management



“Begin with the end in mind”

Steven Covey

Goal: Expert Patients

“I enjoy making graphs out of my lab test data! I like to see how the values have changed over the years for the different labs. I also keep track of and chart my weight gains and losses.”

33 year hemodialysis patient



Goal: Expert Patients

“My iron and Hgb are well within the standards, but the Hgb is not high enough for me. A man’s Hgb (by the charts) should be higher, because of the relative different body mass and activity levels. The standards are not always correct. I’m 5’10” and 172 lbs. I just don’t feel well unless my Hgb is over 13!”

Hemodialysis patient

Goal: Expert Patients

“Over the years (13 on hemo) I have asked for time increases (from 2.25 hours to 3.0 hours) and for reduced blood flow rates (500 to 450). I made my requests always saying that if my labs did not 'prove' my requests as valid, I would consider the less time, higher blood flows. Well, my URR averages 80%.”

Hemodialysis patient



Definition: *Communication*

“Communication is the process of conveying information from a sender to a receiver with the use of a medium *in which the communicated information is understood the same way by both sender and receiver*”



Definition: *Health Literacy*

“Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”

Healthy People 2010

Houston, We Have a Problem

- Albumin
- Antihypertensive
- Calciphylaxis
- Diaphoretic
- Erythropoietin
- Hemodialysis
- Hyperparathyroidism
- Peritoneum
- Renal
- Urticaria
- A1c
- BUN
- Ca x P
- CKD
- ESRD
- Hb
- iPTH
- K/DOQI
- Kt/V
- RRT

Who is More Likely to Have Health Literacy Issues?

- Elderly
- Minority
- Poor



U.S. Health Resources & Services Administration

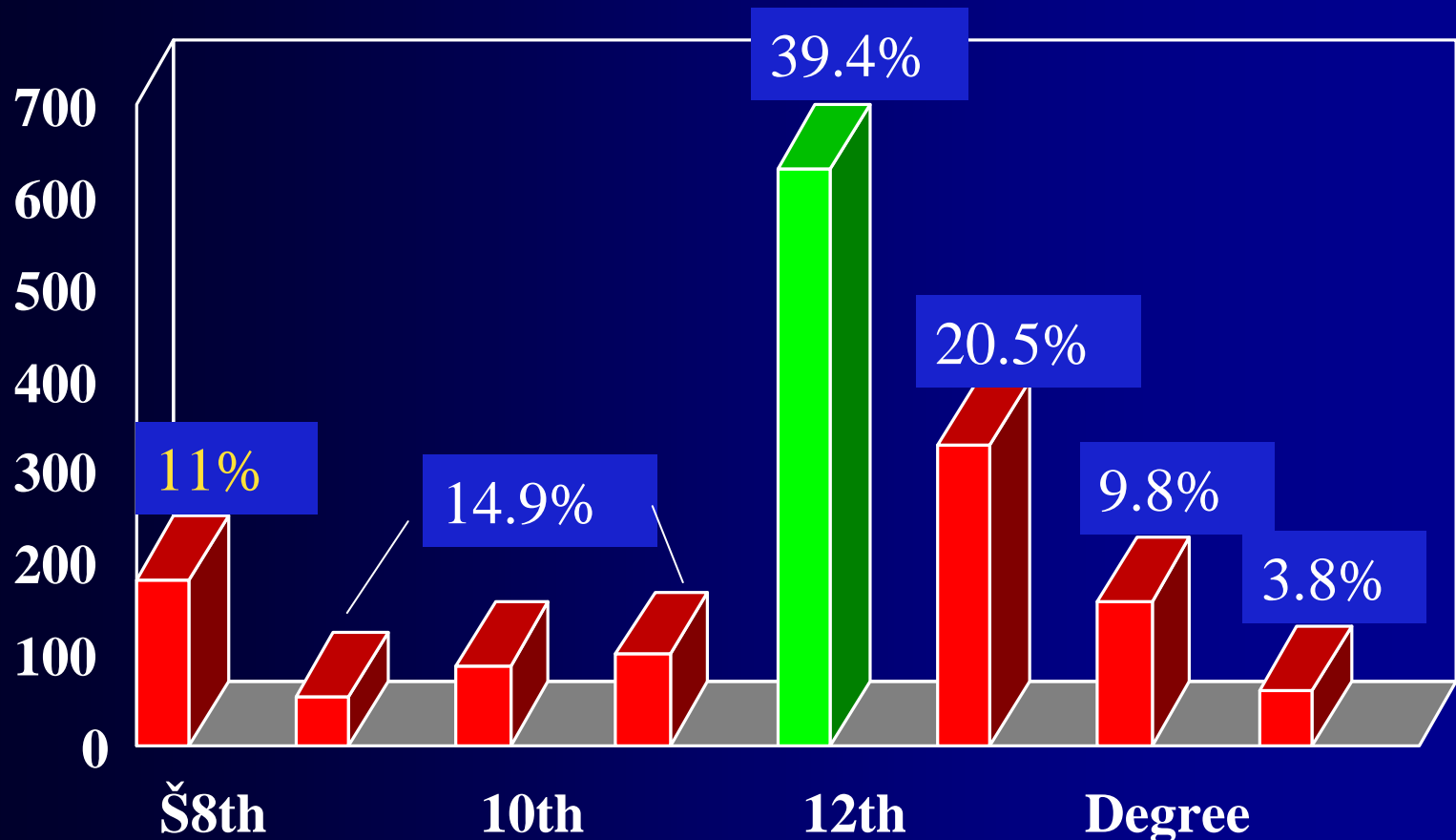


Factors in Health Literacy

- Jargon
- Low education
- Cultural barriers
- Limited English proficiency

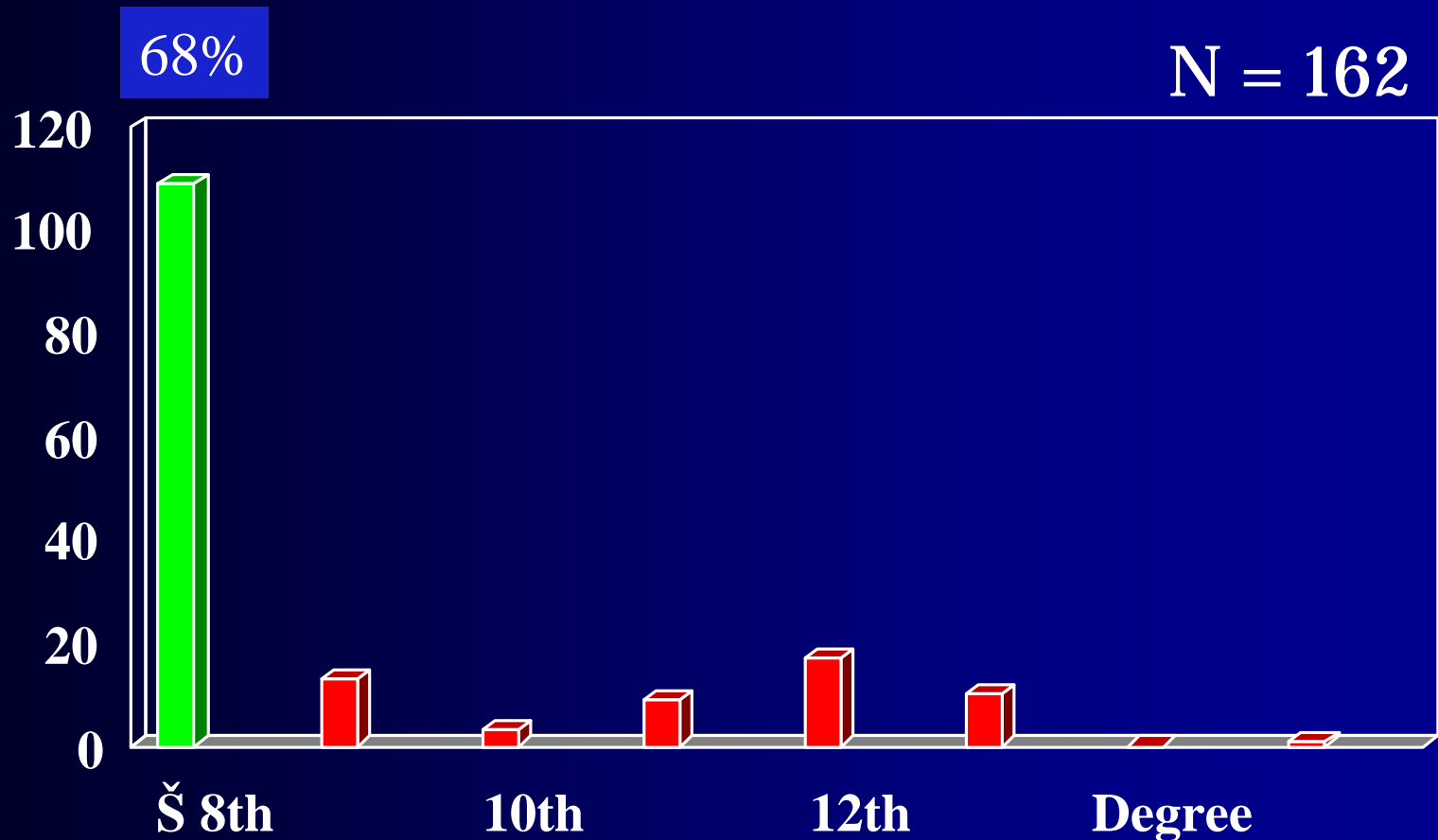
Mean Education Level of English-reading Participants

N = 1599



Schatell D et al. *Am J Kidney Dis.* 2006 Aug;48(2):285-91

Mean Education Level of Spanish-reading Participants?



Educational Attainment vs. Reading Level

- A. People usually read at their education level
- B. People can stretch to a higher reading level than their education would suggest
- C. Most people are comfortable reading at 3-5 grades lower than their education level

Educational Attainment vs. Reading Level

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¹Doak LG, Doak CC (1980): Patient comprehension profiles. Recent findings and strategies. *Patient Counseling and Health Education* 2(3):101-106.

**Aim for the 7th-9th grade level
in most patient education materials**

Tips for Improving Health Literacy

- Identify patients
- Use simple language
- Ask for “teach backs”
- Ask *how* or *what* Qs
- Focus on key points
- Repeat key info



U.S. Health Resources & Services
Administration

Common Dialysis Patient Tasks

- Complete all dialysis treatments
- Take multiple meds correctly
- Note & report symptoms
- Follow diet restrictions
 - for sodium, K⁺, P
- Limit fluid intake
- Care for vascular access
- Exercise



**What Patients Need to
Become Experts:**

Autonomy



Self-Determination Theory¹

- People have innate tendencies toward growth
- Social context can support—or thwart
- Humans have 3 critical developmental needs:
 - **Competence**
 - **Autonomy**
 - **Relatedness**

¹EL Deci, RM Ryan, University of Rochester

Importance of AUTONOMY

A series of studies from Taiwan found that:

- Self-efficacy explained **47.5%** of the variance in 160 dialysis patients' quality of life¹
- Patients randomized to self-efficacy training had **significantly lower intradialytic weight gains** than controls²

1 Tsay SL et al, *Int J Nurs Stud.* 39(3):245-51, 2002

2 Tsay SL. *J Adv Nurs* 43(4):370-5, 2003

Importance of AUTONOMY

- N=2,418 patients from DMMS Wave 2
- Data were adjusted for case mix
- **Patients whose care was “*patient-led*” had:**
 - **Significantly lower unadjusted death rates (p<0.0001)**
 - **Significantly higher transplant rates (p<0.0001)**

Importance of AUTONOMY

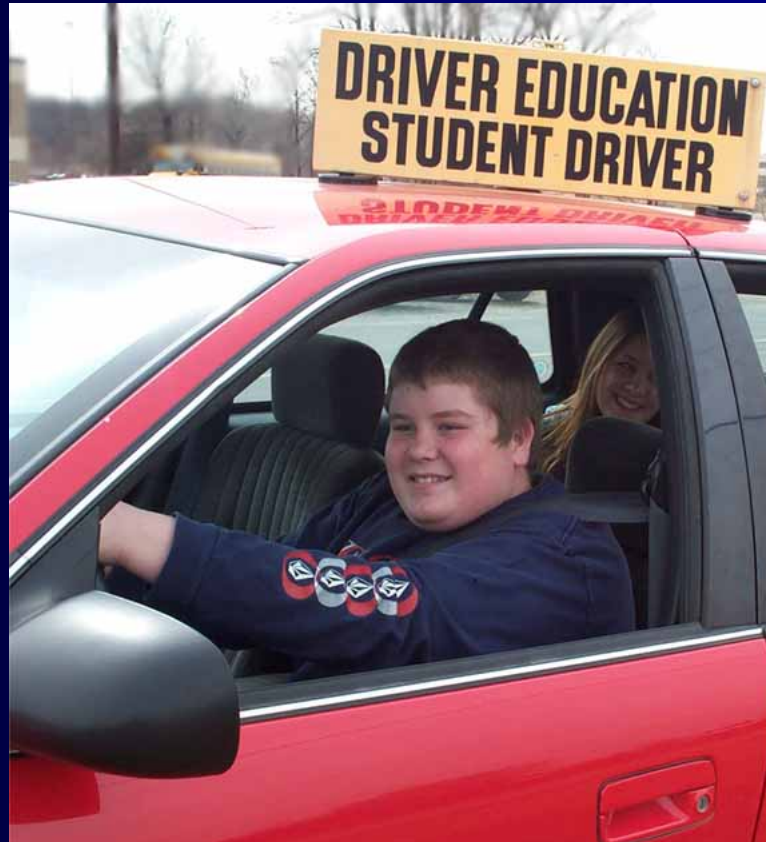
People with diabetes who felt their care team supported their autonomy:

- **Were more motivated**
- **Felt more competent**
- **Had significantly lower Hgb A1c's**

Williams GC, et al, Diabetes Care 1998 Oct;21(10):1644-51

Putting it all Together

How can we help patients to communicate with kidney professionals?



What You Can Do: Educate *for* Self-management

- Begin with the *goal* in mind
- Offer *hope* for a good life
- Socialize patients to partner in their care
- Provide *rationales* for information
- Use other expert patients as role models



Use Free Resources: Dialysis Answers - www.lifeoptions.org

Dialysis Answers



Dialysis Answers

These educational needs assessment tools will help clinic staff identify each patient's learning needs and interests. Answers cover starting dialysis (0-3 months) and early dialysis (4-12 months).















- 🌐 **Starting Dialysis (0-3 months)**
- 🌐 **Early Dialysis (4-12 months)**

Use Free Resources: Dialysis Answers - www.lifeoptions.org





Patient Interest Checklist: Starting Dialysis (0-3 months)

I would like to know more about...

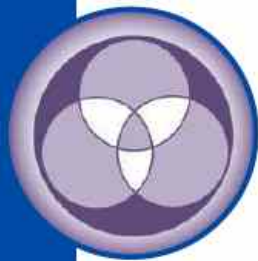
My medical condition:

-  How do my medications help my condition?
-  What is *EPO* and how does it help my anemia?
-  How can I protect my vascular access?
-  How long will it take me to get used to my treatment?
-  How does dialysis clean my blood?
-  How does the dialysis machine protect my safety?
-  What happens to me if I miss some dialysis?
-  What will happen to me if the power goes out during dialysis?
-  What should I do if the dialysis center is closed for an emergency?
-  What supplies should I always keep on hand for emergencies?
-  What is *adequate dialysis* and what does it have to do with time?
-  Why are dialyzers reused?
-  Who should I talk to if I want a kidney transplant?
-  What can I do to make dialysis go smoothly?

My relationships with family and friends:

-  Can my friends and family visit me during dialysis?
-  Who can help me explain dialysis to my family and friends?
-  Who can I talk to about changes in my body that upset me?
-  Is there another patient I can talk to about what to expect?

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Kidney Q&A *0-3 months*

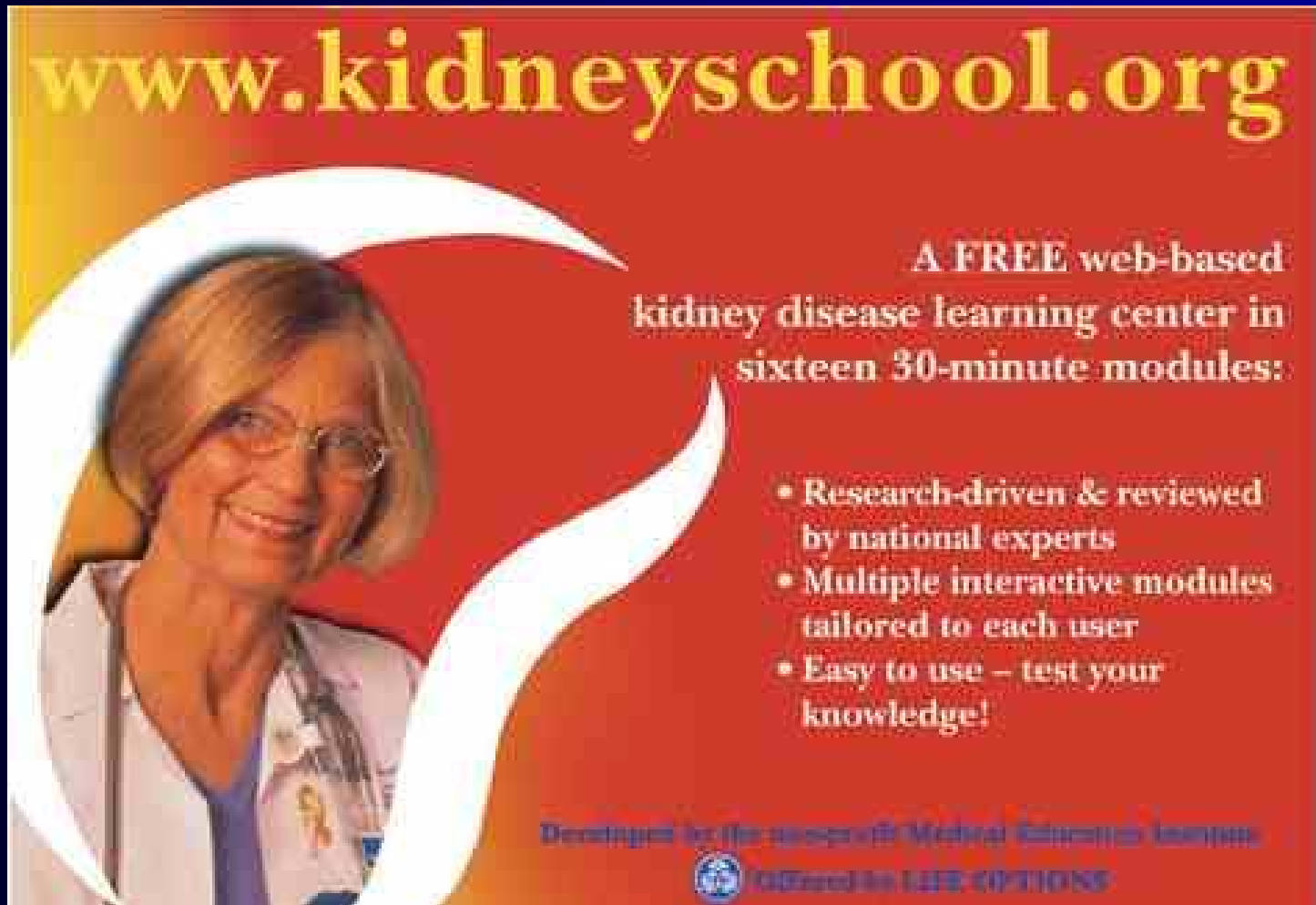
Life Options Rehabilitation Program
414 D'Onofrio Drive, Ste. 200
Madison, WI 53719
www.lifeoptions.org

Q: How do my medications help my condition?

A: People with kidney failure may take eight or more drugs every day. To stay healthy, take your drugs just as your doctor tells you. Here are some common drugs for kidney failure and what they do:

- **Antibiotics** fight infections. Your doctor may order one before you have dental work.
- **Anemia drugs** (Aranesp®, EPOGEN®) work with iron to help your body make
- **Phosphate binders** remove extra phosphorus from your food to help keep your bones healthy. They work best if you take them with food.
- **Stool softeners** make bowel movements easier when you have a fluid limit.
- **Vitamins** help your body stay strong and healthy. You get fewer vitamins than you need on an in-center hemodialysis


Use Free Resources: Kidney School - www.kidneyschool.org



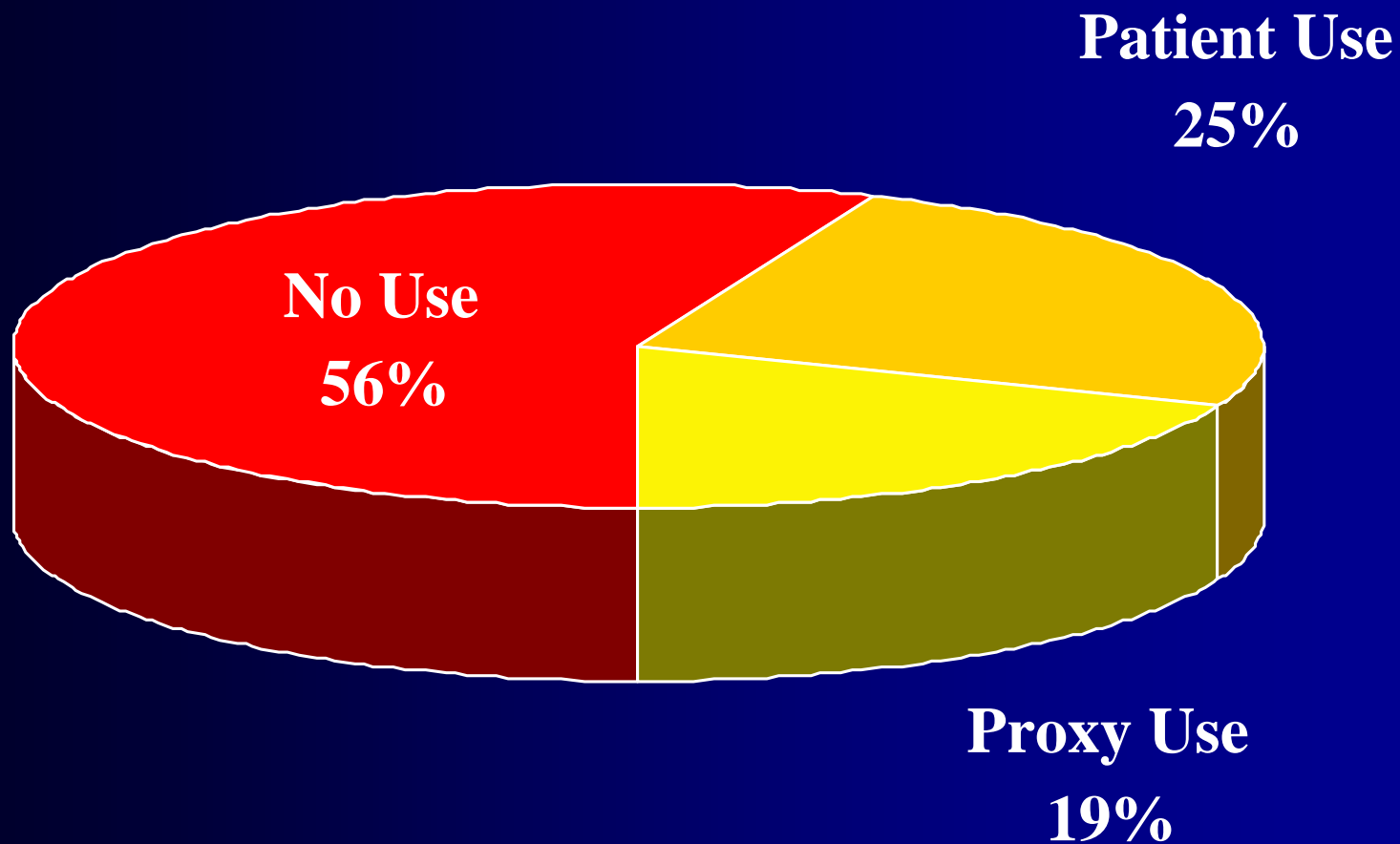
www.kidneyschool.org

A FREE web-based
kidney disease learning center in
sixteen 30-minute modules:

- Research-driven & reviewed by national experts
- Multiple interactive modules tailored to each user
- Easy to use – test your knowledge!

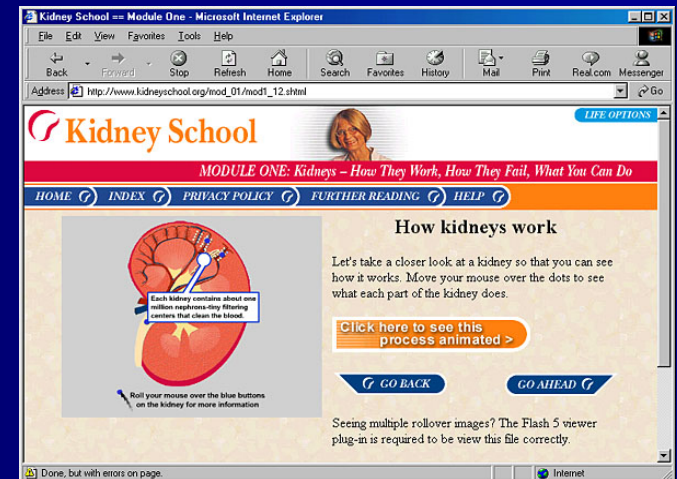
Developed by the **Harvard Medical Education Institute**
 OFFERED IN LIFE-TO-TO-TO

Use of Internet for Health-seeking



Kidney School™

- Interactive, *tailored* learning:
 - Branching content
 - *Personal Action Plans*
- Graphics & animations
- Pre-/posttests
- Evaluations
- Completion certificates
- 7th-9th grade reading level



Kidney School: 16 Modules

- ◆ What kidneys do
- ◆ Treatment options
- ◆ Care team
- ◆ Adherence
- ◆ Coping
- ◆ Anemia
- ◆ Kidney lab tests
- ◆ Vascular access
- ◆ Nutrition & fluids
- ◆ Adequacy
- ◆ Sexuality/Fertility
- ◆ Staying active
- ◆ Heart health & BP
- ◆ Responsibilities
- ◆ Alternative therapies
- ◆ Long-term problems

Sneak Peek: NEW Kidney School



Learning Modules

Book & CD-ROM

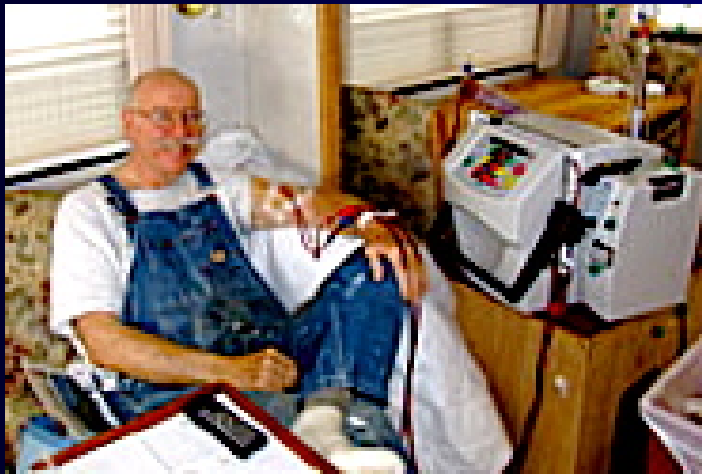
Free Postcards

Earn CE Credits

Download Idea Guide

What You Can Do: Encourage Home Dialysis

- Home dialysis requires *training*
- Outcomes are better than standard in-center



Home HD



Home PD

Home Outcomes are Better than In-center

- PD mortality <in-center HD for 1st 2 years¹
- PD <pneumonia, infection, sepsis¹
- Short daily HD: survival 61% > in-center²
- Survival³:

	In-center	Home
5 years	64%	93%
10 years	48%	72%
20 years	4%	34%

¹USRDS 2007 ADR

²Blagg C et al, *Hemodialysis Int.* 2006 Oct;(10)4:371-4

³Saner E et al. *Nephrol Dial Transplant.* 2005 Mar;20(3):604-10

Home Dialysis Can be More Physiologic

- **BP control:** Better with daily HD¹
- **LVH:** Regresses w. change to NHHD² or SHHD³
- **Neuropathy:** Only develops at GFR <12⁴
- **Amyloidosis:** More B2M removed with NHHD⁵
- **Bone disease:** NHHD removes more P, normalizes vit. D levels⁶

¹ Suri RS et al. *Clin J Am Soc Nephrol.* 2006, 1(1):33-42

² Chan CT et al. *Kidney Int.* 2002, 61(6):2235-9

³ Ayus JC, Achinger SG. *J Amer Soc Nephrol.* 2005, 16:2778-88

⁴ Krisnan AV, Kiernan MC. *Muscle Nerve.* 2007, 35(3):273-90

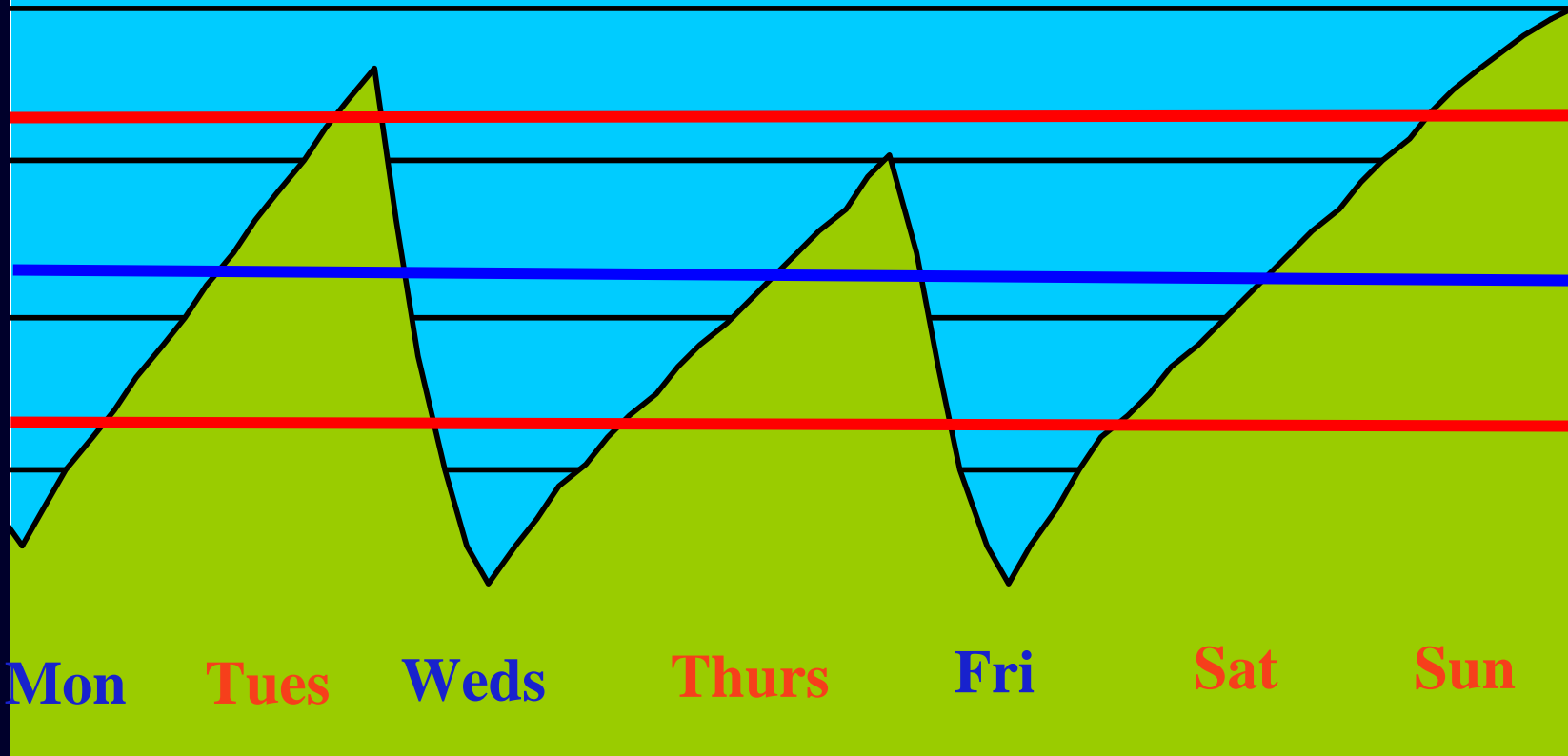
⁵ Raj DS et al. *Nephrol Dial Transplant.* 2000, 15(1):58-64

⁶ Nessim SJ et al. *Kidney Int.* 2007, 71(11):1172-6

Home Dialysis Can be More Physiologic

Standard in-center hemo:

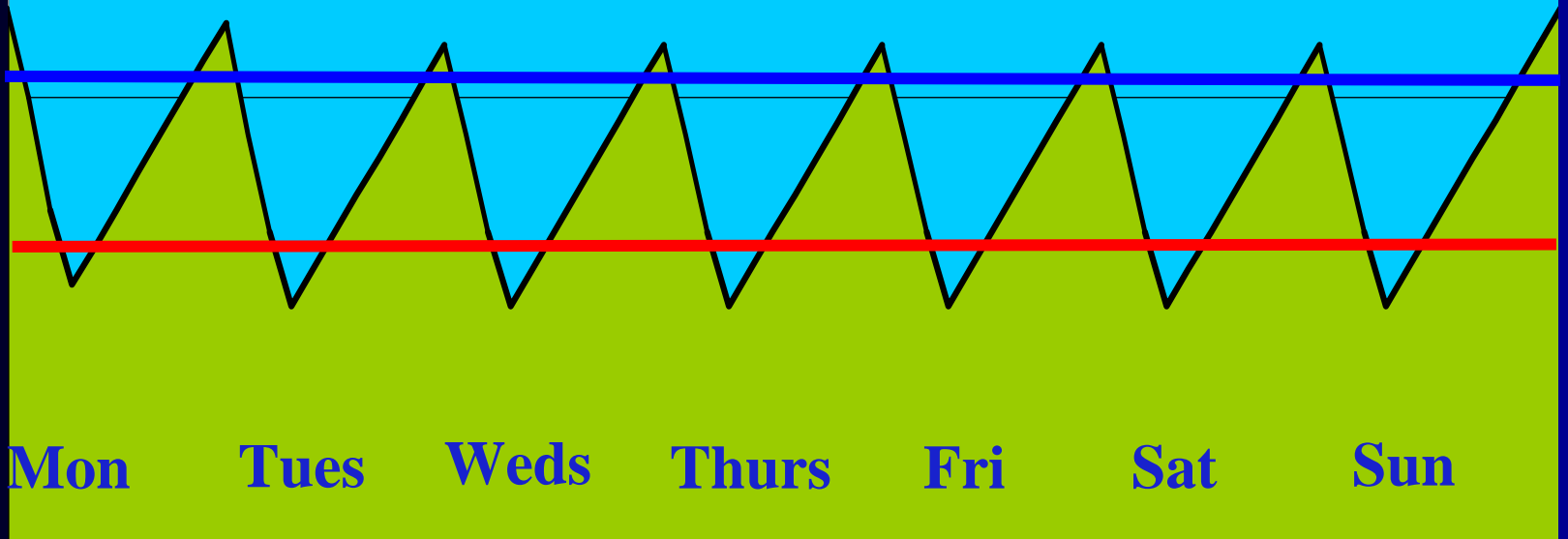
No normal levels of ECV, K, Bicarb, P, Ca, pH



Home Dialysis Can be More Physiologic

PD or longer/more frequent HD:

Normal range of ECV, K, Bicarb, P, Ca, pH



DOPPS: *Time Matters*

- 22,000 HD patients in 7 countries
- HD treatments >240 min (4.5 hrs) reduce relative risk of death by 30% ($p < .0005$)
- *Each extra 30 min. of HD <RR death by 7%¹*

¹ Saran R et al. *Kidney Int.* 2006 Apr;69(7):1222-8



Systematic Bias in Patient Selection for Home

Who is most likely to be offered home dialysis?



A



B



C



D



E



F

Systematic Bias in Patient Selection for Home



A



B



C



D



E



F

- DMMS Wave 2 (n=4,025), PD more likely in:¹
 - Younger
 - White
 - College-educated
 - Employed
 - Married
 - Men

Assess Patients for Home: www.homedialysis.org/MATCH-D

Method to Assess Treatment Choices for Home Dialysis (MATCH-D)

Criteria for Suitability for *Self* Peritoneal Dialysis: CAPD, APD

Strongly Encourage PD
Any patient who <i>wants</i> to do PD or has no barriers to it
Employed full- or part-time
Student – grade school to grad school
Caregiver for child, elder, or person with disability
New to dialysis or has had transplant rejection
Lives far from clinic and/or has unreliable transportation
Needs/wants to travel for work or enjoyment
Has needle fear or no remaining HD access sites
BP not controlled with drugs
Can't or won't limit fluids or follow in-center HD diet
No (required) partner for HHD
Wants control; unhappy in-center

Encourage PD After Assessing & Eliminating Barriers
Minority – not a barrier to PD
Unemployed, low income, no HS diploma – <i>not barriers to PD</i>
Simple abdominal surgeries (e.g. appendectomy, hernia repair; kidney transplant) – <i>not barriers to PD</i>
Has pet(s)/houseplants (carry bacteria) – bar from room at least during PD connections
Hernia risk or recurrence <i>after</i> mesh repair – use low daytime volume or dry days on cycler
Blind, has no use of one hand, or neuropathy in both hands – train with assist device(s) as needed
Frail or can't walk/stand – assess lifting, offer PT, offer CAPD, use 3L instead of larger bags for cycler*
Illiterate – use pictures to train, return demonstrations to verify learning, tape recorders for patient reports
Hearing impaired – use light/vibration for alarms
Depressed, angry, or disruptive – increased personal control with PD may be helpful
Unkempt – provide hygiene education; assess results
Anuric with BSA >2 sqm – assess PD adequacy†‡
Swimmer – ostomy dressings, chlorinated pool, ocean
Limited supply space – visit home, 2x/mo. delivery
Large polycystic kidneys or back pain – use low daytime volume or dry days on cycler†‡
Obese – consider presteral PD catheter
Has colostomy – consider presteral PD catheter
RX drugs impair function – consider drug change

May Not Be Able to Do PD (or will Require a Helper)
Homeless and no supply storage available
Can't maintain personal hygiene even after education
Home is unclean/health hazard; patient/family won't correct
No/unreliable electricity for CCPD; unable to do CAPD
Multiple or complex abdominal surgeries; negative physician evaluation.†‡
Brain damage, dementia, or poor short-term memory*
Reduced awareness/ability to report body symptoms
Malnutrition after PD trial leads to peritonitis†‡
Uncontrolled anxiety/psychosis*



* May be able to do with a helper

† Consider nocturnal HHD

‡ Consider daily HHD

Use Free Resources: www.homedialysis.org



There's no place like



HOME DIALYSIS
CENTRAL

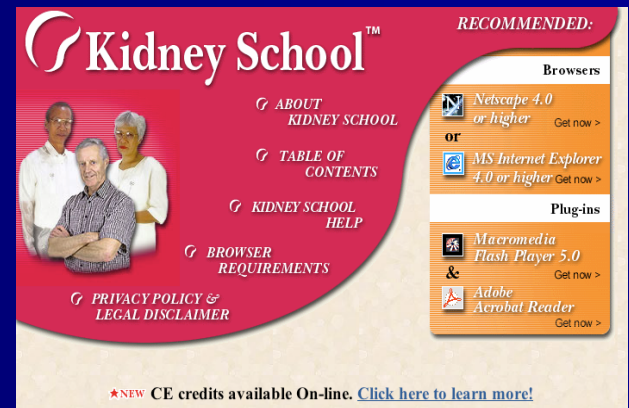
www.homedialysis.org

Your one-stop source
for PD & home hemo
info & support

Created by the non-profit Medical Education Institute, Inc.

MEI Self-mgmt Resources:

www.lifeoptions.org





Communicate with patients as if they have:

- A. PhDs
- B. Medical degrees
- C. Very low IQs
- D. No medical background



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Our goal for dialysis patients should be:

- A. Sleeping patients who don't snore
- B. Expert patients who self-manage
- C. Anxious patients who don't ask questions
- D. Belligerent patients who become violent



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What factor is linked most closely with quality of life in people on dialysis?

- A.** Feeling safe
- B.** A good sense of humor
- C.** Autonomy
- D.** A buddy in the next chair



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Conclusions

- Patients need *education* to communicate
- ESRD is a chronic disease
- Patients' job is to *self-manage*—not comply
- Home dialysis = highest level of self-mgmt
- Free, research-based materials are available