

Navigating the Health Care System

*A Health Literacy Perspective Through
the Eyes of Patients*



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UNC Sheps Center for Health Services Research



NC Program on Health Literacy



Health Literacy

“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

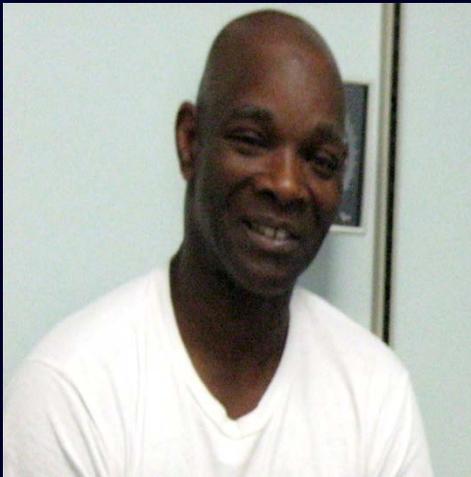
Purpose and Process

- To gain patients' perspectives on...
 - Navigating health care services
 - Interacting with medical providers and staff
 - Understanding health information
 - Self-care
- Understanding their perspective helps us improve our practices
- How?
 - Document and describe the process of scheduling and attending a primary care visit
- Where?
 - UNC Internal Medicine Enhanced Care Clinic
- Who?
 - New patient: Ashley Hink
 - Returning patient: Larry Holt

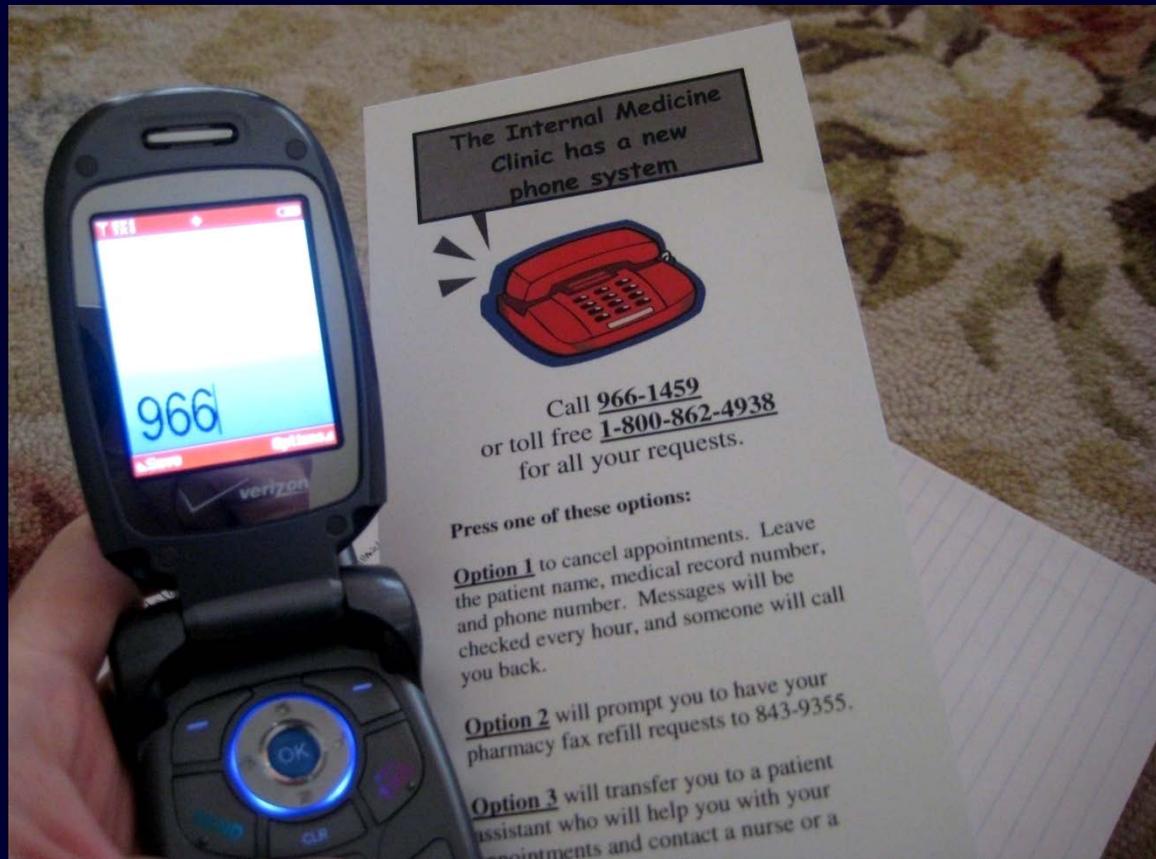
Patients



- Ashley Hink
 - 25 years-old
 - MPH Student
 - Researcher, health educator
 - Has difficulty sleeping
 - For the purpose of the visit, she claims to have high blood pressure and no insurance



- Larry Holt
 - 58 years-old
 - School Custodian, father and grandfather
 - Has diabetes, hypertension and chronic shoulder pain
 - Insured through BCBS State Health Plan



First steps

I referred to a pamphlet about the Internal Medicine phone system to help me schedule my appointment. It was easy to understand, and I knew exactly which option to select.



Scheduling confusion

It took a total of 2 calls, 4 selected options, 2 connections, 1 voicemail message, 1 call-back and a final conversation with an Enhanced Care staff member to get my appointment. Fortunately, I was able to see Dr. Malone within one week.



Paperwork , and lots of it

As a new patient, I am required to fill out a seven-page personal health summary – most of which is very straight-forward and easy to fill out.



Health History Form

- Seven pages inquiring about social and medical history
- Generally easy to follow and read
 - Some medical terms have common names in parenthesis
 - Anemia (low blood)
- Some of the answer options are not appropriate for the question (multiple choice vs. fill-in)
- Often resort to qualifying answers

Y/N

Have you ever had "shots" (immunizations) for:

<input checked="" type="checkbox"/>	<input type="checkbox"/>	Polio	Date of most recent booster	<u>2017</u>
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Tetanus	Year	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Pneumococcal vaccine	Year	
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Hepatitis B	Year	<u>1996</u>
<input type="checkbox"/>	<input type="checkbox"/>	Hepatitis A ?	Year	<u>DONT KNOW</u>
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Tuberculosis	Year	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Zoster vaccine	Year	
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Other <u>URGICAL</u>	Year	<u>2008</u>

Social History

Where were you born? PASADENA, NC

How much schooling have you had? GRADUATE SCHOOL*

1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	1	2	3	4
Grade School								High School				Vocational School			College			

What has been your main occupation? RESEARCH ASSISTANT / HEALTH EDUCATOR

What is your most recent job? RESEARCH ASSISTANT

Yes No

Have you in the past or do you now smoke, use snuff or chew tobacco?
If yes, how much and for how long?

Do you drink alcohol?

Have you ever felt you ought to cut down on your drinking?

Have people annoyed you by criticizing your drinking?

Have you ever felt bad or guilty about your drinking?

Have you ever had a drink first thing in the morning?

Are you under any unusual strain at your job?

Are you unemployed?

Are you (circle one): Single Married Divorced or Separated Widowed LOW-TERM PARTNER (BOYFRIEND)

Who lives in your household? MOTHER, FATHER

Are you sexually active? With men women both

Are there any religious/spiritual or cultural practices which need to be included in your care (example: no blood/blood products)?
If yes, describe:

Do you have any problems at home or work?
Explain: UM, I DONT KNOW WHERE
In difficult times where, or to whom, do you turn? FATHER, BOYFRIEND

VD – not spelled out, examples are hard to read for those with low literacy

- | Yes | No | |
|--------------------------|-------------------------------------|---|
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Anemia (low blood) |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Asthma (wheezing) |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Diabetes (sugar) |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Heart trouble |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Hemorrhoids (piles) ? |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Hepatitis (yellow jaundice) |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | High blood pressure |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Tuberculosis (TB) |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Kidney trouble |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Liver trouble |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Pneumonia |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Rheumatic fever |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Ulcers ? |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | VD (syphilis, gonorrhea, chlamydia) |
| <input type="checkbox"/> | <input checked="" type="checkbox"/> | Do you get shortness of breath that wakes you up from sleeping? |

Release of Medical Information

- No explanation or guidance
- Technical/legal language, written at a high grade level
- Must infer what information is needed
 - I authorize _____ to release to _____ the medical records of _____.
- I decided to leave this blank for now, and will fill it out if requested by the provider

University of North Carolina Health Care System
Internal Medicine Clinic
102 Ambulatory Care Center, CB# 7705 • Mason Farm Road, Chapel Hill, NC 27599-7705
Phone 919-966-1459 • FAX 919-966-9671

 **ATTENTION: RELEASE OF MEDICAL INFORMATION**

I authorize _____
To release to: _____
Name: _____
Address: _____

the medical records of

Name: _____ Date of Birth: ____/____/____
Address: _____
Telephone: (____) _____ *Social Security #: _____
* (SSN voluntarily provided)

UNC Medical Record Number (hospital card) _____
Treatment dates: _____

Information to be released (please check information required):

<input type="checkbox"/> Clinic Notes	<input type="checkbox"/> Progress Notes	<input type="checkbox"/> Nurse Notes	<input type="checkbox"/> X-ray Reports
<input type="checkbox"/> Emergency Room	<input type="checkbox"/> Operative Report	<input type="checkbox"/> Discharge Summary	<input type="checkbox"/> Doctor Consultations
<input type="checkbox"/> Urgent Care Center	<input type="checkbox"/> Pathology Report	<input type="checkbox"/> Lab Reports	<input type="checkbox"/> Other
<input type="checkbox"/> History & Physical	<input type="checkbox"/> Physician Orders	<input type="checkbox"/> EKG, EEG, EMG	

I acknowledge that data to be released may include material that is protected by law. My check mark and my signature below authorizes inclusion of information pertaining to:

Mental Health Drugs & Alcohol HIV / AIDS Genetic Testing Not applicable

Reason for request:
 Patient Care Other _____

I understand the information released is for the specific purpose above and may not be provided in whole or in part to any other agency, organization, or person. I understand a fee may be charged for copying the medical record. I understand that I may revoke this authorization at any time except to the extent that action has already been taken on it. I understand this authorization will automatically expire ninety (90) days from the date of signature.

Date: _____

Revised 1/16/07

_____ Signature of Patient or Legal Representative	Ed. On Fee _____	Office Use Only
_____ Relationship to Patient	Call for: _____	Pickup _____ Review
_____ Witness		

UNC Health Care - APPOINTMENT REMINDER
 101 Manning Drive
 Chapel Hill, NC 27514-4420
 www.unchealthcare.org



UNC
 HEALTH CARE



Medical Record No: 16223539

*****AUTO**3-DIGIT 276
 HINK,ASHLEY B
 4901 FIELDING DR
 RALEIGH NC 27606-4474

Note: Construction on the new N.C. Cancer Hospital is under way. Please note that traffic patterns to the hospitals have changed. Visit www.unchealthcare.org for the latest construction updates.

APPOINTMENT REMINDER

Dear ASHLEY B HINK,

This is an appointment reminder from UNC Health Care. Your appointment information is listed below:

You have an appointment with:

MALONE,ROBERT M
MED INTERNAL MEDICINE
ACC 3RD FLR INTERNAL MEDICINE
TUE JAN 13, 2009
1:45 PM

Please arrive before your appointment time. Parking at sites near UNC Hospitals may take extra time. A map to your appointment location is on the back of this page. If your appointment is not at one of our on campus locations (UNC Hospitals, Ambulatory Care Center, or Aycock Family Medicine), please call the clinic for directions at 919-966-1459.

Note:

If you cannot keep this appointment, please call us as soon as possible at 919-966-1459. Please have your medical record number available when you call.

Si usted no puede cumplir con esta cita, o necesita asistencia en español, por favor llame al 919-966-1459. Por favor tenga su número de la tarjeta del UNC listo.

Our Mission is to serve your health care needs. At your visit, please assist us by bringing:

- Your insurance card;
- Your UNC Medical Record Card;
- All medications you are taking in original container(s);
- Any authorization required by your insurance company.

Please be prepared to pay any applicable co-payments, co-insurance, prior balances and parking fees. Financial Counseling is available if you have any concerns about your ability to pay amounts due at your appointment or prior UNC Health Care balances.

UNC Health Care is proud to announce that we are a Tobacco-Free Campus.

Please notify us as soon as possible at 919-966-1459 if you are unable to keep this appointment.

2713



UNC
 HEALTH CARE

Welcome to the General Medicine Blood Pressure Clinic. We look forward to working with you and your doctor to control your blood pressure. We are located in the Internal Medicine clinic on the 3rd floor of the Ambulatory Care Center.

Reasons for this visit:

- To help get your blood pressure lower.
- To help prevent heart attack, stroke, and kidney damage.

What to expect during the visit:

- You will spend between 15 to 30 minutes with your high blood pressure specialist.
- We will review all of your medicines.
- We will check your blood pressure.
- We may take some blood to make sure your medicines are right for you.

What to do to get ready for the visit:

- Take all of your medicines as usual on the day of the visit.
- Bring all medicines with you to the clinic.
- If you have your own blood pressure machine, bring it with you.
- Go to your local pharmacy or use your home blood pressure machine to check your blood pressure 3 times before your visit. Write down the date, blood pressure, and your pulse.

Date & Time	Blood Pressure		Pulse
	Top Number	Bottom Number	

Contact information for UNC Internal Medicine's Blood Pressure Clinic:

Telephone: (919) 843-0391

Fax: 919.966.4507

Toll-Free: (866) 633-8002

Email: Bloodpressure@med.unc.edu

Please call us if you have any questions or cannot make it to your appointment.

Reminders and homework

In addition to my appointment reminder in the mail and over the phone, I receive an explanation of my upcoming appointment to the blood pressure clinic. It asks me to bring all of my medicine and to take my blood pressure before coming in.



120/83



Requested BP Check

1/10/09 Before giving blood:

108/74

1/11/09 With home monitor:

120/83



Before arriving, I receive a message inquiring about my health insurance... I don't respond



Made it

The UNC Ambulatory Care Center is home to 8 separate clinics. While the sign is hard to read from the road, it lets me know I'm in the right place.



Direction and assistance

While looking at the sign that directs patients to the correct floor, a security guard greets me from the information desks and asks if I need help.





Check-in

A staff member checks me in and I'm pleasantly surprised to find out that I have no additional paperwork to fill out, nor do I have to wait. I was asked if I had health insurance – I turned around after saying 'no' only to see people listening to my conversation.





Waiting...

I paused at the door in attempt to follow directions. After waiting a while a staff member told me to walk to the end of the hall.



Weight and vitals

A cheerful nurse quickly gets my weight, heart rate and blood pressure.



150/99



Excellent physiological acting

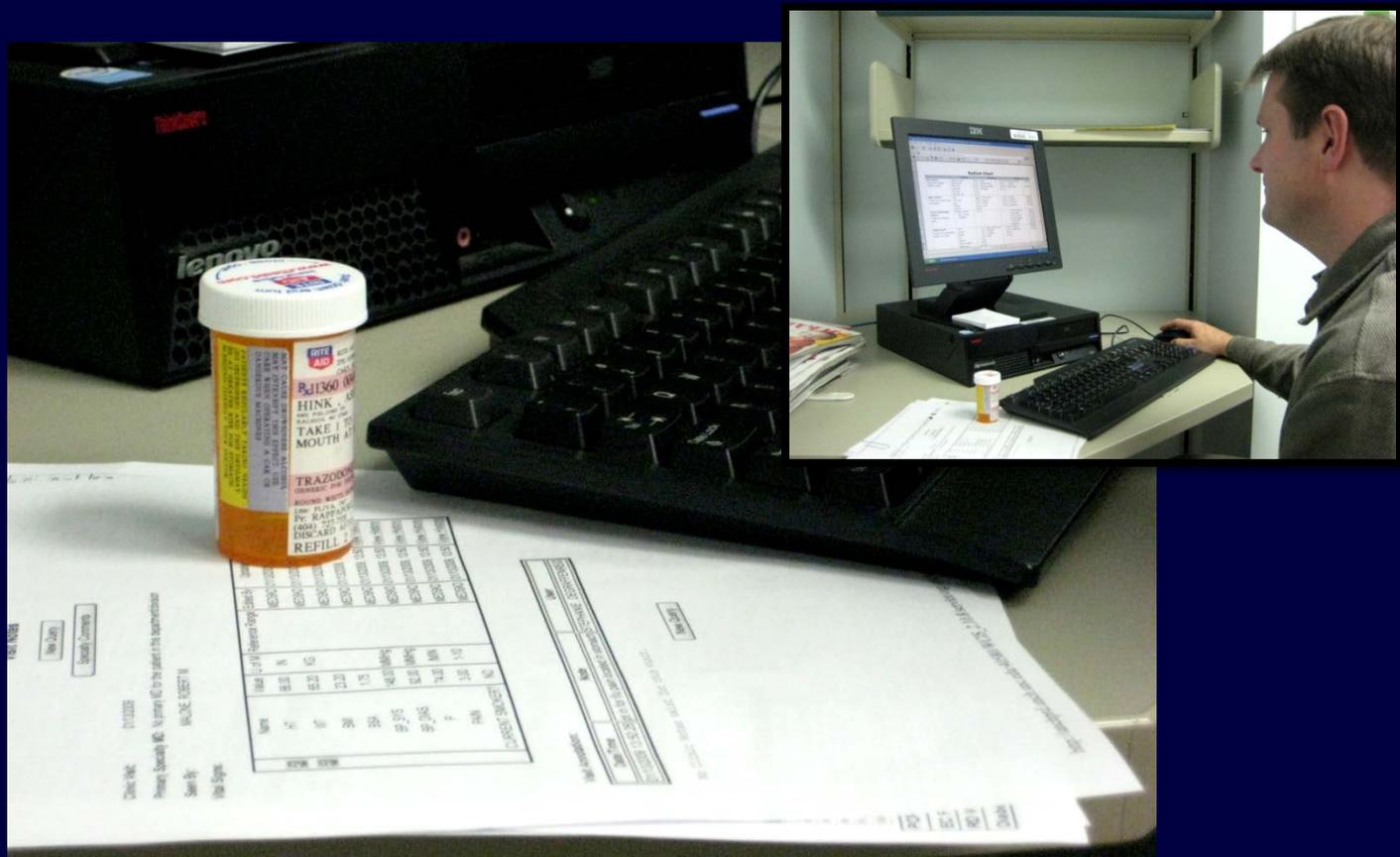
My first blood pressure reading was 150/99. I blame it on taking the stairs and drinking 3 cups of coffee. The nurse tells me to relax. Five minutes later it was 148/92.



Reading material?

I like to read the pamphlets and health magazines while waiting. Hoping to find something relevant to my personal health, I find only 5 options, 3 of which are in Spanish.





The visit

Dr. Malone asks me why I'm here and about my personal and family medical history. I discuss my sleeping problems, and tell him my family physician was considering starting me on a medication for high blood pressure. We discuss sleep hygiene, sodium in my diet, and treatment options for both issues.





Shared decision-making, future steps

Dr. Malone suggests re-starting my sleeping medication and possibly increasing it in the future. He says I don't need to start an anti-hypertensive medication yet, so we discuss how I might change my diet.



Patient Blood Pressure Sheet

Lowering your blood pressure is important. High blood pressure can lead to heart attack, stroke and kidney damage. We can reach your blood pressure goals together! Please complete and mail this form back to us in the envelope provided by _____.

Date: 1/13/09 Educator/Nurse: _____
Name: Ashley Hink Provider: Malone
Phone #: 272-4176 Best time to reach you: _____

Your blood pressure should be less than 140/90

There are many ways for you to help get your blood pressure under better control.

Working on the following goals can help you get your blood pressure down.

- Use less salt and decrease salt/sodium in foods you eat. Watch out for canned vegetables.
- _____

Medicine Changes:

- No medicines for blood pressure today.
- Restart Trazodone for sleep
- _____

Please go to your local pharmacy or use your home blood pressure machine to check your blood pressure 3 times in the next week. Write down the date and your pulse, too.

Date	Blood Pressure (both numbers)	Pulse

Do you have any concerns or are you having side-effects from your blood pressure medicines?

Goals, changes and more homework...

The blood pressure visit summary sheet provides a good overview of our visit and what I need to do at home...

- Decrease sodium intake
- Re-start Trazodone
- Check BP three times in the next week





Pharmacy cold shoulder

After waiting about 15 minutes, I sit down to a seemingly half-interested counselor. I told her I'd be getting my medicine here soon and wanted to start the paperwork. She said she wouldn't give it to me until I had a prescription... so much for being proactive.





45 minutes later...

Overall, my visit was an excellent experience. The process was relatively easy, the health care provider communicated clearly and included me in the decision-making process, and the staff were friendly.

Number of Steps?

3

- Call to make the appointment
- Fill-out necessary paperwork
- Take my blood pressure twice before the visit (pharmacy and blood drive)

4

- Prepare for appointment: get papers, medicine, directions
- Drive from Raleigh to Chapel Hill, find the clinic
- Follow the signs to the General Internal Medicine Clinic
- Check-in at front desk

5

- Nurse takes my weight, blood pressure
- Review medical history and reason for visit with provider
- Agree on treatment plan and verify understanding
- Check-out at front desk
- Attempt to speak with pharmacy benefits counselor

3

- Re-fill prescription at the pharmacy medicine and check BP
- Have friend check BP, send BP values to Dr. Malone
- Examine food labels for sodium content, attempt to change diet

= 15!



Notable Points

Needs Improvement

- Specify directions on the Enhanced Care phone system
- Make forms and pamphlets easy-to-read (language and design)
- Sensitivity toward uninsured
- More pamphlets/health information in rooms
- More signs in Spanish

Done Well

- Multiple appointment reminders and directions
- Friendliness of staff (most)
- Short wait time to schedule and see provider
- Provider communication, visit summary forms
- Signage in English was clear and helpful





Established Enhanced Care Patient

Followed for over 7 years at UNC, Mr. Holt is more than familiar with the appointment process. He arrives 30 minutes early for his 9:00 a.m. appointment and is happily greeted by two front desk staff that know him by name. In less than 5 minutes, he is called back to see Dr. Malone.

"I had been on about 8 different pills a day. Sometimes, you just forget it."

"It frightened me – I was scared to death. I had 4 doctors. It was overwhelming."

How did you feel when you were first diagnosed with diabetes?

Did the medical providers clearly explain what diabetes is and how to take care of it?

"It was easy to understand. They told me what to eat, what not to eat, and they explained my medicine to me."



120/76



Blood pressure check

Mr. Holt is here for a regularly scheduled diabetes and blood pressure follow-up. Dr. Malone intends to simplify his medication regimen so he can take all of his pills once a day.





Mr. Holt takes 5 medicines a day – he takes them out one by one, explaining what they are for, how many he takes and how much they cost

- Metformin B.I.D.
- Enalapril/HCTZ B.I.D.
- Lantus Q.D.
- Baby Aspirin Q.D.
- Simvastatin Q.D.

He checks his blood sugar at least once a day, often before work at 5 a.m.

Medication review

Mr. Holt takes two medications twice a day, and admits that he sometimes forgets the second dose.



Review of Warning Labels



“Take it when you eat food.”



“It looks like a glass... I don’t know what it means.”



“It looks like they are showing you how to run your water.”

“If I go out of town, I take what I need. I put the pills in aluminum foil, and I keep my insulin on ice.”

“Sometimes if I miss one, I’ll take 2 later.”

How do you remember to take all of these medicines?

“I’ve used a pill box before.”

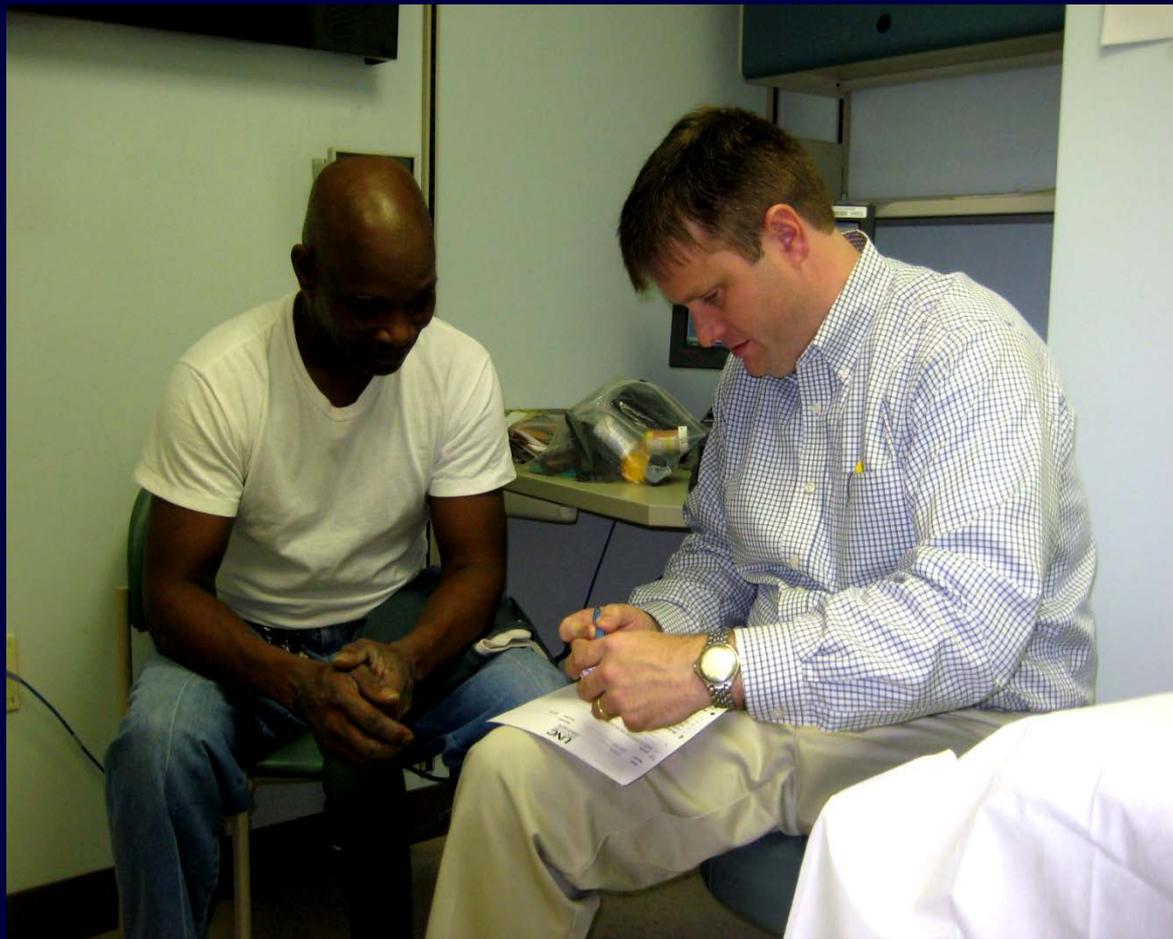
“I set my bag of medicine at the table where I eat. I have to keep it where I see it.”





Review meds, create a plan

Dr. Malone reviewed each of Mr. Holt's medications and interrogated his glucometer. He made sure Mr. Holt was up-to-date on lab work and discussed options to simplify his medication regimen.



1. *Check BS before breakfast and dinner*
2. *Increase insulin to 19 units*
3. *Start Metformin ER 500mg, 4 pills in the morning*
4. *Start Lisinopril/HCTZ 20/25mg, 1 pill in the morning*
5. *Stop Metformin and Enalapril/HCTZ*

Teach-back

Dr. Malone says, “Tell me what you are going to do.” Mr. Holt repeats each of the changes one by one, and Dr. Malone clarifies the directions if needed. At the end of the visit Dr. Malone asks, “Are we good? Any other questions I need to answer?”



Limits visit to 5 main points or changes





Date: 1/23/09 Educator: _____
Name: Larry holt Provider: Malone



Goals:

1. Switch to medicines that can be taken once a day.
- 2.



Medicine Changes:

1. Increase Lantus to 19 units at ~~bedtime~~ BREAKFAST
2. Stop Enalapril/HCTZ. Start Lisinopril/HCTZ once a day.
3. Stop Metformin. Start Metformin ER, 4 tablets at breakfast.
- 4.
- 5.



Blood Sugar Testing:

Date	Before Breakfast	After Breakfast	Before Lunch	After Lunch	Before Dinner	After Dinner	Bedtime	2 to 3 AM
1/24/09	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

Call 919.843.0391 or fax my blood sugars to 919.966.4507 on _____

Best contact phone number: 919-923-5227

Best time to reach you:

Adherence Reinforcement

1. Visit summary sheet
2. Threw away discontinued medications to avoid confusion
3. Patient can now get all medicines at one pharmacy
4. Prescriptions faxed in and ready for pick-up in the afternoon
5. Requested follow-up to review changes and BS



Patient Advice

If you had any advice to people that work in the clinic to make information they give you easier to understand, what would you tell them to do?

“I would tell them that they need to write it – not in cursive, in print, and to use small words so I can read it. You see, I can hardly understand those real big words. You have to break down the syllables to understand the big words.”

Patient Advice

What about the way they talk to you? Do they explain things in a respectful way? Do they look at you when speaking with you? Do they explain things clearly?

“They explain it very well. They all know me! I come in and say good morning to everyone and they say hello. Everybody is fantastic out there. The nurses are fantastic, too. Since I’ve been coming here I really enjoy myself with the doctors and nurses and staff. They look out for me, so if I make a mistake it will be mine, not theirs, because they really explain things to me.”



Acknowledgements

Last updated 3.26.09

Thanks to Dr. Robb Malone and Mr. Larry Holt for their participation. All personal information was used with permission.