Ageing, Chronic Disease and Long-Term Care
With the reduction of infant mortality rates, the conquest of most epidemic diseases, and the increased longevity of the population, a much greater proportion of the people than formerly are afflicted with heart disease, cancer, rheumatism, diabetes, and other non-bacterial disorders. Being chronic, these diseases require medical care that is expensive and beyond the means of many individuals. Public action, therefore, is deemed necessary—especially in the development of numerous institutions for the aged and chronically ill.

Ageing can be defined as a progressive, generalized impairment of function resulting in a loss of adaptive response to stress and in a growing risk of age-associated disease.

From: ActiveAgeing, A Policy Framework, WHO 2002
How Old is Older?

This booklet uses the United Nations standard of age 60 to describe "older" people. This may seem young in the developed world and in those developing countries where major gains in life expectancy have already occurred. However, whatever age is used within different contexts, it is important to acknowledge that chronological age is not a precise marker for the changes that accompany ageing. There are dramatic variations in health status, participation and levels of independence among older people of the same age. Decision-makers need to take this into account when designing policies and programmes for their "older" populations. Enacting broad social policies based on chronological age alone can be discriminatory and counterproductive to well being in older age.
As the proportion of children and young people declines and the proportion of people age 60 and over increases, the triangular population pyramid of 2002 will be replaced with a more cylinder-like structure in 2025.

Source: UN, 2001
Some trends in population ageing:

- Definition: Decline in the proportion of children and young people and an increase in the proportion of people age 60 and over.

- Causes: Decreasing fertility rates and increasing longevity

- By 2025, 120 countries will have reached a fertility rate below replacement level (2.1 children per woman). Currently 70 countries are at this level.

- Over half of the world’s older people live in Asia

- The fastest growing segment is those over 80

- At age >80, there are fewer than 6 men for every 10 women (In more developed countries, ratio can be < ½; in Brazil and South Africa women comprise about 2/3 of the population over 75).

- “While developed countries grew affluent before they became old, developing countries are getting old before a substantial increase in wealth occurs.”

- Important issues in developing countries with respect to social support of the aged: urbanization, migration of young to cities, smaller families, more women in the workforce, increasing trend for elderly to live alone

From: ActiveAgeing: A Policy Framework, WHO 2002
<table>
<thead>
<tr>
<th></th>
<th>2002</th>
<th></th>
<th>2025</th>
</tr>
</thead>
<tbody>
<tr>
<td>Italy</td>
<td>24.5%</td>
<td>Japan</td>
<td>35.1%</td>
</tr>
<tr>
<td>Japan</td>
<td>24.3%</td>
<td>Italy</td>
<td>34.0%</td>
</tr>
<tr>
<td>Germany</td>
<td>24.0%</td>
<td>Germany</td>
<td>33.2%</td>
</tr>
<tr>
<td>Greece</td>
<td>23.9%</td>
<td>Greece</td>
<td>31.6%</td>
</tr>
<tr>
<td>Belgium</td>
<td>22.3%</td>
<td>Spain</td>
<td>31.4%</td>
</tr>
<tr>
<td>Spain</td>
<td>22.1%</td>
<td>Belgium</td>
<td>31.2%</td>
</tr>
<tr>
<td>Portugal</td>
<td>21.1%</td>
<td>United Kingdom</td>
<td>29.4%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>20.8%</td>
<td>Netherlands</td>
<td>29.4%</td>
</tr>
<tr>
<td>Ukraine</td>
<td>20.7%</td>
<td>France</td>
<td>28.7%</td>
</tr>
<tr>
<td>France</td>
<td>20.5%</td>
<td>Canada</td>
<td>27.9%</td>
</tr>
</tbody>
</table>

*Source: UN, 2001*
Figure 3. Distribution of world population over age 60 by region, 2002 and 2025

NAm: North America
LAmC: Latin America and the Caribbean

Source: UN, 2001
A New, Expanded Definition of Chronic Conditions

In summary, chronic conditions are no longer viewed conventionally (e.g., limited to heart disease, diabetes, cancer, and asthma), considered in isolation, or thought of as disparate disorders. The demands on patients, families, and the health care system are similar, and, in fact, comparable management strategies are effective across all chronic conditions, making them seem much more alike than different. Chronic conditions therefore include:

- noncommunicable conditions
- persistent communicable conditions
- long-term mental disorders
- ongoing physical/structural impairments

Innovative care for chronic conditions: building blocks for action: global report

© World Health Organization 2002
By the year 2020, chronic conditions including injuries (e.g., transport injuries that result in persistent disability) and mental disorders will be responsible for 78% of the global disease burden in developing countries.
Why are Chronic Conditions Increasing?

The Demographic Transition

Throughout the world birth rates are declining, life expectancies are increasing, and populations are ageing. For example, in the 1950s, the expected number of children a woman would bear over a lifetime was six; today, the total fertility rate has declined to three. In addition, over the last century, life expectancies have increased by 30 to 40 years in developed countries. Longer lives are due, in part, to advances in medical science and technology, but also are because of successful public health and development efforts during the past 100 years.
<table>
<thead>
<tr>
<th>Major chronic conditions affecting older people worldwide</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cardiovascular diseases (such as coronary heart disease)</td>
</tr>
<tr>
<td>• Hypertension</td>
</tr>
<tr>
<td>• Stroke</td>
</tr>
<tr>
<td>• Diabetes</td>
</tr>
<tr>
<td>• Cancer</td>
</tr>
<tr>
<td>• Chronic obstructive pulmonary disease</td>
</tr>
<tr>
<td>• Musculoskeletal conditions (such as arthritis and osteoporosis)</td>
</tr>
<tr>
<td>• Mental health conditions (mostly dementia and depression)</td>
</tr>
<tr>
<td>• Blindness and visual impairment</td>
</tr>
</tbody>
</table>

*Note: The causes of disability in older age are similar for women and men although women are more likely to report musculoskeletal problems.*

*Source: WHO, 1998a*
The WHO defines **long-term care** as “the system of activities undertaken by informal caregivers (family, friends and/or neighbors) and/or professionals (health and social services) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfillment and human dignity.”
Measuring functional status:

- **Activities of Daily Living (ADL)**
  - Eating
  - Bathing
  - Dressing
  - Getting into and out of bed or chair
  - Going to bathroom

- **Instrumental Activities of Daily Living**
  - Preparing meals
  - Managing medications
  - Shopping
  - Housework
Figure 4. Maintaining functional capacity over the life course

Early Life
Growth and development

Adult Life
Maintaining highest possible level of function

Older Age
Maintaining independence and preventing disability

Functional Capacity

Age

Range of function in individuals

Disability threshold*

Rehabilitation and ensuring the quality of life

Source: Kalache and Kickbusch, 1997

*Changes in the environment can lower the disability threshold, thus decreasing the number of disabled people in a given community.

Functional capacity (such as ventilatory capacity, muscular strength, and cardiovascular output) increases in childhood and peaks in early adulthood, eventually followed by a decline. The rate of decline, however, is largely determined by factors related to adult lifestyle – such as smoking, alcohol consumption, levels of physical activity and diet – as well as external and environmental factors. The gradient of decline may become so steep as to result in premature disability. However, the acceleration in decline can be influenced and may be reversible at any age through individual and public policy measures.
Quality of Care Concerns and Regulatory Responses - Institutional Care

Concerns:
- Inappropriate use of physical and pharmacological restraints
- Pressure ulcers (bed sores)
- Severe deficits in dementia care, e.g., inappropriate and/or insufficient support for eating and drinking
- Lack of privacy and basic patient rights
- High staff turnover and shortages of qualified personnel

Regulatory Responses:
- Re-accreditation (Australia 1997)
- New and Higher Standards (Austria 1994)
- Quality Regulations (Germany 2002)
- New National Regulator and Care Standards (UK 2001)
- Publication of Quality of Care Findings (Australia and U.S.)
- Higher salaries and more training for personnel in nationalized systems (Sweden)

From: Toward High-Performing Health Systems, OECD 2004
Institutional Capacity

- Widespread shortages: Japan, Spain
- Localized shortages: Australia, UK, US
- Growing supply: Germany, Japan
- Stable ratio of beds/elderly population: Austria, New Zealand, UK
- Declining ratio of beds/elderly population: Luxemburg, the Netherlands, Norway

From: Toward High-Performing Health Systems, OECD 2004
Home Care Issues

- Most people prefer home care to institutionalization
- Lack of consumer information about available services (Austria, U.K.)
- Limited access to services that support informal, primary caregivers, e.g., respite care, training and counseling
- Recent policies for quality assessment and improvement (Australia, Canada, Germany, UK)
- Home-based options considered first is mandated in many countries, e.g., UK
- Targeted approach to disabled elderly rather than all at risk of institutionalization (Sweden, UK, US)
- Enabling private sector growth by increasing funding for home care (Germany)

From: Toward High-Performing Health Systems, OECD 2004
## Use Of Medicare Home Health Services, FFY 1997–2001

<table>
<thead>
<tr>
<th>Year</th>
<th>1997</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>FFS beneficiaries (1,000s)</td>
<td>32,755</td>
<td>32,059</td>
<td>31,629</td>
<td>31,715</td>
<td>32,640</td>
</tr>
<tr>
<td>Incidence of use</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of users (1,000s)</td>
<td>3,296</td>
<td>2,953</td>
<td>2,518</td>
<td>2,417</td>
<td>2,277</td>
</tr>
<tr>
<td>Users per 1,000 beneficiaries</td>
<td>100.6</td>
<td>92.1</td>
<td>79.6</td>
<td>76.2</td>
<td>69.8</td>
</tr>
<tr>
<td>Visits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number (1,000s)</td>
<td>259,816</td>
<td>183,510</td>
<td>116,276</td>
<td>100,291</td>
<td>71,939</td>
</tr>
<tr>
<td>Per beneficiary</td>
<td>7.9</td>
<td>5.7</td>
<td>3.7</td>
<td>3.2</td>
<td>2.2</td>
</tr>
<tr>
<td>Per home health user</td>
<td>78.8</td>
<td>62.1</td>
<td>46.2</td>
<td>41.5</td>
<td>31.6</td>
</tr>
<tr>
<td>Payments in nominal dollars</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (billions)</td>
<td>$16.37</td>
<td>$11.96</td>
<td>$7.83</td>
<td>$7.46</td>
<td>$8.10</td>
</tr>
<tr>
<td>Per beneficiary</td>
<td>499.90</td>
<td>373.21</td>
<td>247.66</td>
<td>235.16</td>
<td>244.19</td>
</tr>
<tr>
<td>Per home health user</td>
<td>4,968.68</td>
<td>4,051.85</td>
<td>3,110.28</td>
<td>3,085.48</td>
<td>3,556.90</td>
</tr>
<tr>
<td>Per visit</td>
<td>63.02</td>
<td>65.20</td>
<td>67.37</td>
<td>74.36</td>
<td>112.60</td>
</tr>
</tbody>
</table>

**Source:** Authors' analysis of Centers for Medicare and Medicaid Services (CMS) 1 Percent Denominator and Home Health Standard Analytic Files.

**Notes:** The sample sizes for home health users are 35,516 for 1997; 31,778 for 1998; 27,074 for 1999; 25,904 for 2000; and 24,453 for 2001. The sample sizes for nonusers are 47,742 for 1997, 47,084 for 1998; 46,973 for 1999; 314,598 for 2000; and 325,942 for 2001. Beneficiaries are weighted by the proportion of the year they were Medicare-eligible, and users and nonusers are weighted up to their proportions in the Medicare population. The reduction in enrollment for the 1997–1999 time period is the result of increasing enrollment in Medicare managed care plans during these years. FFY is federal fiscal year. FFS is fee-for-service.

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Financial Issues for Long-Term Care

- Contribution vs. General Taxation
- Universal (Need-based) vs. Means Tested (Income-based, safety net)
- Caregiver payments (Australia, UK) or increased payments that can be used to compensate caregiver (Austria, Germany)
- Part of Healthcare System vs. Social-Care
- Rising incomes and net worth of elderly, particularly in developed countries → Increasing user responsibility for payment (Australia, Sweden, some Canadian provinces)
- Minor role for private insurance (US has largest share at 11% of total LTC spending) Problems: Low uptake by non-elderly, poor policy retention, problems projecting future cost and use, premium stability required for sale, decision to purchase insurance vs. self-funding
- Rising number of elderly + macroeconomic downturn + no accounting for indexing of benefit rates = Unsustainable financial solvency (Germany-deficits, Japan- 10% increases in premiums 3 years after introduction of policy)
- By 2050, to maintain a constant ratio between working and pension aged populations would require Germany’s population to consist of 80% immigrants (or progeny) or require the average Japanese to work until age 83
- Suggested financial changes to social security benefits: Eliminate early retirement schemes; make benefits actuarially neutral, e.g., pensions reflect actual time working; raise standard retirement ages; increase childcare subsidies; eliminate tax discrimination against female participation (due to higher marginal rate for two worker families); enhance the role of part-time work; mid-life enhanced job training

# The Cost of Nursing-Home Care

<table>
<thead>
<tr>
<th>City</th>
<th>Daily Cost for a Private Room</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birmingham, Ala.</td>
<td>$133</td>
</tr>
<tr>
<td>San Diego</td>
<td>217</td>
</tr>
<tr>
<td>Washington, D.C.</td>
<td>260</td>
</tr>
<tr>
<td>Jacksonville, Fla.</td>
<td>180</td>
</tr>
<tr>
<td>Des Moines</td>
<td>209</td>
</tr>
<tr>
<td>Chicago</td>
<td>136</td>
</tr>
<tr>
<td>Boston</td>
<td>284</td>
</tr>
<tr>
<td>Fargo, N.D.</td>
<td>188</td>
</tr>
<tr>
<td>Spokane, Wash.</td>
<td>196</td>
</tr>
</tbody>
</table>

*The highest nursing-home rates were reported in Alaska, where the cost is $204,765 a year, or $561 a day on average. The lowest rates were found in Louisiana at $36,135 a year, or $99 a day.*

Measures to improve efficiency in delivery of long-term care:

- Pre-admission screening
- Enhanced flexibility to individualize services (avoiding costly “either-or” options, like “3 day rule” for Medicare in US)
- Allowing payment for home care services as an alternative to institutionalization
- Enhance coordination of care (case management)
- Support family care-givers

*** All these measures were adopted, to some degree in Japan after 2000 and some adopted in Australia, Canada, the Netherlands, UK and US

From: Toward High-Performing Health Systems, OECD 2004
Disease Management is a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant. Disease management:

- supports the physician or practitioner/patient relationship and plan of care,
- emphasizes prevention of exacerbations and complications utilizing evidence-based practice guidelines and patient empowerment strategies, and
- evaluates clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health.

Disease Management Components include:
1. Population Identification processes
2. Evidence-based practice guidelines
3. Collaborative practice models to include physician and support-service providers
4. Patient self-management education (may include primary prevention, behavior modification programs, and compliance/surveillance)
5. Process and outcomes measurement, evaluation, and management
6. Routine reporting/feedback loop (may include communication with patient, physician, health plan and ancillary providers, and practice profiling)

Full Service Disease Management Programs must include all 6 components. Programs consisting of fewer components are Disease Management Support Services.

Source: Disease Management Association of America
RMS Disease Management, LLC is one of six organizations selected by CMS for the Care Management for High Cost Beneficiaries (CMHCB) demonstration. The Demonstration will test the ability of direct-care provider models to coordinate care for high-cost/high-risk beneficiaries by providing such beneficiaries with support to manage their conditions and enjoy a better quality of life.
Example of DM Effectiveness in the U.S. and Abroad

Staged Diabetes Management (SDM) is a set of guidelines and clinical pathways for managing diabetes in primary care settings. It provides clinical templates and flowcharts to guide care decisions, helping to improve the standard of care, reduce variation in practice, and increase surveillance for diabetes-related eye, foot, heart, and kidney disease. The model was developed by the International Diabetes Center (IDC) of Minneapolis, Minn., supported through an educational grant from Becton Dickinson and Company, and piloted in the United States, Brazil, Mexico, and Poland...

Based on the specific studies conducted, SDM resulted in: lower pregnancy and neonatal complications among pregnant women with type 1 diabetes in Poland; reduced blood glucose levels and rate of concurrent morbidities of people with diabetes in poor Mexican communities; and significantly improved [HbA.sub.1c] levels and increased surveillance for eye disease and foot disease in rural primary care settings in Minnesota.

Source: Clinical Diabetes, Sept/Oct 1997
Innovative Care for Chronic Conditions Framework

Positive Policy Environment
- Strengthen partnerships
- Support legislative frameworks
- Integrate policies
- Provide leadership and advocacy
- Promote consistent financing
- Develop and allocate human resources

Community
- Raise awareness and reduce stigma
- Encourage better outcomes through leadership and support
- Mobilize and coordinate resources
- Provide complementary services

Health Care Organization
- Promote continuity and coordination
- Encourage quality through leadership and incentives
- Organize and equip health care teams
- Use information systems
- Support self-management and prevention

Better Outcomes for Chronic Conditions

Innovative care for chronic conditions: building blocks for action: global report

© World Health Organization 2002
How do we measure success?

“As the survival rate from acute and short-term disease increases, there will be an increase in long-term and intractable chronic illness. Thus, other indices of ‘payoff’ need to be brought into an evaluation of the ‘effectiveness’ of a health service. These indices involve relief of pain, relief of anxiety, measures of satisfaction, and a graceful adjustment to inevitable disabilities as a person ages. In other words, these are ‘quality’ of life rather than ‘quantity’ of life measures and will require a concept of payoff as yet undeveloped.”

Odin Anderson in: HEALTH CARE: Can There Be Equity? (1972)