WHAT FAMILY CAREGIVERS NEED FROM HEALTH IT AND THE HEALTHCARE SYSTEM TO BE EFFECTIVE HEALTH MANAGERS

MaryAnne Sterling
Co-Founder,
Connected Health Resources
April 6, 2015
AGENDA

- Connected Health Resources
- The White Paper
- Real World Example: Care Planning  (making data actionable)
- Conclusions and Wrap-up
ABOUT ME

- 18+ years as caregiver/healthcare navigator for my aging parents
- 3-out-of-4 parents/in-laws living with or died from dementia or Alzheimer’s
- Activist, entrepreneur, healthcare system transformer
- Focused across health policy, health IT, healthcare delivery and medical research

- ONC Health IT Policy Committee, Consumer WG
- Alzheimer’s Assn Ambassador, Senator Mark Warner
- PCORI Ambassador
- Former HIMSS Executive in Residence
- Personal story featured in Kiplinger, New York Times, USA Today, Wall Street Journal
CONNECTED HEALTH RESOURCES
INTRODUCTION

- Company: Connected Health Resources
- Solution: Patient and Caregiver Gateway
- What we do:

We connect individuals and families to community-based health and social services resources with easy-to-understand information, moving 93 Million family caregivers from crisis to recovery.
OUR SERVICES: E-HEALTH LITERACY PLATFORM

Plain language and multi-lingual resources for patients and caregivers

- Web and call center solution
- Easy to understand discharge instructions & medication information
- Help in navigating healthcare and community services
- Support for alternative staffing
- Increased community collaboration

Early adopters will likely be Case/Care Managers, Navigators, Community Health Workers
OUR SERVICES TEAM

- Technology partners (individual tools already in production):
  - Datuit: technology that creates a partnership between consumers and their healthcare providers
  - Polyglot Systems Inc.: plain language and multi-lingual patient communication tools
  - Peninsula Aging & Disability Resource Network (PADRN): community resource directory

- Services collaborators
  - Caregiver Action Network: on-line support community for family caregivers
  - MAXIMUS Inc.: call center support for Medicaid programs across the country and founders of the Center for Health Literacy
  - Secure Exchange Solutions: secure communication of healthcare information between patients and providers
PROBLEMS WE ARE ADDRESSING

- **Health Literacy**
  - 1 in 3 Americans have low health literacy
  - 50M Americans do not speak English at home

- **Social Determinants of Health**
  - Income, housing, food security and social support are significant contributors to health outcomes

- **Care Transitions**
  - Lacking or inadequate patient & family education are drivers of poor transitional care
  - Inability to understand health needs coupled with limited access to community resources drives avoidable readmissions

Social determinants of health are significant drivers of ED overutilization and avoidable readmissions
CONSEQUENCES OF LOW HEALTH LITERACY

Non-Adherence
- Medication adherence is “critical for discharged patients to remain stable at home”*

Increased Costs
- $290B economic drain/yr
- 2225 hospitals penalized for Readmission Rates
- 2% VBP penalty

Low Health Literacy
- Growing elderly population
- Low literacy levels
- Language diversity
- Inaccessible medical terminology

Low Patient Satisfaction
- 58%: Communication is the most important part of patients’ experience*

Poor Health Outcomes
- 40% of nursing home admissions
- 11% of hospitalizations
- 125,000 deaths/year

*Source: Katz et al., Am J Health-Syst Pharm, 2006
*Source: New England Healthcare Institute
*Source: Ngoh, Lucy, Jrnl Amer Pharmacists Association, 2009
*Source: Study by American Medical Association, 1999 JAMA
*Source: Institute of Medicine, HEALTH LITERACY: A PRESCRIPTION TO END CONFUSION, 2004

Courtesy: Polyglot Systems

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COMMUNITY RESOURCE FINDER

1) Think about your family’s needs

2) Learn about available services

3) Find service providers in your community

Capital Home Care, Inc.
14820 Physicians Lane, Suite 242, Rockville, MD 20850
301-841-0599 Can be reached 24 hours a day at 866-930-2273

Email:

Description:
Capital Home Care, Inc. provides companion services to patients requiring monitoring in and around the home, and need assistance preparing light meals, and completing light housekeeping tasks.

Web Site: http://www.capitalhomecare.com

Hours of Operations: Monday through Friday 9AM-5:30PM

Financial Information: Accepts the Maryland Medicaid Waiver or Private Pay (Check)
DISCHARGE INSTRUCTIONS

Clear, simplified discharge instructions in patient’s language and English

Activity
Exercise regularly as you are able.

Avoid doing too many activities at one time. Spread it throughout the day to avoid becoming too tired.

Sleep with your head elevated on 2-3 pillows, or sleep in a reclining chair. This will help you breathe better at night.

Elevating your feet when they become swollen will help reduce the swelling.

Eating & Drinking
Try to eat healthy foods, including plenty of fruits and vegetables, whole grains, and foods low in fat, cholesterol, sodium, and sugar.

What to do
If you smoke, it is really important for your health that you stop smoking. If you think that you are ready to stop, you can help.

The American Lung Association also offers help for smokers who are thinking about quitting. Please call 1-800-656-4672 for help.

Check your blood pressure once a week and write down the two numbers. Bring the list of blood pressure readings to your next doctor's appointment.

Medicines you need to take every day:

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Morning</th>
<th>Noon</th>
<th>Evening</th>
<th>Bedtime</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spiriva Inhaler 18 mcg/inh</td>
<td>1 puff</td>
<td></td>
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<tr>
<td>Albuterol Tablet 100 mg</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potassium Chloride 10 MEQ</td>
<td>1</td>
<td></td>
<td></td>
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<tr>
<td>Docusate Sodium Tablet 100 mg</td>
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<tr>
<td>Tramadol-HCl Tablet 37.5 mg/25 mg</td>
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</table>

This medicine is used to treat asthma.

This medicine is used to help treat a weak heart.

This medicine is used to replace potassium in the body.

This medicine is used to treat infection.

This medicine is used to treat high blood pressure.

This medicine is used to treat high blood pressure.

Medicines you should take as needed:

<table>
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<tr>
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<tbody>
<tr>
<td>200 ACTIQ (Tobutamid) 0.09 mg/ACTIQ Metered Dose Inhaler (Ventolin)</td>
<td>No</td>
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<td></td>
<td></td>
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<tr>
<td>Hydrocodone-AAP Tablet 5 mg/500 mg</td>
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</table>

<table>
<thead>
<tr>
<th>Medical name</th>
<th>Instructions</th>
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<tbody>
<tr>
<td>Use the medicine four times a day.</td>
<td></td>
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<tr>
<td>Inhale two (2) puffs each time.</td>
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<tr>
<td>Take the medicine by mouth every 6 hours.</td>
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<tr>
<td>Take one (1) pill each time.</td>
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</table>

This medicine is used to treat shortness of breath.

This medicine is used to relieve pain.

If you take any medicine that is not on this list, please tell your healthcare provider. If you have questions about your medicines, please call 1-800-555-2422.

To view, update, or print your medication list, please go to www.dchinstuctions.com. You will need the document ID and password (shown above).

English, Spanish, Mandarin, Cantonese, Korean, Haitian Creole, Italian, French, Arabic, Russian, Bengali, Polish, Karen, Burmese, Somali, Swahili, Vietnamese, Yiddish
PILOT PROJECTS

Self funded

- Montgomery County, MD
- 10 – 15 patients/family caregivers
- Targeting medication therapy management and access to community resources
- Supporting the elderly and disabled in low income housing residence

Seeking funding support

- Prince Georges (PG) County, Maryland
- Teamed w/PG County Health Department
- Community Health Workers will be early adopters
- Project will address an underserved population in a designated health enterprise zone
CHR “FIRSTS”

- First to develop a shared platform where health and social service providers, patients, and family caregivers ALL contribute information to support the patient’s health goals
- First to use SureScripts pharmacy data via the Maryland HIE to support medication therapy management
- First to tackle a plain-language consent process
AUDACIOUS GOALS

- Reduce hospital readmissions and non-emergent ED use in 250 of the costliest health communities in the US
- Have communities using Gateway services in every US state
- Make family caregivers informed, active, confident members of the patient’s care team
- Become the “standard of care”
COMMUNITY VISION

Healthier Community

- Care planning and daily living support for patients and families in health crisis
- Easy access to coordinated healthcare, social services, community supports
- Patients and families engaged thru plain language and multilingual information

Healthcare happens in the community.
THE WHITE PAPER
GOALS OF THE WHITE PAPER

- Bring attention to the information needs of family caregivers
- Provide an information framework for developers
- Discuss family caregiver technology needs and current tech limitations
- Address the elements of culture change necessary to create a healthcare ecosystem that empowers family caregivers
STATS YOU SHOULD KNOW

- 93M family caregivers provide $522B in care every year
- 86% ages 30 – 64

- > 30M annual hospital discharges
- ~ 40M annual ED discharges
- > $50B avoidable readmissions
- ~ $290B due to lack of medication mgmt
CAREGIVING INFORMATION CYCLE

- Crisis
  - Accident/injury
  - New Diagnosis

- Care Transition
  - New Care Setting
  - New Phase of Recovery/Illness

- Maintenance
  - Chronic Condition
  - Permanent Disability
CRISIS

Caregivers may need to *provide* patient information to healthcare professionals, including…

- Allergies and health history
- Family health history
- Immunizations
- Test results/labs/films
- Health insurance

Caregivers need to *gather* information, including…

- Diagnosis or injury details
- Disease-specific information
- Care options
- Next steps

Accident, injury, or new diagnosis
CARE TRANSITION

Caregivers may need to gather information about…

- The patient’s care plan
- Housing/caregiving options (i.e. rehab, home health, nursing home, hospice)
- Community resources (i.e. meals on wheels, transportation)
- Instructions for performing caregiving activities
- Medical equipment
Caregivers may need to gather information about …

- Long-term care supports
- Financial options
- Assistive devices
- Medication regimens
- Respite care
- Support groups
## FAMILY CAREGIVER TECHNOLOGY NEEDS

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<tr>
<td>Track</td>
<td>immunizations, vital signs, blood sugar, weight, food intake, mood, rest, patient location</td>
</tr>
<tr>
<td>Manage</td>
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<tr>
<td>Coordinate</td>
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<tr>
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TECH CHALLENGES FOR FAMILY CAREGIVERS

- Very few tools are designed specifically for family caregivers and their information needs
- Availability of these tools does not guarantee access to information
- Electronic access to personal health data is spotty. Blue Button is still in its infancy. It is difficult to obtain medical records
- Finding time to incorporate new technology into daily routines is often prohibitive, along with the applicability of technology to real-life caregiving scenarios
- Uncoordinated technology (e.g. multiple patient portals) may simply create more silos
- The language of healthcare is not the language of the average American
- Not all caregiving challenges can be solved with technology
OTHER BARRIERS

- Widespread adoption of existing family caregiver technology is painfully slow. Family caregivers simply don’t know what tools are available to them.

- Information on the web is not curated and written at a high literacy level. It becomes a mine field for caregivers to find, sift through, and comprehend medical information.

- Connectivity/monitoring do not imply “action”. They must be coupled with people in the community (in addition to first responders) who can take action when red flags arise.

- Patient (and Caregiver) Generated Health Data are not widely accepted and no framework exists for receipt/review/response.
REAL WORLD EXAMPLE:
CARE PLANNING
MY MOTIVATION

- Mom stays several weeks at in-patient rehab with severely fractured right arm
- At discharge, mom still not able to function independently
- Staff does not inquire about mom’s living situation or who would care for her
- “Care plan” at discharge = list of 53 home health agencies to choose from and 35 pages of cryptic discharge instructions
Discharge from Inpatient Rehab ≠ Care Plan
Data ≠ Information
CARE PLANS: STATUS QUO

- Typically used to coordinate care among providers, and with regard to specific health conditions
- Medicare *Plan of Care*:
  - The structure used to define the management actions for various conditions, problems, or issues. A care plan must include at a minimum the following requirements: problem (focus of care plan), goal (target outcome) and any instructions provider has given to the patient.
  - A goal is defined as a target or measure to be achieved in the process of patient care (an expected outcome).

Courtesy: Consumer Partnership for eHealth
MY DEFINITION OF A CARE PLAN

Care Plan Re-defined:
An actionable plan to assist caregivers in providing and/or coordinating care for their family members – that links the healthcare, social services, and community supports needed to support them in healthcare transition, medication management, treatment and recovery.
WHAT COULD AN ACTIONABLE CARE PLAN LOOK LIKE?
4 STEPS
START WITH THE BASICS...

- Patient goals
- Family caregiver role(s)
- Next steps in recovery or treatment
- Medication and discharge instructions in plain language
- Follow-up schedule
- More information on diagnosis/health issue
ADD SOCIAL SERVICES AND COMMUNITY SUPPORTS...

What supports does the patient need to meet their goals?

- Advocacy services
- Companion care
- Emergency assistance
- Housing options (assisted living, memory care, in-patient rehab)
- Meal services
- Medical supplies
- Respite care
- Support groups
- Transportation
TAILOR FOR THE FAMILY CAREGIVER...

What roadblocks does the family caregiver face in supporting their loved one?

- Access to technology
- Disability
- Distance
- Financial
- Transportation
- Work schedule

HOW CAN THE COMPONENTS OF THE CARE PLAN BE TAILORED TO OVERCOME THESE ROADBLOCKS?
CONNECT THE PLAN WITH MOBILE…

How can mobile support the patient and family caregiver in meeting their goals?

#4

- Access to critical information
- Connection to the care team
- Reminders for upcoming appointments, care plan checkpoints, and prescription refills
- Accountability
  - Meal has been delivered
  - Visiting nurse has arrived
  - Medicine has been taken
HOW DO WE MAKE THIS EASY FOR PATIENTS AND FAMILY CAREGIVERS?
### Jane Smith

#### Care Plan Dashboard

**My Goals:**
1. Recover from heart attack
2. Lower my blood pressure with medication
3. Bring my blood sugar down by eating healthy diet and taking medication
4. Start exercise program, begin with walking

**My Current Health Issues:**
1. Heart attack (on July 2nd)
2. High blood pressure
3. Diabetes
4. Lack of exercise/high fat diet

**My Allergies:**
- Peanuts
- Penicillin
- Demerol

**My Team:**
My caregiver:
- Amy Smith, my daughter, 703-888-9999

Family Doctor: Dr. Smith, 703-222-5555
[drrsmith@familydoc.com](mailto:drrsmith@familydoc.com)

Heart Doctor: Dr. Jones, 703-333-6666
[drjones@heartdoc.com](mailto:drjones@heartdoc.com)

Nutritionist: Kelly Dale, 703-444-7777
[kelly@nutrition.com](mailto:kelly@nutrition.com)

Pharmacist: Tom Harrison, 703-555-8888
[tom@localpharmacy.com](mailto:tom@localpharmacy.com)

**My Next Steps:**

This is what I need to do now:
- Make apt with my family doctor for follow-up
- Make apt with a cardiologist (a heart doctor)
- Begin taking blood pressure and diabetes medication
- Use oxygen when I have trouble breathing
- Wear a heart monitor

This is what I need to do next week:
- Walk for 10 min daily
- Work with nutritionist to plan low-fat diet

This is what I need to do in two weeks:
- Update care plan with my care team
- Walk for 15 min daily
- Join wellness program at senior center

**Supports I May Need to Achieve My Goals:**
- Meal services (for two weeks)
- Medical supplies (for oxygen and heart monitor)
- Nutritionist (to assist in planning new diet)
- Transportation to doctor appointments (until your doctor says you can drive)
- Visiting nurse (to monitor your heart for three weeks)

**My Medications:**

![Medication Chart]

**Mobile Alerts:**

- **Who:** My daughter
- **When:** My prescription refills, my doctor appts., meal delivery, visiting nurse arrives, my medicine has been taken

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CONSUMER PRINCIPLES FOR HEALTH & CARE PLANNING

1) Health & care plans should be goal-oriented, dynamic tools.

2) Tools that facilitate health & care planning should enable all members of the care team to securely access and contribute information, according to their roles.

3) Health & care plans should identify and reflect the ability and readiness of an individual to successfully meet their goals, as well as potential barriers.

4) Health & care planning and tools should facilitate decision-making and specify accountability.

5) Every individual would benefit from health & care planning and tools.

Courtesy: Consumer Partnership for eHealth. Care Plans 2.0: Consumer Principles for Health & Care Planning
CONCLUSIONS AND WRAP-UP
HOW DO WE MOVE FORWARD?

- Established resources in every community for healthcare, services, and technology coordination
- Education for family caregivers on tools and technologies that can support their caregiving needs
- Re-tooling of existing medical information into plain language and multilingual resources that family caregivers can easily understand
- Widespread use of secure messaging technology between patients, their family caregivers, and their providers
- Blue Button capability across providers so family caregivers can aggregate the patient’s medical records and test results in one place
- Comprehensive care planning that is actionable and tailored to the needs of patients and family caregivers
NEXT STEP: CULTURE CHANGE

**Listen**
- Pay close attention to the information they have to share
- Add their observations to the patient’s medical record
- Begin a dialogue with them and enable them to reach you via secure messaging

**Educate**
- Refer them to resources in the community that can help support them as caregivers
- Make them aware of tools such as patient portals, Blue Button, online resources and support communities

**Train**
- Show them how to use your patient portal effectively
- Provide hands-on training for any medical tasks they will be performing
- Assist them in navigating the next steps in care
CONTACT INFO

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Personal: sterlinghealthit.com
Twitter: @SterlingHIT