

## **Re-forming Healthcare: *Americans Speak Out About Chronic Conditions & the Pursuit of Healthier Lives***

### **Findings from a National Survey of Americans 44 and Older with Chronic Conditions**

*March 18, 2009* – The National Council on Aging, with support from The Atlantic Philanthropies and the California HealthCare Foundation, commissioned a study that offers a rare glimpse into the lives of Americans with chronic health conditions such as heart disease, arthritis, and diabetes. Lake Research Partners conducted a national telephone survey among n=1,109 Baby Boomers (44-63) and older Americans (64+) with at least one chronic condition,<sup>1</sup> January 5-30, 2009. The survey included an oversample of Latinos, and was conducted in both English and Spanish.

The survey provides a window into the lives, health care struggles, and needs of people with chronic conditions. It shows the diversity of this population, and provides in-depth analysis of the factors that correlate with health care needs and barriers, such as racial/ethnic background, gender, income, and number of chronic conditions.

One shared experience among these adults with chronic conditions is putting off medical care due to costs. One in four Americans 44 and older with chronic condition(s) reports they are putting off care because they cannot afford it. Latinos, women, and those with multiple chronic conditions are among the most likely to be delaying health care because of cost.

Another common theme in the survey is the degree to which this population looks to the medical system for support and care, and the frustrations many face interacting with this system. Many are not getting the care and support they want and need. Specifically, many report that they do not get enough time with their doctors and feel tired of trying to manage their health problems on their own. Large numbers also report that their providers do not refer them to support groups, classes, dieticians or others who can help them manage their conditions.

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<sup>1</sup> These include heart disease, cancer, stroke, diabetes, arthritis, asthma, hypertension or high blood pressure, emphysema, chronic bronchitis, depression, and anxiety, among others.

The survey also shows that many individuals with chronic conditions are in constant physical pain and are always or frequently fatigued. Others face depression, stress, and anger as a result of their health problems. Some say their health conditions have strained family relationships. While they rely on health care providers, family members and friends, nearly half says they only occasionally, rarely, or never get the ongoing help and support they need.

In terms of types of support, majorities say learning from others like them, sharing tips and advice and setting goals together, would help in managing their health conditions. A large proportion also wants help learning how to eat right and exercise in ways that work with their limitations. Some need help learning *what* they need to do to take better care of their health, as well *how* to do it. While most want ongoing help and support from their health care providers, 85% of Americans 44 and older with chronic conditions are interested in sources of help outside the medical system – such as from people they know around them, events held in their community, websites and online courses. Finally, the survey shows a willingness among this population to help each other. Some are already involved in supporting others who have health care needs, and a majority says they are willing to do more to help people with chronic conditions in their communities.

Following are key findings from the study.

## **Key Findings**

### ***Americans 44 and Older with Chronic Conditions Are Diverse***

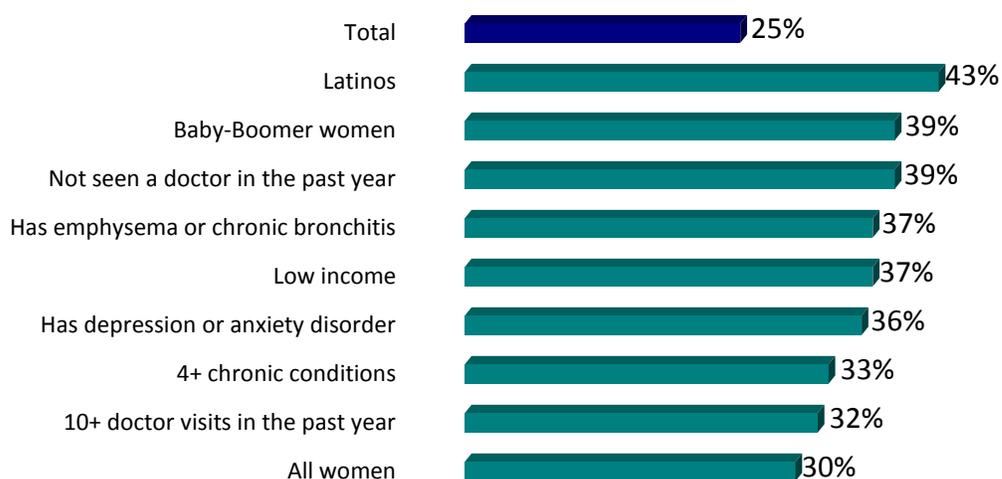
Americans 44 and older with chronic conditions are a diverse group of people with varying needs and barriers to taking care of their health. Those with *one* chronic condition versus *multiple* conditions look starkly different. More than two-thirds (68%) of respondents have two or more chronic conditions – and 20% have four or more chronic conditions. Those with one chronic condition are healthier, have higher incomes, and have more support at home; while those with multiple conditions tend to have low incomes and less support. The data show low-income individuals consistently face the most challenges to managing their health, and have the greatest needs. Latinos, in particular, confront more challenges than white Americans, and are especially interested in support from people and places in their community.

### ***One in Four Has Delayed Health Care Due to Cost***

In the past year, one in four Americans 44 and older with chronic conditions (25%) has postponed health care or getting prescription medications because they cannot afford it. Latinos (43%) and Baby-Boomer women (39%) are most likely to have delayed care because of cost (see Figure 1). While low-income individuals are among the most likely to have put off care, even 22% of those with household incomes of \$50,000 or more have made decisions to delay care.

**Figure 1: Most Likely to Have Postponed Care Due to Cost**

In the past year have you had to put off or postpone getting prescriptions or health care because of cost?  
% yes



Individuals who have delayed health care due to cost also face some of the toughest challenges in their daily lives. They are nearly twice as likely as others to always or frequently be in physical pain (45% vs. 28% of those who have not delayed care), tired (49% vs. 28%), and stressed (40% vs. 17%) as a result of their health conditions. They are among the most frustrated with the health care system, and they are among the most interested in trying to find support and help from sources outside the system, such as online and at community events.

### ***Most Rely on Health Care System for Help, But Not Working Well for Many***

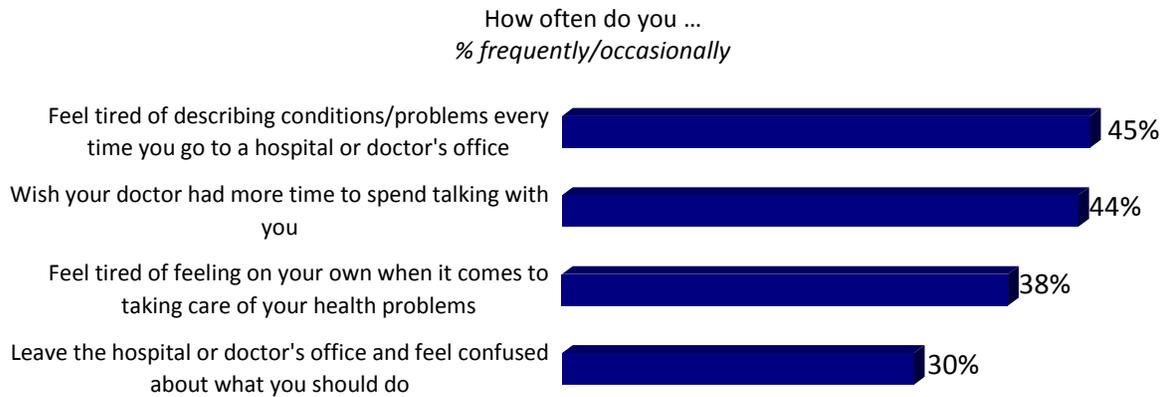
Americans 44 and older with chronic conditions tend to rely most on health care providers (65% rely a lot or some) for ongoing help and support to manage their health problems, followed by spouses/partners (52%), and friends and relatives (50%).

However, the health care system is not working well for many individuals with chronic health conditions. Forty-four percent say they frequently or occasionally wish their doctor had more time to spend talking to them, and 45% feel tired of explaining their health problems every time they see a health care provider (see Figure 2). Thirty percent say they frequently or occasionally leave a doctor's office or hospital feeling confused about what they should do. Close to four in ten (38%) say they feel tired of feeling on their own when it comes to taking care of their health. Those most likely to feel tired of feeling on their own include:

- Latinos (58% frequently or occasionally);
- Those without health insurance (57%);
- Low-income individuals (56% of those with less than \$20,000 household income);
- Individuals who have postponed care due to cost (55%);
- Heavy users of the health care system (55% of those with 10+ doctor visits in the past year);

- Individuals with depression or anxiety (53%); and
- Those with four or more chronic conditions (52%).

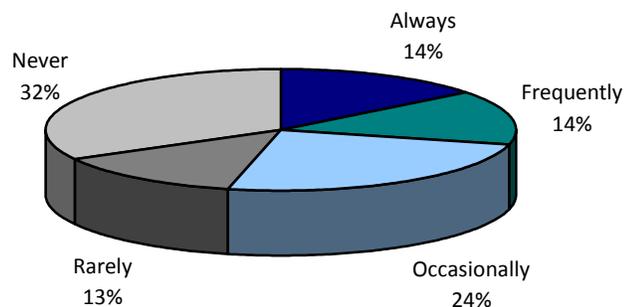
**Figure 2: Experiences with Health Care System**



In addition, many say their health care providers are not doing things that could help. More than half (57%) says their health care providers have not asked whether they have help at home to manage their health problems, including 52% of those with four or more chronic conditions. Forty-four percent say their health care providers rarely or never ask for their own ideas about how to take care of their health problems. Forty-five percent say their health care providers rarely (13%) or never (32%) refer them to support services, such as classes, groups, counselors, dieticians, and health educators (see Figure 3). Individuals 75 and older are most likely to say their health care providers rarely or never refer them to support services (56%).

**Figure 3: How Often Providers Refer to Support Services**

How often do your health care providers tell you about other people who can help you with your health problems, such as groups, classes, counselors, dieticians, and health educators?



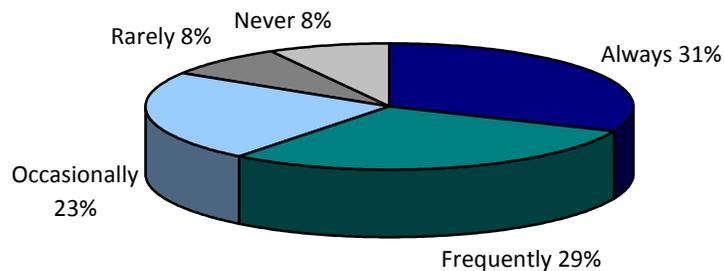
## ***Many Not Getting Help and Support They Need***

Four in ten (39%) Americans 44 and older with chronic conditions say they only occasionally, rarely, or never get the help and support they need to manage their conditions and improve their health (see Figure 4). Those least likely to say they get the help and support they need include:

- Individuals without health insurance (55% say occasionally, rarely, or never);
- Latinos (53%);
- Those with household incomes of \$20,000 or less (50%); and
- Individuals who have postponed care due to cost in the past year (49%).

**Figure 4: Many Not Getting Help and Support They Need**

How often do you feel you get the help and support you need to improve your health and manage your health problems?



## ***Daily Life a Struggle for Some***

Insights into their daily lives help explain why many Americans 44 and older with chronic conditions may not be getting enough ongoing support. Their needs are many, and significantly affect quality of life. One in three (32%) is always or frequently in physical pain as a result of their health problems. This increases with number of chronic conditions – 58% of those with four or more conditions are always or frequently in physical pain. One in three (34%) says their health problems result in always or frequently feeling tired and lacking energy. Two-thirds (65%) say they feel stressed at least occasionally due to their health problems. Half says their health problems make them feel depressed (50%) and angry (49%) at least occasionally. Again, those with multiple chronic conditions face these emotional and mental struggles more frequently.

As a result of their health problems, Americans 44 and older with chronic conditions have had to cut back on social activities (32%), helping family and friends (26%), and others in their community (27%). More than one in four (28%) of those with low household incomes have felt strains on family relationships due to their health problems. One in four who are currently employed (26%) have had to miss work due to their health.

## ***Cost, Confidence, Lack of Knowledge Are Barriers to Managing Conditions***

In addition to the physical and mental challenges many face as a result of their chronic conditions, 38% say they do not have the money it takes to do things to improve their health or conditions. Others lack confidence in their ability to change (37%). Individuals most likely to lack confidence are those with heart disease (55%), emphysema or chronic bronchitis (54%), and depression or anxiety (51%). In addition, some lack knowledge about *what* they should be doing to take better care of their health (30%), as well as *how* to do these things (35%). Individuals with multiple chronic conditions say dealing with their different health problems makes it difficult to take better care of their health.

These barriers vary across a number of factors including race/ethnicity, income, and number of chronic conditions (see Table 1). For example,

- A majority of Latinos face a number of these barriers;
- Half of those with depression or anxiety (50%) need help learning *how* to take better care of their health in a way that works for them;
- Low-income individuals and those with four or more chronic conditions are much more likely than others to face these barriers; and
- Those who live alone are more likely than others to lack confidence in their ability to change (45% vs. 34% of those who live with another adult).

**Table 1: Barriers to Self-Care**

Many things can get in the way of taking care of your health problems and doing things like exercising, eating right, and taking medications as prescribed. Please tell me if you agree or disagree with the following statements.

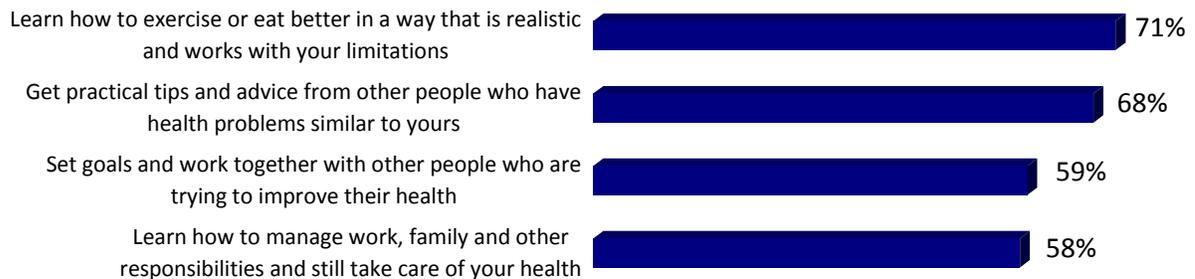
| <i>% agree</i>     | <b>I don't have the money to do things that will improve my health or condition</b> | <b>I wish I could change and do things that are healthier, but I just don't think I can</b> | <b>I need help learning <u>how</u> to take better care of my health in a way that works for me</b> | <b>All of my different health problems make it difficult to take better care of myself</b> | <b>I need help learning <u>what</u> I should be doing to take better care of my health</b> |
|--------------------|---|---|--|--|--|
| <i>Total</i>       | 38%   | 37%   | 35%  | 31%  | 30%  |
| White              | 34%   | 35%   | 32%  | 28%  | 27%  |
| Black/AA           | 58%   | 44%   | 45%  | 36%  | 40%  |
| Latino             | 63%   | 60%   | 70%  | 58%  | 62%  |
| <\$20K HH income   | 65%   | 57%   | 46%  | 51%  | 42%  |
| \$20K-\$50K        | 37%   | 36%   | 31%  | 31%  | 27%  |
| \$50K+             | 22%   | 26%   | 32%  | 16%  | 26%  |
| 1 chronic cond.    | 27%   | 24%   | 25%  | 14%  | 21%  |
| 2                  | 36%   | 33%   | 35%  | 25%  | 28%  |
| 3                  | 38%   | 40%   | 39%  | 38%  | 35%  |
| 4+                 | 59%   | 62%   | 47%  | 59%  | 41%  |
| Live alone         | 46%   | 45%   | 33%  | 39%  | 28%  |
| Not alone          | 34%   | 34%   | 35%  | 28%  | 30%  |
| Depression/anxiety | 54%   | 51%   | 50%  | 44%  | 39%  |

## ***Learning How to Change Behaviors in Realistic Ways and Getting Tips and Advice from Others Would Be Most Helpful***

Seven in ten (71%) Americans 44 and older with chronic conditions say learning how to exercise or eat better in realistic ways that work with their limitations would be helpful in managing their conditions and improving their health. More than two-thirds (68%) say getting practical tips and advice from others who have similar health problems would also be helpful. Nearly six in ten (59%) say the same about setting goals and working together with others. About the same proportion (58%) would find helpful learning how to manage work, family, and other responsibilities while taking care of their health (see Figure 5).

**Figure 5: Types of Support and Help**

I'd like to ask you about things that might help you manage your health problems and improve your health. Please tell me how helpful would each of the following be for you personally: How helpful would it be for you to:  
% helpful



Individuals most likely to say these types of supports would be helpful include Baby-Boomer women, Latinos, African Americans, low-income individuals, and those who have delayed care due to cost.

## ***Many Interested in Support from Providers, Community, Online, and Work***

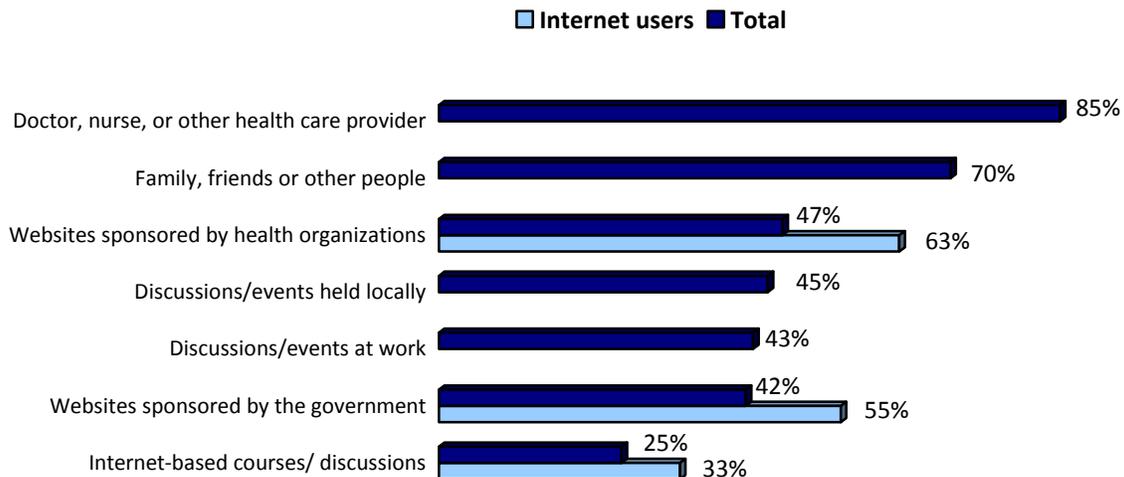
Americans 44 and older with chronic conditions are open to a number of ways in which to get more help and support. A majority (85%) is interested in getting help from their health care providers, and the same proportion (85%) expresses interest in one or more other sources of help. Seven in ten (70%) say they would be interested in getting help from the people they know around them (see Figure 6).

Fifty-six percent of Americans 44 and older with chronic conditions are internet users – and of these, 63% say they would be interested in going to websites sponsored by health organizations to get information and support. Even one in four (27%) who rarely or never use the internet says they would be interested in going to websites for information and support. Already, 39% of internet users are going on blogs, discussion groups, or other websites to read about people’s experiences with health problems similar to their own. One in three current users (33%) would be interested in online courses or discussion groups.

In addition to online support, 45% are interested in getting information and support from discussions or events held at places in their community. Four in ten (43%) of those working full time say they would be interested in discussions or events at work.

**Figure 6: Interest in Getting Information & Support From Various Sources**

How interested would you be in getting information and support from:  
*% interested*



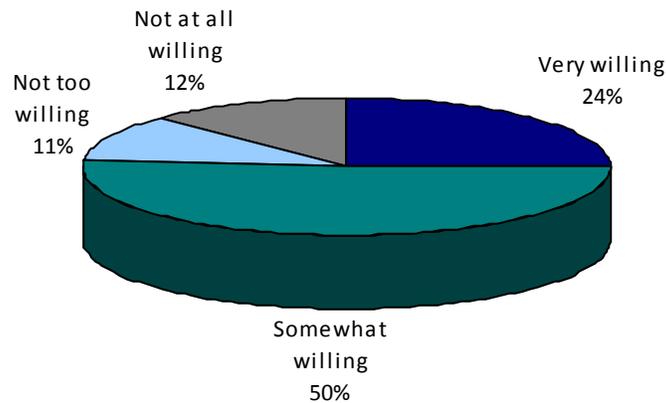
Individuals most interested in getting information and support from all of these sources include women, Baby Boomers, Latinos, African Americans, those who have delayed care due to cost, and those without insurance.

## Majority Willing to Help Each Other

Finally, the survey shows Americans 44 and older with chronic conditions are willing to help each other. One in four (24%) is already providing care and assistance to friends or family members who are elderly, have disabilities or long-term illnesses, and 13% are receiving such support. Three in four (74%) say they are willing to help others in their community with chronic health problems (see Figure 7).

**Figure 7: Willingness to Help Others with Chronic Conditions**

In the future, how willing would you be to help others in your community who have chronic health problems?



### Methodology

This survey was conducted via telephone January 5 - 30, 2009, among 1,109 Americans age 44 and older nationwide, who have at least one chronic condition. The survey included an oversample of those 65 and older (n=594 total), as well as an oversample of Latinos (n=142 total). The data were weighted by age, race, and region to reflect the overall population of Americans 44+ with chronic condition(s). Interviewing was conducted using random digit dialing (RDD) sample. For the Latino oversample, a combination of targeted RDD and listed sample was used. Interviews were conducted in both English and Spanish. The margin of sampling error for the total results is  $\pm 2.9$  percentage points. Margin of error is greater when analyzing smaller subgroups within the sample.

Respondents were screened for chronic condition(s) with the following question(s): "Q. Have you ever been told by a doctor, nurse or other health professional that you have \_\_\_\_: [diabetes or high blood sugar, arthritis, asthma, chronic bronchitis or emphysema, hypertension or high blood pressure, heart disease, cancer, depression or an anxiety disorder, had a stroke, any other serious or chronic health condition.]" Only respondents who reported "yes" to at least one of these items were included in the survey.