



# CONTACT DETAILS

## **PATIENTVIEW**

### **HEALTH AND SOCIAL CAMPAIGNERS' NETWORK INTERNATIONAL**

*Health and Social Campaigners' News International*

WOODHOUSE PLACE

UPPER WOODHOUSE

KNIGHTON

POWYS, LD7 1NG

WALES

TEL: +44-(0)1547-520-965

FAX: +44-(0)1547-528-501

EMAIL: [INFO@PATIENT-VIEW.COM](mailto:INFO@PATIENT-VIEW.COM)

INTERNET: [HTTP://WWW.PATIENT-VIEW.COM](http://WWW.PATIENT-VIEW.COM)

Please note that PatientView is not responsible for, and may not necessarily agree with, the opinions expressed within the pages of *HSCNews International* by contributors or interviewees.

COVER ILLUSTRATION: Thanks to Alkoholpolitik; Birmingham Focus on Blindness; Henry Nead; and the World Diabetes Federation.

## **COPYRIGHT**

© 2006 PatientView Ltd. All rights reserved.

This booklet is the property of PatientView, and no part may be reproduced without permission, or passed on to any third party without the permission of PatientView.

Registered Address for PatientView:

Millennium Bridge House,

2 Lambeth Hill,

London, EC4 4AJ, UK

Data protection registration number: Z7133076

VAT registration number: GB-760-985-885

Company number: 3944382

**HEALTH AND SOCIAL  
CAMPAIGNERS'  
NEWS INTERNATIONAL**

**ISSUE 33  
NOVEMBER 2006**

**PUBLISHED BY PATIENTVIEW**



# C ONTENTS

THE RISE AND RISE OF THE CARERS' MOVEMENT .....	PAGES 6-36
THE CARERS' MOVEMENT: AN OVERVIEW .....	PAGES 7-24
JEAN GEORGES: A VIEW FROM ALZHEIMER EUROPE .....	PAGES 26-28
LIAM O'SULLIVAN: A VIEW FROM CARE ALLIANCE IRELAND .....	PAGES 29-30
K. R. GANGADHARAN: A VIEW FROM THE HERITAGE HOSPITAL, HYDERABAD .....	PAGES 31-33
GAIL HUNT: A VIEW FROM THE INTERNATIONAL ALLIANCE OF CARERS ORGANIZATIONS .....	PAGES 34-36
MEMBERS' NEWS ON CARERS.....	PAGES 38-40
▶ PRINCESS ROYAL TRUST FOR CARERS [SCOTLAND]	
▶ EXTRA CARE [NORTHERN IRELAND]	
RESEARCH ON CARERS .....	PAGES 41-42
▶ COFACE [BELGIUM]	



# The rise and rise of the carers' movement

OVER THE PAST TWO DECADES, THE CARERS' MOVEMENT HAS EVOLVED INTO AN INTERNATIONAL FORCE. PATIENT GROUPS, TOO, HAVE BEGUN TO ADVOCATE ON BEHALF OF CAREGIVERS.

THIS ISSUE OF *HSCNEWS* LOOKS AT THE MOVEMENT'S MANY SUCCESSES, AND CONSIDERS WHY CAMPAIGNERS BELIEVE THAT NUMEROUS COUNTRIES STILL NEED TO DO FAR MORE TO RECOGNISE THE IMPORTANT CONTRIBUTIONS MADE BY CARERS. AN 18-PAGE OVERVIEW OF THE SUBJECT IS FOLLOWED BY INTERVIEWS WITH FOUR KEY INDIVIDUALS INVOLVED WITH THE CARERS' MOVEMENT:

- JEAN GEORGES, EXECUTIVE DIRECTOR OF ALZHEIMER EUROPE—*PAGES 26 TO 28.*
- LIAM O' SULLIVAN, NATIONAL DEVELOPMENT OFFICER OF CARE ALLIANCE IRELAND —*PAGES 29 TO 30.*
- K. R. GANGADHARAN, MANAGING DIRECTOR OF THE HERITAGE HOSPITAL, HYDERABAD, AND REGIONAL VICE PRESIDENT (ASIA) OF THE INTERNATIONAL FEDERATION ON AGEING (IFA)—*PAGES 31 TO 33.*
- GAIL HUNT, HEAD OF THE INTERNATIONAL ALLIANCE OF CARERS ORGANIZATIONS, AND PRESIDENT OF THE NATIONAL ALLIANCE FOR CAREGIVING (NAC)—*PAGES 34 TO 36.*

# Carers: an overview

---

## OUT FROM THE SHADOWS

When a person falls sick, the burden of care frequently falls on family members (and, sometimes, on friends). If the illness is chronic, those closest to the person may have to provide emotional—or even economic—support. In cases where the ill person has a mental health problem or dementia, carers may also be responsible for making routine healthcare choices on behalf of the cared-for person. In extreme circumstances, a carer might be required to take a decision that holds life-or-death consequences for the sick person. Yet, although carers assume these important duties—which can, themselves, produce significant hardships for carers—the welfare of carers has, until recently, been largely overlooked.

## HOW THE CARERS' MOVEMENT BEGAN

One person, above all, has been widely seen as responsible for bringing the subject of carers out from among the shadows—British social worker Jill Pitkeathley. In the 1980s, she was among the first to elevate carers' interests into a high-profile issue. A pivotal figure in the fledgling movement, she became Chief Executive of the London-based Carers National Association (now Carers UK) in 1986, and worked hard to get her association's activities publicly known. The media quickly grasped Ms Pitkeathley's simple but worrying message: that many of the country's sick were being cared for, not by the National Health Service (NHS), but by forgotten family members—people who were probably unpaid, unhappy, and unhealthy.

As news stories about the phenomenon multiplied, British politicians found that they could no longer afford to ignore the country's quiet population of carers.

The few carers' organisations already existing in other countries

### BARONESS PITKEATHLEY

Jill Pitkeathley trained as a social worker in the UK. She became Chief Executive of the London-based National Council for Carers in 1986. Ms Pitkeathley transformed the small organisation into a national movement capable of pushing the needs of Great Britain's six million carers into the political spotlight. She has been an equally important figure in the development of the international movement of carers. The UK government awarded her a Life Peerage in 1997. Baroness Pitkeathley is currently President of Volunteering England and the Community Council for Berkshire, and Vice President of Carers UK and the Princess Royal Trust for Carers. She has been appointed President of Eurocarers, an organisation due to be launched in 2007.

### INTERNATIONAL ALLIANCE OF CARERS ORGANIZATIONS (IACO)

The IACO operates a straightforward remit: 1. Increase the visibility of family caregiving as an international issue. 2. Promote best practices in caregiving. And 3. encourage (and provide assistance in developing) national family carer organisations. The IACO would also like, in time, to establish a United Nations 'Day for Carers'. "We are at a very early stage on this one, and still have to bring the agency's attention to what is a global issue," reports IACO's Director, Gail Hunt. Ms Hunt believes that a decade of advocacy and lobbying will probably be needed before the IACO can penetrate and win over the bureaucracy of the United Nations [see 'Gail Hunt: a view from the International Alliance of Carers Organizations', pages 34-36.

<http://www.internationalcarers.org>

noticed the recognition accorded their UK counterparts. The now-Baroness Pitkeathley continued to play her part in the process of raising public awareness of carers. She travelled abroad extensively, lecturing and holding meetings on the subject of carers' needs. Her aim was to see carers' issues expand onto the international stage. Baroness Pitkeathley told *HSCNews*: "I was invited to Australia, for example, to speak to the carers' group there—which has since slowly grown into a more international movement".

Carers' groups emerged in Australia, Belgium, Ireland, the Netherlands, Sweden, and the USA during the 1990s. By 1998, the carers' movement comprised sufficient organisations to be able to mount its first international conference in London. By 2004, a handful of national bodies had decided that the time was right to launch a global carers' umbrella organisation, the London-based International Alliance of Carers Organizations (IACO).

The carers' movement continues to grow apace. To date, carers' groups have sprung up most readily in Anglo-Saxon, northern European, or English-speaking nations. But, with the formation of the IACO, and with the official launch of the European Network of Carers Organisations (Eurocarers) pencilled in for 2007, the carers movement looks destined to assume global influence. India and Taiwan are the first Asian countries to establish a noticeable carers' lobby. Although the two countries have no national umbrella carers' groups, local organisations are taking part in IACO events.

Another recent trend is for patient groups that specialise in a particular condition—most notably dementia and mental health—to become more interested in the condition and activities of the carers who look after people with that condition. Alzheimer Europe is an example. In September 2006, the group published a report, *Who Cares: the State of Dementia Care in Europe*, summarising the findings of a survey of 1,100

Continued on page 11

## National Carers' Groups: examples

<p><b>Association des Parents et Professionnels autour de la Personne Polyhandicapée (AP<sup>3</sup>)</b> [Association of Parents and Professionals Caring for People with Handicaps] <a href="http://www.ap3.be">http://www.ap3.be</a> BELGIUM</p>	<p>Founded in 1998. Provides support and help to people who care for children with a disability. Conducts conferences and seminars, and organises days out and support in the home.</p>
<p><b>Canadian Caregiver Coalition</b> <a href="http://www.ccc-ccan.ca">http://www.ccc-ccan.ca</a> CANADA</p>	<p>The national body representing and promoting—in the community and at all levels of government—the voice, needs, and interests of family caregivers. Provides information and education, and conducts policy development and research. Members can be individuals (caregivers, professional service providers, and researchers) as well as organisations (national, regional, and local).</p>
<p><b>Caregiver Network Inc (CNI)</b> <a href="http://www.caregiver.on.ca">http://www.caregiver.on.ca</a> CANADA</p>	<p>Toronto-based, has the goal of acting as a single, national information source capable of making the lives of caregivers easier. Founded by Karen Henderson, who has “been through all the care-giving phases—from a broken hip to the ‘edge of the end’ “.</p>
<p><b>Carers Association Ireland</b> <a href="http://www.carersireland.com">http://www.carersireland.com</a> IRELAND</p>	<p>Established in 1987, Ireland's national voluntary organisation for (and of) family carers in the home. Provides care services to a range of people (including frail older people, people with severe disabilities, the terminally ill, and children with special needs).</p>
<p><b>Carers Association South Africa (CASA)</b> c/o <a href="http://www.age-in-action.co.za">http://www.age-in-action.co.za</a> SOUTH AFRICA</p>	<p>Established in 2002 by Age-in-Action, South Africa's national older people's charity. Provides caregivers with services and support (including training).</p>
<p><b>Carers Australia</b> <a href="http://www.carersaustralia.com.au">http://www.carersaustralia.com.au</a> AUSTRALIA</p>	<p>The national voice for carers. Has a vision of an Australia which accepts its responsibility for caring. Acts as advocate, conducts research, networks with strategic partners, and provides carers with information and educational resources.</p>
<p><b>Carers NSW</b> <a href="http://www.carersnsw.asn.au">http://www.carersnsw.asn.au</a> AUSTRALIA</p>	<p>A Sydney-based association for relatives and friends who are caring for people with a disability, mental illness, chronic condition, or who are frail and aged. The peak body for carers in New South Wales, and the only state-wide organisation to primarily focus on carers.</p>
<p><b>Carers UK</b> <a href="http://www.carersuk.org">http://www.carersuk.org</a> UK</p>	<p>The country's leading campaigning group for carers. Aims to combat the ill-health, poverty, and discrimination experienced by carers. Campaigns for carers to get the practical, financial, and emotional support they need.</p>
<p><b>Caring for Carers</b> <a href="http://www.caringforcarers.org">http://www.caringforcarers.org</a> IRELAND</p>	<p>A national NGO that provides support to home-based carers via a network of 57 carers' groups throughout Ireland.</p>

.....continued on next page

<b>Examples of National Carers' Groups (continued)</b>	
<b>Crossroads</b> <a href="http://www.crossroads.org.uk">http://www.crossroads.org.uk</a> ENGLAND AND WALES	Founded in 1974, aims to improve the lives of carers by providing respite. Member groups regularly support 180 schemes nationwide, providing 4.4 million care hours each year to 35,000 carers.
<b>Family Caregiver Alliance (FCA)</b> <a href="http://www.caregiver.org">http://www.caregiver.org</a> USA	Founded in 1977, the country's first community-based nonprofit organisation to concentrate on the needs of families and friends. Offers programmes at national, state, and local levels to support and sustain caregivers.
<b>Mezzo</b> <a href="http://www.mezzo.nl">http://www.mezzo.nl</a> NETHERLANDS	Formed in 2006 in a merger of Vereniging van Mantelzorgers (LOT) and Xzorg, two associations responsible for representing the interest of carers and the voluntary sector respectively. Lobbies on behalf of carers and voluntary helpers, so that "they can keep doing their invaluable work".
<b>National Alliance for Caregiving (NAC)</b> <a href="http://www.caregiving.org">http://www.caregiving.org</a> USA	Maryland-based, dedicated to providing support to family caregivers and the professionals who help them, and to increasing public awareness of issues facing family caregivers.
<b>National Family Caregivers Association (NFCA)</b> <a href="http://www.thefamilycaregiver.org">http://www.thefamilycaregiver.org</a> USA	Educates, supports, empowers, and speaks for the 50 million Americans who care for loved ones with a chronic illness, disability, or the fragilities of old age.
<b>Omaishoitajat ja Läheiset-Liitto ry</b> <a href="http://www.omaishoitajat.com">http://www.omaishoitajat.com</a> FINLAND	[The Finnish Association of Care-Giving Relatives and Friends.] Supports family caregivers and promotes their interests. Provides help through a network of 598 local groups and over 7,800 individual helpers.
<b>Princess Royal Trust for Carers</b> <a href="http://www.carers.org">http://www.carers.org</a> <a href="http://www.youngcarers.net">http://www.youngcarers.net</a> FINLAND	The largest provider of comprehensive carers' support services in the UK. Operates a network of 129 independently-managed carers' centres and two interactive websites [Carers.org and youngcarers.net]. Provides information, advice, and support services to 290,000 carers (including over 15,000 young carers).
<b>Röda Korset</b> <a href="http://www.redcross.se">http://www.redcross.se</a> SWEDEN	[The Swedish Red Cross.] Runs carer support groups.
<b>Well Spouse Association</b> <a href="http://www.wellspouse.org">http://www.wellspouse.org</a> USA	The only national organisation focusing exclusively on the needs of spouses caring for a chronically-ill and/or disabled husband, wife, or partner. Brings together caregivers to share their experiences.
<b>Werkgroep Thuisverzorgers v.z.w.</b> <a href="http://www.mantelzorg.be/js/vs_en.htm">http://www.mantelzorg.be/js/vs_en.htm</a> BELGIUM	[The Belgian Workgroup 'Homecarers'.] Founded 1989, a Flanders-based, non-profit association that helps people and families who look after ailing, disabled, or elderly relatives and friends in their homes. Advocates for the recognition of the contribution made by these families, and defends their interests.

Continued from page 8

carers that it had conducted [see 'Jean Georges: a view from Alzheimer Europe', pages 26-28].

Baroness Pitkeathley believes that the carers' movement attracts public attention simply as a matter of natural justice. She points out: "Too much is asked from carers—who are not given enough support. ... Even countries like India and Italy have all the problems that beset carers".

Evidence of the growing presence of the carers' movement includes:

- Eurocarers (to be presided over by Baroness Pitkeathley) will include groups from four Catholic or Latin countries: France, Italy, Portugal, and Spain.
- Between November 29th and December 1st 2006, the Bethesda, Maryland-based National Alliance for Caregiving (NAC) hosted a first Pan-American Conference on Caregiving in Miami, Florida. Participants were drawn from eight countries in the region.
- During June 16th-19th 2007, the 'Caregivers: Essential Partners in

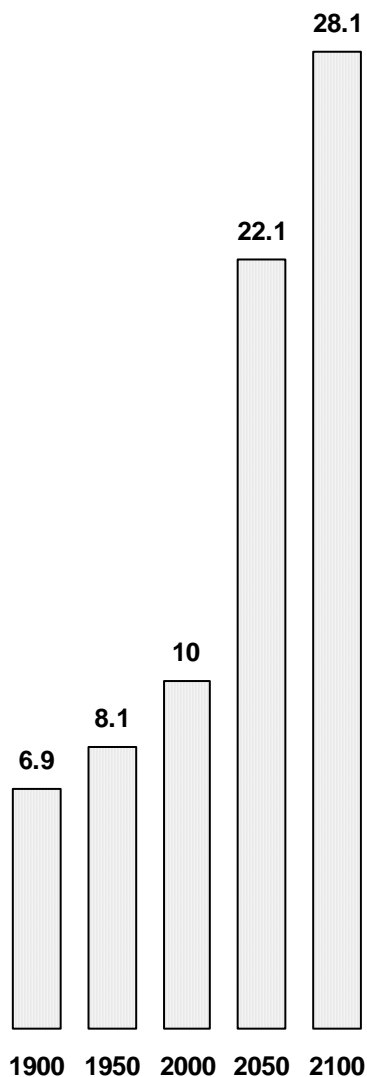
Care' conference will take place in Toronto, Canada. Baroness Pitkeathley and Senator Hillary Clinton are scheduled as keynote speakers at the conference, which will be one of four other conferences on the related themes of ageing, carers, disability, and technology, all being held at the Festival of International Conferences on Caregiving, Disability, Aging, and Technology (FICCDAT).

Gail Hunt, Director of the IACO and President of the NAC, insists that the carers' movement is here to stay: "The whole issue of family care is going to explode. The population is ageing. Women are now working. Sooner or later, we will have to deal with these issues".

### CHANGING DEMOGRAPHICS

Ranks of carers are set to swell. Demographic and socioeconomic shifts will effect that change in developed and developing countries alike. As people grow older, they inevitably sicken. Age-related

**% OF POPULATION AGED 60-PLUS  
LONG-RANGE WORLD POPULATION FORECASTS**



Source: Long-Range World Population Projections: Based on the 1998 Revision, the Population Division, Department of Economic and Social Affairs, United Nations Secretariat.

THE EUROPEAN COMMISSION'S DEFINITION OF CARERS

Carers are non-professional people who take care of patients at home. Carers can be relatives of the sick person, or other volunteers. The individuals they usually help or support have long-term physical or mental ill-health or disability, or problems related to old age. Carers deal with serious matters under difficult circumstances, and, in their turn, need help from national and regional authorities. In general, to carry out their duties smoothly and efficiently, carers require flexible working time and financial support.

[http://ec.europa.eu/health-eu/care\\_for\\_me/carers/index\\_en.htm](http://ec.europa.eu/health-eu/care_for_me/carers/index_en.htm)

medical conditions (such as circulatory disease, dementia, and diabetes) have burst into global prominence. The healthcare systems of virtually every nation are under financial pressure, are failing to deliver, and are forcing families and other volunteers to shoulder an ever-greater burden of care.

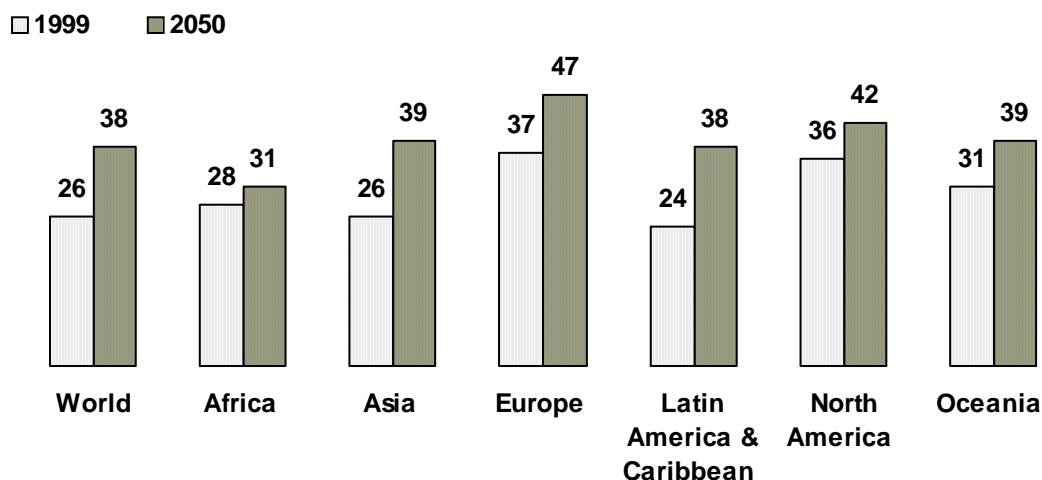
**The global picture**

The statistics are unambiguous. The world's population is growing, ageing, and ailing. *World Population Ageing, 1950-2050*, a report prepared by the UN Population Division for the 2002 World Assembly on Ageing, describes the

predicted increase in the numbers of older people as "unprecedented in human history—pervasive and enduring".

In 1950, 205 million people were aged 60 or over. Fifty years later, in 2000, the total had tripled to over 600 million. The UN estimates that nearly one quarter of the world's population will be aged 60 or over by the middle of the 21st century. Given the increasing prevalence of chronic diseases (cancer, dementia, diabetes, heart disease, respiratory conditions, and stroke), the world of 2050 promises to be sicker than the planet we inhabit today. The quantity of carers needed will be hard to calculate.

**MEDIAN AGE BY REGION (1999 AND 2050)**



Source: *World Population Prospects: the 1998 Revision, Volume II: Sex and Age*, the Population Division, Department of Economic and Social Affairs, United Nations Secretariat.

**AGEING AND HEALTHCARE SPEND**

According to the OECD, the over-65 age group accounts for 40%-50% of present healthcare spending. Their per-capita healthcare costs are three-to-five times higher than those of people aged under 65.

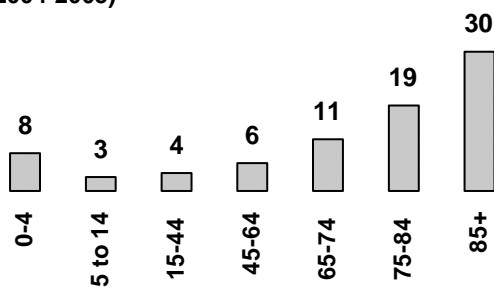
These costs will strain already over-stretched national healthcare systems. In the UK, for example, a 2003 report by a York, England-based social research charity, the Joseph Rowntree Foundation (JRF), estimated that National Health Service (NHS) spending on long-term care could rise from £13bn [US\$25bn, Euros 19bn] in that year to £54bn [US\$104bn, Euros 80bn] by 2050.

Without the unpaid voluntary work undertaken by carers, the cost pressures imposed on healthcare systems by ageing populations would be even higher.

**In developed countries**

Today's developed economies are likely to contain the highest future proportion of older people. A drop in fertility rates resulting from cultural and lifestyle changes, plus advances in medical science (especially in treatments that enhance the quality of people's lives) are said to be behind the altering age balance in developed societies.

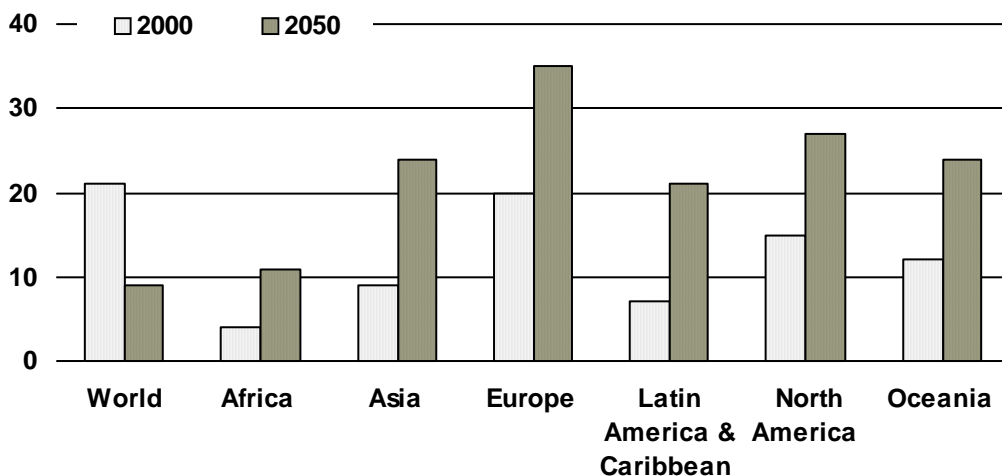
**% AGE DISTRIBUTION OF UK NHS SPENDING (2004-2005)**



Source: Assumptions by PriceWaterhouse Coopers, March 2005.

The Organisation for Economic Co-operation and Development (OECD) forecasts the age 65-plus population increasing from 8.7% in 2000 to 25% by 2040 in 19 of the world's developed economies. The fastest-growing section of the old will be people aged 80 or over. The OECD anticipates

**PERCENTAGE OF POPULATION AGED 60 OR OVER BY REGION (2000 AND 2050)**



Source: *World Population Prospects: the 1998 Revision, Volume II: Sex and Age*, the Population Division, Department of Economic and Social Affairs, United Nations Secretariat.

that 7% of the population among the 19 countries analysed will be aged 80-plus by 2040, compared with just 3% in 2000.

By 2050, 37% of Europeans are expected to be 60years or over—the highest proportion from any part of the world of people in this age bracket.

**In developing economies**

Increased economic wealth has increased life expectancies in developing countries (with the exception of parts of Africa). By 2050, China alone will be home to 437 million people in the 60-plus age bracket. India will follow with 324 million, Indonesia with 70 million, and Brazil, 58 million.

Populations in middle- and low-income countries seem to sometimes contract cardiovascular disease and diabetes at an earlier age—under 60 years—than in the western world. The World Health Organization (WHO) warns of a common misconception—chronic diseases merely strike the rich and the very old. Only one fifth of all deaths due to chronic illness occur in high-income countries.

**ON DEMENTIA**

A study published in 2000 by the Rotterdam-based European Community Concerted Action on the Epidemiology and Prevention of Dementia Group (EURODEM), and endorsed by Luxembourg-based Alzheimer Europe, pooled data on the prevalence of moderate-to-severe dementia in several European countries. The study included people with dementia who were living at home, as well as those in institutions, nursing homes, and residential care. The study found that under 1% of people aged below 60 have diagnosed dementia. But up to one third of people aged 95-99 exhibited symptoms of the disease.

Latest data from Alzheimer Europe suggests that 5.4 million EU citizens have dementia. The number of people with dementia is set to double by 2040 in Western Europe, and treble in Eastern Europe.

PREVALENCE RATES OF DEMENTIA AS ESTIMATED BY EURODEM % OF POPULATION		
AGE	MALE	FEMALE
30-59	0.16	0.09
60-64	1.58	0.47
65-69	2.17	1.10
70-74	4.61	3.86
75-79	5.04	6.67
80-84	12.12	13.50
85-89	18.45	22.76
90-94	32.1	32.25
95-99	31.58	36.00
Source: EURODEM		

### **COSTING THE CARERS PHENOMENON**

The idea that ageing populations will place unprecedented financial burdens on society is well documented. Also predicted is the likelihood that billions of older, sicker people falling upon the state for support and succour will trigger a catastrophic meltdown of pension and healthcare systems.

The full financial, social, and healthcare consequences of a worldwide surge in the numbers of *carers*, however, has yet to be fully assessed.

Carers undeniably save healthcare systems money through their provision of unpaid care

work. More of a moot point, though, is whether these savings outweigh the significant financial costs to business—which must make consequent adjustments within the workforce—and the psychological and health damage regularly endured by carers (and which must be ultimately paid for by the state).

### **The savings that carers bring to healthcare systems**

Carers already make a significant contribution to healthcare—which, when translated into hard cash—adds up to billions of dollars- or Euros-worth of annual savings to governments and healthcare payers.

- **In the US.** In 2004, the National Alliance for Caregiving (NAC) and the Washington DC-based American Association of Retired Persons (AARP) conducted a joint study, *Caregiving in the US*, which estimated that over 44 million Americans (or 21% of all US households) provide care for an adult family member or friend. These carers' unremunerated contribution to the US healthcare system was reckoned by the study report to stand at US\$257bn [Euros 196bn] annually. More recent research published in November 2006 by Dr Peter Arno, a health economist at Montefiore Medical Center/Albert Einstein College of Medicine, New York,

### **A CARERS' CRISIS IN INDIA**

Speaking at a roundtable on global ageing at a White House Conference on Ageing, December 11th-14th 2005, Dr K. R. Gangadharan, Managing Director of the Heritage Hospital, Hyderabad, India, noted that India's population (which is currently comparatively young) will hold the world's second largest national total of older people by the middle of the century. Some 80% of today's older Indians live in rural areas, and nearly one third exist below poverty line. Dr Gangadharan explained the Indian situation: "People suffering anaemia, fractures, or stroke that result in permanent immobility, or from loss of adequate recovery after major illnesses (including surgeries), and a limited number of people suffering terminal illness—all these rely on carers at home. The responsibility for caring for the elderly traditionally falls on the immediate family—most often, the sons. However, a growing trend towards nuclear-family set up, and the associated decay of the extended family structure, is increasing the vulnerability of the ageing population". [See also 'K. R. Gangadharan: a view from the Heritage Hospital', pages 31-33.]

gauges that this figure has jumped to US\$306bn [Euros 229bn]. Dr Arno was commissioned to undertake the research by the Kensington, Maryland-based National Family Caregivers Association (NFCA) and the San Francisco-based Family Caregiver Alliance. [Research reference: [http://www.thefamilycaregiver.org/pdfs/State\\_Caregiving\\_Databrank2006.pdf](http://www.thefamilycaregiver.org/pdfs/State_Caregiving_Databrank2006.pdf)]

- **In Australia.** The Deakin, Australian Capital Territories-based umbrella group, Carers Australia, published an August 2005 report, *The Economic Value of Informal Care*, which judged that nearly 500,000 Australians are a 'primary carer'—someone who provides the majority of care for a recipient. The report noted that such carers devoted over a billion hours of their time to caring during 2005. The Australian Bureau of Statistics emphasises

that the burden of caring falls hardest on people who are least financially able to cope with the tasks of caring.

- **In Ireland.** The Kilkenny-based Carers Association has estimated that family carers in Ireland spend three million work hours per week looking after their loved ones—thereby saving the state upwards of Euros 2bn [US\$2.6bn] each year (if Ireland's prevailing home-help rate of pay is used as a measure).

## DEMENTIA AND CARERS

People with dementia commonly depend upon carers for support. On September 21st 2006, Luxembourg-based Alzheimer Europe (AE) published *Who Cares? The State of Dementia Care in Europe*, a report on the results of an AE survey of more than 1,100 dementia carers in five European countries (France, Germany, Poland, Scotland, and Spain). The survey found that most dementia care (60% in France and Scotland, rising to 80% or more in Germany and Italy) occurs at home, rather than in a hospital setting or in a professional residential care home. Almost half of the surveyed carers spent at least 10 hours a day looking after their loved one.

The *Who Cares?* survey confirmed that the work of caring takes a physical and psychological toll on the carers themselves. Carers reported being affected by depression, musculoskeletal injuries, and other problems. One of the respondent carers painted a vivid picture of her life since her husband fell ill: "My life—as well as my husband's—ended when he developed Alzheimer's. I had to give up the job I loved to look after the man I loved. But my job was eight hours a day. Caring for someone with Alzheimer's disease is 24 hours a day. There is no time off".

Alzheimer Europe is now calling on national governments in EU countries to develop national plans for dementia. Included, says AE, should be help, support, and the provision of comprehensive information for carers.

Source: <http://www.alzheimer-europe.org/index.php?lm3=6C831951B6DF>

**The cost to business**

The above costs only refer to the savings that carers afford to healthcare systems. Caring, however, also brings negative financial consequences for the employers of carers. In July 2006, the NAC and MetLife Mature Market Institute (MNI; the gerontology research arm of a US insurance company) co-published *MetLife Caregiving Costs Study: Productivity Losses to US Business*.

<b>Total Cost to US Employers (US\$bn)</b>	
Replacing employees	6.6
Workday interruptions	6.3
Absenteeism	5.1
Full-time to part-time	4.8
Eldercare crisis	3.8
Unpaid leave	3.4
Partial absenteeism	1.9
Supervisor time	1.8
<b>Total</b>	<b>33.6</b>
<i>Source: MNI, July 2006</i>	

The report calculated that the impact of caring on the US workforce equated to an annual US\$33.6bn [Euros 25.3bn] financial loss for US businesses.

The *Study* submitted that at least six-out-of-ten US caregivers who are employed are forced to make some care-related adjustment to their work pattern. Each year, an estimated 9% of employed caregivers, for instance, have to leave their jobs. An additional 10% change to part-time working [see table, left].

**Carers suffer from poor health**

Aside from the monetary and employment consequences of caring, the health of carers is another factor that needs to be considered when looking at the economic and social implications of caring.

In September 2006, the NAC and Evercare (a Minnesota-based healthcare firm that coordinates services for the chronically ill, older people, and people with a disability) published the results of a nationwide online survey that the two bodies had conducted

among 529 caregivers. The survey report, *Caregivers in Decline: a Close-Up Look at the Health Risks of Caring for a Loved One*, stated that all the respondent carers mentioned deterioration in their health. The more common reported problems were:

- Lack of energy; sleep deprivation (87%).
- Stress and/or panic attacks (70%).
- Pain, aching (60%).
- Depression (52%).
- Headaches (41%).
- Weight gain/loss (38%).

The *Carers' Week June 2006 Survey*, a study of 5,000 UK carers conducted by London-based Carers UK, obtained similar results. The survey report emphasised that any decline in the health of a carer also represents a risk for the person in that carer's charge.

## WHAT DO CARERS NEED?

An awareness of the unenviable situation of individual carers, and the findings of recent research into the socio-economic impact of carers have helped push the carers' movement into making demands for political change. Although well aware of the financial pressures confronting national healthcare systems, carers' organisations nonetheless believe that government action is necessary to improve the lot of carers. Above all, the movement recommends that the time

is right for carers to be accepted as an official third party in care, and admitted alongside patients to consultations with healthcare providers, and to negotiations with patients' financial advisors. In essence, carers want to be recognised, and afforded specific rights.

The Leuven, Belgium-based European Federation of Associations of Families of Mentally-Ill People (EUFAMI) published a June 2003 report entitled *Legislation Affecting Carers of People with Mental Health Problems*,

documenting the findings of a survey of 25 of EUFAMI's national member groups. Respondent organisations admitted being aware of some forms of legislation favouring carers with an official role in society, but specified also that they still sensed insufficient acknowledgment among politicians that families can provide support and care for people with mental health problems.

EUROFAMCARE, an EU-funded project which ran from 2003 to 2005, found evidence of discrimination against carers within healthcare systems—

## FACILITIES THAT CARERS NEED

### • RESPITE

Caring is a 24-hour-a-day, 365-days-a-year task. That level of activity is unsustainable, and carers need time off. Respite can be provided through volunteer care-attendant services, or by paid carers, day care, family placement, and other schemes.

### • SUPPORT SERVICES

Carers around the world highlight the importance of having help with certain key tasks that they have to perform as carers, including: bathing, house cleaning, lifting, maintenance, and toileting. Alzheimer Europe insists that support in the home is vital for carers. "Many people think that the main problem caring for Alzheimer's patients is coping with their cognitive difficulties (such as their loss of memory). But normal daily routines, like bathing the Alzheimer's patient, or taking them to the lavatory, tend to be just as difficult", says Jean Georges, Executive Director of Alzheimer Europe.

### • INFORMATION

Carers need more relevant information. Carers UK states that its surveys constantly show carers needing information which is readily accessible, particularly from key healthcare professionals. Carers want more data about the illness of the person they are looking after, about available support services, and about financial entitlements. A 2001 Carers UK survey, entitled *You Can Take Him Home Now: Carers' Experiences of Hospital Discharge*, found that half of carers believed their comments and concerns were not taken into account when patients were discharged from hospital. The picture, it seems, has not changed greatly over the past five years.

most notably, a lack of proper recognition of the status of carers.

EUROFAMCARE noted that many countries provide services and financial support to

carers. In Finland, for example, the 1998 Social Welfare Act has enabled municipalities to give carers a Home Care Allowance (HCA, or an Informal Care Allowance, as it is sometimes called).

A further amendment to the 1998 Act entitles carers to two free days a month, during which time the municipality has to supply substitute care.

#### CARERS' RIGHTS IN THE UK

The carers' movement's first home, the UK, has seen the passage of three Acts relevant to carers:

- The Carers (Recognition and Services) Act of 1995 gave carers the right to be listened to, and to have their needs assessed by social services.
- The Carers and Disabled Children Act of 2000 extended the right of assessment to people 16 or 17 years old, as well as to the parents of children with a disability.
- The Carers (Equal Opportunities) Act of 2004 ensured that carers are able to accept opportunities that people without similar responsibilities take for granted. The Act aims to promote closer working relationships between local councils and healthcare services, to ensure that support for carers is delivered in a coherent manner.

Baroness Pitkeathley applauds these laws. "A lot has been achieved. There are three separate Acts of Parliament for carers. You will now find no national department or local authority putting out any policy about social care or healthcare without mentioning the contribution of family carers", she says.

The legislation has allowed day-care centres to be established in many parts of the UK, providing services for people with different disabilities. Assistants are available to help ill or disabled people living at home. Assisted-living places run by local authorities, private companies, and voluntary organisations cater for people who can no longer live in their own homes.

Nonetheless, carers feel that more can still be done. When, in November 2006, the National Institute for Health and Clinical Excellence (NICE—a government-appointed agency responsible for deciding which drugs are sufficiently cost-effective for UK prescription) issued two new, apparently conflicting guidelines on caring for dementia, the move was roundly criticised by the London-based Alzheimer's Society. The Society argued that the government had yet to get to grips with the whole care issue.

The first NICE guideline, announced on November 17th 2006, recommended that certain life-enhancing dementia drugs should not be available on the National Health Service (NHS).

NICE's second guideline, issued on November 22nd 2006 in conjunction with the Social Care Institute for Excellence (SCIE), called for health- and social-care agencies to operate a more co-ordinated approach to people with dementia and their carers. Advice was also given that carers be offered access to counselling.

On November 22nd 2006, Neil Hunt, Chief Executive of the Alzheimer's Society, released the following statement to the press: "On the one hand, the health body [NICE] is moving to improve care ... and with the other, snatching away the only drugs that can improve quality of life for patients with dementia and their carers."

Sweden also has a number of provisions aimed at carers, including: counselling; information; respite care; resources centres offering training; and support groups. Other schemes allow carers to be absent from their employed jobs for up to 60 days a year.

The Prague-based Česká Alzheimerovská Společnost (CALs) [Czech Alzheimer Society] runs a 'granny-sitting' service, furnishing regular respite to carers.

Nonetheless, EUROFAMCARE stipulates that seven countries within the European Union still provide family carers with no public recognition or support (aside from some tax relief). The organisation adds that a further six countries assign only partial recognition.

In Germany, for instance, training courses are available for volunteers who wish to support family carers, allowing

them to qualify as 'voluntary senior citizens'. But, apart from a guarantee of social security (under certain circumstances) for family carers, Germany has passed no laws which lay down rights and obligations for family carers. Care in Germany remains a family affair.

#### AUSTRALIA'S POTENT CARERS' MOVEMENT

Carers Australia states that 2.6 million Australians—or 10% of the population—currently provide care to someone close to them. Nearly one fifth of these carers is a primary carer—the main source of unpaid informal support to an individual. Carers are conservatively estimated to save the Australian state and economy A\$16bn [US\$12bn, Euros 10bn] each year.

The Australian government—as judged by the record of most countries—has been generous to its population of carers:

- Around 70% of Australian primary carers receive government income support.
- A National Respite for Carers Programme funds Carers Australia (the national advocacy body), eight Commonwealth Carer Resource Centres, 82 Commonwealth Carer Respite Centres, a National Dementia Behaviour Advisory Service, and training and counselling services for carers.
- On October 16th 2006, Carers Week was officially launched by the Minister for Ageing and the Minister for Community Services. On the same day, Carers Australia received formal recognition in the federal Parliament.

Even so, Carers Australia believes that if carers are to have the same "rights, choices, and opportunities as other Australians to enjoy optimum health, and the social and economic wellbeing needed to participate in social life", then the federal government should allocate more budget to carers' services.

At state level, one major move has been the October 2004 decision of the Western Australian Legislative Assembly to approve a Carers Recognition Bill. The Bill created a mechanism for the involvement of Western Australian carers in the provision of services that impact upon them. Carer associations in other Australian states, encouraged by the passage of the Carers Recognition Bill, have been pushing for the introduction of similar legislation.

**THE 1991 CARERS' RIGHTS CHARTER PROPOSED BY  
CARING FOR CARERS IRELAND**

1	The right of carers to be recognised for the central role which they play in community care, and in creating a community of caring.
2	The right of carers to acknowledge and address their own needs for personal fulfilment.
3	The right of carers to acknowledge and address their own needs in relation to their contribution to their family and community.
4	The right of carers to practical help in carrying out the tasks of caregiving (including help with appliances, domestic help, home adaptations, incontinence services, and transport).
5	The right of carers to domestic, medical, and personal support services (such as day centres, home helps, and nurses).
6	The right of carers to respite care (both for short spells—day hospitals, for instance—and for longer periods), to enable them to have time for themselves.
7	The right of carers to emotional and moral support.
8	The right of carers to financial support and recompense—which does not preclude carers accepting paid employment, or in sharing care with other people.
9	The right of carers to regular assessment and review of their needs, and of those of the people for whom they care.
10	The right of carers to easy access to information and advice about caring.
11	The right of carers to expect the involvement of all family members in caring.
12	The right of carers to have counselling made available to them at different stages of the caring process (including bereavement counselling).
13	The right of carers to skills' training and development.
14	The right of carers to expect their families, public authorities, and community members to provide a plan for services and support for carers.
15	The right of carers to involvement in all levels of policy planning, and to participate and contribute to the planning of an integrated and co-ordinated service for carers.
16	The right of carers to an infrastructure of care—a supportive network to which they can relate when the need arises.

Source: *Caring for Carers Ireland* [<http://www.caringforcarers.org>]

**A RIGHTS-BASED  
CARERS' MOVEMENT**

In principle, at least, today's human rights' laws should supply carers with the power to challenge local councils, hospitals, and other public bodies if these institutions fail to respect carers' basic rights.

In a published interview with Carers UK, Katie Ghose, director of the London-based British Institute of Human Rights (BIHR), stated that "public organisations which take their duties seriously should be thinking about carers' rights to life, and to be free from inhuman or degrading treatment" [<http://www.carersuk.org/Newsandcampaigns/Humanrights/Interview>].

However, the carers' movement is generally of the opinion that human rights' laws do not go far enough, and that unless national governments or countries adopt charters or laws that specifically include carers, the rights of carers cannot be assured. Certainly, the evidence from EUROFAMCARE and others would back up that view.

**EUROFAMCARE'S DRAFT EUROPEAN CARERS' CHARTER: NINE CARERS' RIGHTS**

1. Carers' central role in society should be recognised.
2. Carers should have greater access to information about caring.
3. Carers should be able to choose whether or not (or to what extent) they want to be involved in caring.
4. Carers should be able to receive practical and emotional support in their role as carers.
5. Carers should have access to respite care.
6. Carers should have the right to participate in society and in social networks.
7. Carers should have the right to health protection.
8. Carers should have the possibility of combining (full-time) work with care.
9. Social security policies should compensate carers financially.

Source: WP 16: *European Carers' Network, Carers' Charter, and Carers' Day, February 2006, EUROFAMCARE* [<http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/deliverables/charta.pdf>]

In 1991, Ennis, County Clare-based Caring for Carers Ireland launched its own charter [see previous page]. The document outlined 16 different rights that the group wished to be accorded to carers. Among the Charter's many ambitions is the inclusion of family carers into health policymaking. In January 2004, the group hosted 'Carers Charter: a European Charter', an international conference in Dublin to promote the Charter on a global stage.

EUROFAMCARE, in the interests of "promoting recognition of carers and carers' interests, and shaping a policy-

environment that is more favourable to carers", is currently trying to encourage the adoption of its draft European Carers' Charter [see above].

**CONCLUSIONS**

The carers' movement has come a long way since its beginnings, twenty years ago. Caregivers are on the political agenda, and many countries operate schemes to compensate and support people who devote a part (or all) of their life to care for someone close to them.

The movement has jumped the north-south

divide, and is expanding into developing nations, where social awareness of carers' issues is also on the rise.

Gail Hunt of IACO spells out what remains to be done: "I think that we still need to improve public awareness. Once family caregivers get a political voice, I believe we can then start to move on to asking for legislation".

Some of the problem areas for today's carers' movement include:

- In Hungary—as in many countries—NGOs, rather than the state, play the more important role in providing services for

- 
- older people and their family carers.
  - Carers in the Netherlands insist that assessments for government support should not take into account the carers' own contributions. But, in practice, assessors often make an assumption that an ill or disabled person can call on
  - carers for significant amounts of care.
  - Even in more carer-aware countries, such as the UK, doctors are frequently slow to recognise that the carer is a partner in care. The medical profession may not always be aware of the existence of local carer groups.
  - Employers, too, have much to learn. Baroness Pitkeathley comments: "One of the things we haven't achieved in the UK is helping carers to combine caring with work. Today's six million carers will be nine million by 2025. Interestingly, the great majority of carers don't want to
- 

#### IN THE USA

About 50 million Americans care for loved ones who have a chronic illness or a disability. Yet only a few US states possess carer support programmes. Current and pending federal laws concerning caregivers have only limited powers:

- The National Family Caregiver Support Program (NFCSP), enacted in 2000, calls for all states to provide information, assistance, training, respite care, and other services to complement the care provided by caregivers. Federal funding for the NFCSP is the region of US\$150m [Euros 112m]—equivalent to only US\$3 [Euros 2.25] per American caregiver.
- The Family Caregiver Relief Act of 2003 provides a partially-refundable tax credit of up to \$5,000 [Euros 3,700] to help pay the expenses of families who care for loved ones with chronic care needs.

Further legislation on the books includes:

- The Long-Term Care and Retirement Security Act was first introduced in 2000 and has undergone various revisions. The Bill seeks to amend the Internal Revenue Code to allow a deduction for eligible long-term care-insurance premiums for a taxpayer and the taxpayer's spouse and dependents; and a credit for eligible caregivers who care for individuals with long-term care needs.
- The Lifespan Respite Act of 2003, sponsored by Senator Hillary Clinton and Senator John Warner, seeks to provide further support, and to expand and streamline planned and emergency respite, providing recruitment and training.
- The Living Well With Fatal Chronic Illness Act seeks to improve provision for carers aged 55-65 years under the Medicare scheme (the federally-funded healthcare system for older people).

Two recent studies published in the November 21st 2006 edition of the *Annals of Internal Medicine* focus on the importance of carers for patients with dementia. An accompanying editorial in that issue of the journal, by Dr Kenneth Covinsky and Dr C. Bree Johnson of the University of California and the San Francisco Veteran Affairs Medical Center argues that Medicare and other providers should be required to reimburse an extensive array of caregiver support services. "It is time for the public to recognise their part of this social contract", the editorial concludes.

give up caring. What they want is more help, so that they don't have to abandon employment, or go part time. The ability of carers to get respite—when and where they want—has also not been achieved”.

Legislation and direct support could certainly improve the situation for carers. But the struggle for more rights, recognition, and resources promises to be an uphill one for the carers' movement. Even if the movement achieves political backing, complex and highly individualistic societies are limited in what they can do to help carers. Voters in democratic societies are almost always more

concerned with the level of their taxes than with alleviating the lot of the carers of older people, disabled people, or the ill.

On the other hand, carers have undeniably made major strides. A defining signature of the carers' movement is the unique manner in which carers' advocates have managed to tackle the public's apathy about carers. Caregivers stand among some of the most invisible and forgotten components of society. Yet carers' campaigners have managed to bring about profound improvements for their constituency. Given its track record of past achievements, the carer's movement will probably continue to better the lot of society's carers.

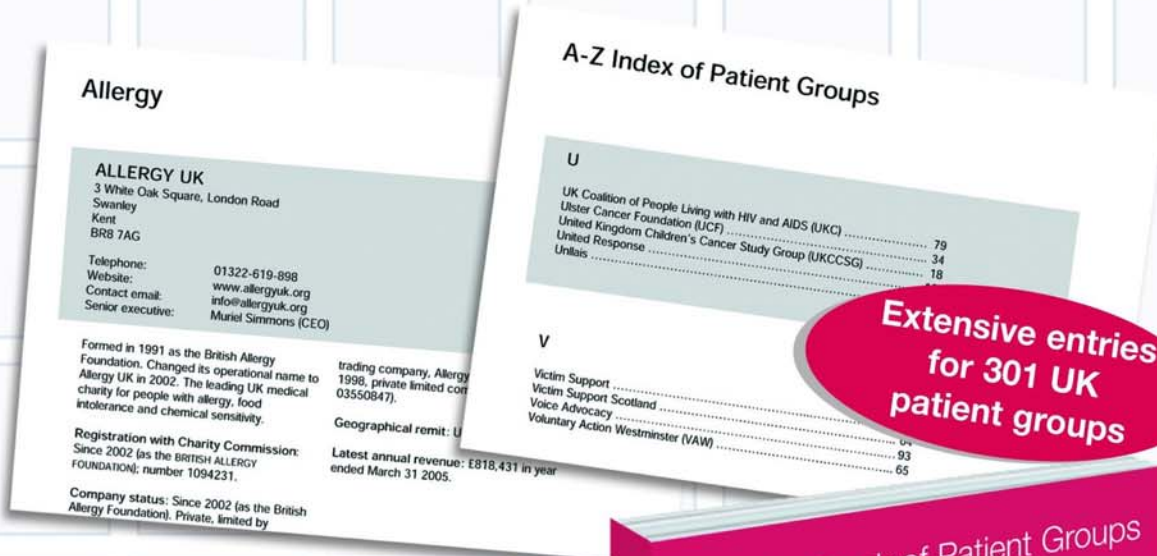
Next in this issue of *HSCNews* are interviews with four key executives from dementia or carers' organisations. These people explain why their groups believe that carers need more legislative and government support.



# The Handbook of Patient Groups

**NEW!**

**New and essential for anybody needing to identify and contact patient organisations**



## Useful additional information

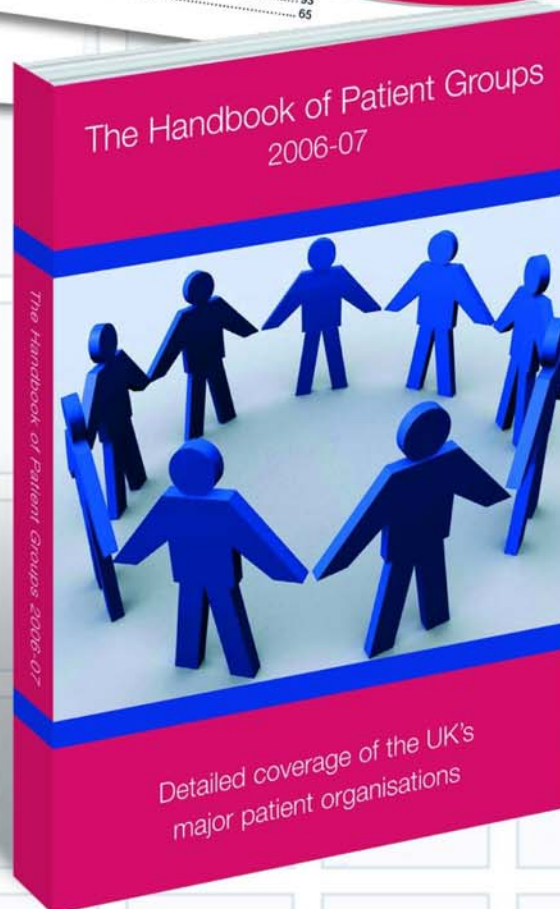
- Geographical remit
- Charity Commission reg. no. & date
- Company reg. no. & date
- Revenue
- Pharmaceutical company funding
- Donor pharmaceutical companies
- Group history

## Easy to use

- A5, approx. 200 pages
- Entries listed within 23 disease areas and 51 sub-categories
- Clear page layouts with helpful tabs, headers and footers
- Useful A-Z index for easy identification of patient groups by name

*"Better access to information at the point of diagnosis..."*

**Rosie Winterton, Health Minister,  
The Department of Health**



Allergy
Arthritis
Bone
Brain
Cancer
Children
Circulatory
Congenital
Continence
Diabetes
Disfigurement
Endocrine
Gastrointestinal
General Patient Organisations
HIV/AIDS
Immune
Infectious
Mental Health
Neurological
Reproductive
Research
Respiratory
Skin

Authored by

**PatientView**

Just £27.45 (inc. p&p). **Save £5.00** by ordering online at [www.binleys.com](http://www.binleys.com)  
**01268 495600 sales@binleys.com**

Published by



# Jean Georges: a view from Alzheimer Europe

---

In September 2006, Alzheimer Europe published a report, *Who Cares: the State of Dementia Care in Europe*, summarising the findings of a survey of 1,100 carers. The project was conducted by national Alzheimer's patient organisations in five European countries between November 2005 and January 2006. The *Who Cares* survey highlighted serious gaps and deficiencies in dementia care in Europe. Half of the carers interviewed in the five countries—France, Germany, Poland, Scotland and Spain—spent more than 10 hours a day caring. Four out of five of the interviewees complained of inadequate information on dementia, and wanted more information on help and services. Only 17% were satisfied with the level of care for the elderly in their country. To learn more about the results of this fascinating survey, and to discover what one of the world's major Alzheimer's groups considered should be included among future priorities for carers, *HSCNews* interviewed Jean Georges, Executive Director of Alzheimer Europe.

## **ALZHEIMER EUROPE (AE)**

A Luxembourg-based non-profit umbrella organisation founded in 1990. Now has 31 member groups from 26 countries. AZ works to alter current perceptions of Alzheimer's disease. The group promotes the right to early diagnosis, and insists that diagnosis should be accompanied by a referral to the appropriate local Alzheimer's organisation. AZ places considerable emphasis on the importance of improving the support and counselling of Alzheimer's carers, and of boosting quality of care at home.  
<http://www.alzheimer-europe.org>

**HSCNews International:** How important are carers to people with Alzheimer's disease?

**Jean Georges:** "Dementia is a major issue for the 21st century. Over 5 million people in the EU currently have dementia. One in every 20 of these people over the age of 65 have Alzheimer's disease (the most common form of dementia). Alongside most individuals with dementia is a carer—a wife, husband, daughter, son, or other relative. This addition of a 'carer dimension' to the problems imposed by Alzheimer's disease effectively doubles the number of people affected. The impact of caring on carers' lives is enormous, but has generally been overlooked by health services and policymakers. The latter tend to give little recognition to the vast amount of money they save when care is provided free of charge by carers. Carers may have to give up their employment, their free time, and, in fact, a normal daily life to care for their loved one. The *Who Cares* survey shows that half of dementia carers spend more than 10 hours a day looking after their loved one with dementia. Unlike paid workers, carers can expect no weekends off, and no holidays—no respite at all, as it happens—a fact that obviously cannot fail to have a massive negative impact on the health and wellbeing of carers."

**HSCNews International:** What are the main problems faced by dementia carers?

**Jean Georges:** "Clarifying this point is important, because some existing misconceptions about dementia may influence service and treatment provision. Cognitive problems in relation

to thinking and memory are commonly perceived to be a major issue. But our survey showed that carers were confronted with two more problematic areas—difficulties in performing daily activities (such as using the lavatory), and some behavioral symptoms (such as aggression and personality changes) that are very distressing for carers."

**HSCNews International:** Do carers receive much help from EU governments?

**Jean Georges:** "Our *Who Cares* survey found great differences between EU countries in the services they make available to people with dementia and to their carers. For instance, the essential service of respite care was available to 51% of carers in Scotland, but to only 3% of carers in Spain. Similarly, the level of financial support provided to carers to allow them to access these services varied considerably from one country to another. In Germany, carers are able to receive funding from long-term care insurance for most of the services. In Poland and Spain, by contrast, carers have to contribute from their own finances to the majority of services."

**HSCNews International:** What needs to be done?

**Jean Georges:** "Alzheimer Europe and its member organisations believe that dementia should be given a higher public-health priority in all European countries. For that reason, we incorporated some of what we think are the most important priorities into a Declaration adopted at our latest Annual General Meeting. This Paris Declaration calls on governments to set up (among

---

other things) clear action programmes on Alzheimer's disease—as has been done by the French government. Such action programmes should result in better funding for research. Equally vital, they should lead to more appropriate and generously-funded services for the carers of people with dementia.”

**HSCNews International:** What do you think the future holds?

**Jean Georges:** “The ageing of European populations makes political action to address the situation of carers of people with dementia an absolute imperative. Alzheimer Europe has been encouraged by the interest and support that policymakers have given to our Paris Declaration. A number of Members of the European Parliament have already pledged their support for the Declaration.

Their names can be found on the website that Alzheimer Europe developed specifically for the presentation of its political priorities: <http://www.dementia-in-europe.eu>. Finally, we are confident that continued research into Alzheimer's disease will lead to a better understanding of the mechanisms of the illness—which will, in turn, allow better treatments to be created. Hopefully, delaying, preventing, and even curing the disease will all be possible one day.”

**HSCNews International:** Many thanks.

# Liam O’Sullivan: a view from Care Alliance Ireland

---

The carers movement in the Republic of Ireland began in 1995, when a group of voluntary organisations concerned with family carers came together to form an alliance. In 1999, the four-year-old umbrella body received funding from the Department of Health, allowing a National Development Officer to be employed. A year later, the Alliance mounted its first annual conference. Now, the Alliance board is considering whether the group should become a member of the International Alliance of Carers Organizations (IACO). To learn more about the carers’ advocacy movement in Ireland, *HSCNews* talked to Liam O’Sullivan, Care Alliance Ireland’s National Development Officer.

## CARE ALLIANCE IRELAND

A Dublin-based national network of voluntary organisations that support family carers. Care Alliance is undertaking research into the health status of carers and into the operation of home-care packages.

<http://www.carealliance.ie>

***HSCNews International:*** How important are carers in Ireland?

**Liam O’Sullivan:** “About 149,000 people identified themselves in the 2002 Census as family carers. A large variety of individuals are being cared for by those carers—from older people, and people with a chronic disability, to people with a mental health problem. The Kilkenny-based Carers Association estimates that Ireland’s family carers save the state upwards of Euros 2bn [US\$ 2.6bn] per annum. The figure has been calculated at the home-help rate of pay.”

**HSCNews International:** The Republic of Ireland is an English-speaking Catholic country. In your culture, are carers expected to take over this type of healthcare provision, rather than the government or private healthcare providers?

**Liam O'Sullivan:** "Public expectation is changing. We now expect the state to provide more support. The problems faced by carers are very obvious: isolation, stress, and insufficient access to respite care—both in the home and at an institutional level. However, whether the public is willing to pay more taxes to enable this support to be delivered remains unclear."

**HSCNews International:** Does the government help in any way?

**Liam O'Sullivan:** "Yes, to some degree. Approximately 27,000 carers receive an allowance—a means-tested payment of Euros 180 [US\$238] per week. Some also receive home-care support, and access to carer support groups. Family carers do have the right to leave a job for two years to provide care—a provision backed by legislation. Private home-care providers are playing an increasing role in home-care support."

**HSCNews International:** How does your organisation help carers?

**Liam O'Sullivan:** "We coordinate all the information relevant to the people who are involved in supporting family carers—including NGOs, academics, and policymakers. We are currently undertaking qualitative research looking at rights-based approaches used by

family carer organisations in Ireland and abroad. We are also developing quantitative research looking at the health status of family carers. Both projects are part funded by the Combat Poverty Agency. We also organise regular seminars, including an annual conference. In addition, we are actively involved in making pre-budget submissions to government departments on various matters. We liaise with opposition political parties, to influence their own policies and their future election manifestos."

**HSCNews International:** What needs to be done?

**Liam O'Sullivan:** "A lot! Our priorities are likely to be increased financial support, removal of the means-tested element of the carers' allowance payment, plus more respite support (at home and institutionally)."

**HSCNews International:** What does the future look like?

**Liam O'Sullivan:** "Promising. Women in the past were seen as the natural carers. With employment opportunities so good nowadays, this is no longer accepted. Family carers will inevitably need to be supported more, though."

**HSCNews International:** Thank you.

# K. R. Gangadharan: a view from the Heritage Hospital, Hyderabad

---

India is the largest democracy and the second-most populated nation in the world. By 2050, India will be home to the second-largest number of older people in the world. Despite the seriousness of the statistic, the carers' movement is still very much in its infancy in the country. One of the most notable figures in India's nascent carers' movement is K. R. Gangadharan, Managing Director of the Heritage Hospital, and Regional Vice President (Asia) of the International Federation on Ageing (IFA). The Heritage Hospital, Hyderabad, is the country's first hospital for the elderly. It aims to offer affordable medical services, and has focused part of its efforts on programmes that offer respite to families and caregivers.

***HSCNews International:*** How important are carers in India?

**K. R. Gangadharan:** "Carers in our country have not joined together as a national organisation. But they are a strong presence within families and communities. With increasing longevity, and women living longer than men, women—who tend to marry at a younger age than men—are forced to care for their older male family members irrespective of their financial, emotional, or physical limitations. New

## HERITAGE HOSPITAL

Established in 1994 in Hyderabad, Andhra Pradesh, the Heritage is India's only multi-specialty geriatric hospital. The services provided by the facility include: home care, seniors' club, service clubs, 'meals on wheels', doctor on call, dial a driver, and a helpline.

No website.

## INTERNATIONAL FEDERATION ON AGEING (IFA)

Founded in 1973, a Montreal, Canada-based umbrella organisation of groups, bodies, and individuals that have a mission to improve the quality of life of older people around the world. Campaigns for the rights of older people. Publishes, conducts research projects, and runs conferences.

<http://www.ifa-fiv.org>

trends are coming into play—among them, Indian women (the traditional family carers) are pursuing careers now. Older people, though, continue to remain at home, and produce a significant demand for caregiving. So far, nobody in India has attempted to measure the economic impact of caregivers. But they are obviously very important.”

**HSCNews International:** What are the main problems faced by carers in India? Are carers expected to shoulder this type of healthcare provision, rather than the government or private healthcare providers?

**K. R. Gangadharan:** “Since economic considerations outweigh every other aspect of caregiving, carers have little choice. The middle class (who number a little less than 100 million in India) and the tiny minority who can afford anything (barely 1 million in India) can always pay for formal caregiving assistance. Some in the private sector, like the Heritage Hospital that I established in 1994, work with NGOs that focus on identifying younger people who are suitable to pursue a career in caregiving for the elderly, and then training them. Unfortunately, the majority of the people we train in caregiving go on to switch careers, as they find professional caregiving extremely demanding. Globalisation now means that India’s youth—even those not well educated—are attracted by the ‘new-economy’ jobs.”

**HSCNews International:** What kind of help does the government give to caring?

**K. R. Gangadharan:** “The government’s role in healthcare in India has always been ‘low key’. With extremely restricted budget provision, they are unable to cater to the needs of even the poorest sections of the population. There is the National Policy for Older Persons, a government-funded initiative dating from January 1999. The National Policy was set up with three intentions: to encourage individuals to make provisions; to help families take care of their older family members; and to support voluntary groups and NGOs supplement the care provided by the family. The care and protection of vulnerable older people falls within the objectives of the programme. But the National Policy is weakened by a lack of commitment to its implementation at various levels—beginning with that of the central (Union) government.”

**HSCNews International:** What is happening to caring in the private sector?

**K. R. Gangadharan:** “Private-sector investment is in hi-tech healthcare facilities that offer them a higher return on investment (ROI). NGOs are getting involved in caring, but they are usually unable to invest.”

**HSCNews International:** What happens to the people who cannot afford caregiver services? An estimated 80% of older people in India live in rural areas. Are services available for them?

**K. R. Gangadharan:** “People who cannot afford services seek government services—which are not always comprehensive. People living below the poverty line (a daily income of less than a US dollar) are estimated to comprise about 26% of India’s population today—far less than the 46% of about a decade ago. Rural care is taking root in the country, with plenty of healthcare centres coming up to meet primary healthcare needs. Patients do not always have to travel to large cities for every type of healthcare. Many medium-sized healthcare facilities are being established.”

**HSCNews International:** What is your organisation doing to help carers?

**K. R. Gangadharan:** “The Heritage Hospital of Hyderabad is a hospital for older people, and assists when respite is needed by family carers. We also provide bedside assistants to work (on 12-hour shifts) with families through the day. We run a ‘Call-a-Doctor’ service to families that care for older people, and is available any time of the day. We also run a ‘Dial-a-Driver’ service, allowing older people to remain mobile, visit relatives and friends, call on doctors, and participate in community events. One of our unique programmes is training the children of disadvantaged families to

offer bedside assistance to older people. We have trained over a thousand young people in this manner.”

**HSCNews International:** What needs to be done?

**K. R. Gangadharan:** “I am a member of the National Council of Older Persons and the Andhra Pradesh State Council of Older Persons. Therefore, along with many other organisations in the country, we are attempting to meet the needs of people suffering due to a caregiving burden. One of our most important aims is the building of a national pool of ‘down-to-earth’ trained caregivers. The task is made harder, however, by a huge amount of migration among younger people, to destinations both within the country and overseas. The availability and the creation of trained caregivers will be this country’s major challenge!”

**HSCNews International:** And as to the future?

**K. R. Gangadharan:** “Even middle-aged women are looking for opportunities that would enable them to earn more. Literacy level are improving in the rural areas of India. Youth is pursuing education and better job opportunities. I believe that we now have an ideal opportunity to get youth involved in formal caregiving activity in large numbers.”

**HSCNews International:** Many thanks.

# Gail Hunt: a view from the International Alliance of Carers Organizations

---

The International Alliance of Carers Organizations (IACO) has been around for only two years, but is moving ahead quickly. *HSCNews* spoke to Gail Hunt, who, as head of the IACO and President of the National Alliance for Caregiving (NAC), a US umbrella organisation with over 40 member national groups, is well placed to contemplate the movement's future.

***HSCNews International:*** The international carers movement started in the UK and has a very clear presence in Anglo-Saxon and northern European countries. Why is that? Is an economic or cultural rationale at work here?

**Gail Hunt:** "I think it is more cultural than economic. If you compare countries with similar economic structures but different cultural backgrounds (like France and Italy on the one hand, and Sweden and the UK on the other), you can see that economics is not a factor. Italians, for instance, don't think of family

## **INTERNATIONAL ALLIANCE OF CARERS ORGANIZATIONS (IACO)**

A global umbrella organisation founded by national carer groups from five countries in 2004. The IACO works to internationalise the issue of caregiving. It also assists countries form their own carer organisations, and promotes the sharing of best practices.

<http://www.internationalcarers.org>

## **NATIONAL ALLIANCE FOR CAREGIVING (NAC)**

Founded in 1996, a Bethesda, Maryland-based non-profit coalition of national organisations that focus on issues of family caregiving. Conducts research, analyses policy, devises national programmes, and works to increase public awareness on the subject of caregiving.

<http://www.caregiving.org>

caregiving in the same way as people in the UK. There is no recognition in Italy that a category of people exists who are carers. People who care for their loved ones there are not carers, they are just carrying out a time-honoured family duty.

Another factor is also present. My organisation in the US has carried out a lot of research on family carers, and we now have an important national data collection on the subject. We know that a fifth of all adults are providing some kind of care to another adult (the latter would typically be frail, disabled, or old). The Australians have also built up data on caregiving. The two countries view the topic as worthy of data collection. After Japan, Italy is the country with the oldest population, but their attitude is completely different. Of course, they take care of their elders. But they do not see themselves as carers. This doesn't mean that the problems associated with caring do not exist in countries like Italy. I am glad, therefore, that my organisation is hosting the first Latin American carers conference in Miami at the end of November 2006. Eight countries have been invited to send 3-or-4-person teams to develop five-year plans for caregiving in their countries."

**HSCNews International:** What are the main problems faced by carers?

**Gail Hunt:** "One of the most well-known difficulties that confront carers is the need to take a respite, a break. But carers also have a requirement for information about the task of caring. I have met carers who say that they don't know whether they are caring for a child

with disability, or a spouse, or what. People who don't know where to turn to for help. Help can come from the government, but also from religious organisations, such as the church. Another problem for carers is their lack of training. Very often, when a patient is sent home from hospital, or a person becomes progressively ill, the carer has very little training in how to deal with the whole situation. For instance, if a sick person comes home from a hospital with a respirator, the carer has to figure out how to work the machine. And what do they do, they wonder, if the equipment develops a fault? Even apparently simple daily routines (such as moving a sick or frail person out of bed and into a wheel chair, or from a wheel chair into the bath) are tackled best by the carer who has been properly trained in the appropriate techniques."

**HSCNews International:** Are any governments around the world taking the initiative and providing help to carers ?

**Gail Hunt:** "I think that government response is growing in Australia, New Zealand, the UK and the US. Australia and the UK offer stipends for carers. In the US, though, only Arkansas and California are beginning to pay some money to family carers. Even these subsidies are limited to the poorer carers, reflecting the US 'public' healthcare system's slant towards very poor people only (unlike the Australian and UK equivalents, which provide healthcare to all citizens). In terms of legislation, the UK is the most advanced. It was the first country to legislate on

this. One important piece of the UK legislation establishes that carers can have, as a base level, their needs met equally to those of the person for whom they are caring.”

**HSCNews International:** Do you think that the first step for the carers’ movement should be to get legislation in place that recognises the problems they face while caring, and then to move on?

**Gail Hunt:** “I think that public awareness has to be built up first. The responsibility for this includes NGOs. Some big national organisations (like those specialising in diabetes, Parkinson’s, or stroke) do not currently seem to recognise that the family caregiver is an important person. I think that once you have then built yourself a voice at that level—a political voice—you can start to move on to asking for legislation. Getting money for programmes that can offer respite to carers, for instance, is a very important issue. But, to succeed, it needs a level of public awareness behind it.”

**HSCNews International:** What can be done at international level to help national carers’ movements?

**Gail Hunt:** “We want to get more people involved at an international level. For this purpose, I went to an ageing conference in Copenhagen some time ago. I met with people from Finland, the Netherlands, and Sweden, and made sure that they came into the international carers’ movement. I hope that the November 2006 conference in Miami will get Latin American countries on board. IACO would like to become a non-profit

NGO, and obtain a formal relationship with the World Health Organization, so that caregivers are recognised at an international level. No one in the WHO focuses on that issue at the moment. If the UN accepts the worthiness of the caregiving cause, we would maybe like to have a ‘Day of the Carer’. Getting something like this accepted usually takes about 10 years—but you have to get started, somehow.”

**HSCNews International:** And as to the future?

**Gail Hunt:** “The whole issue of family care is going to explode. The population is aging. Women are working more than ever—so that in the US, for instance, almost 40% of the carers are now men. How is society going to support these carers? How are these carers going to be helped to carry on caring? And, at the same time, how do we make sure that carers don’t drop out of the workforce? Nobody really wants that to happen. Sooner or later, society will have to deal with these issues.”

**HSCNews International:** Many thanks.

# THE WARNING SIGNS of Primary Immunodeficiencies

Primary Immunodeficiencies (PIDs) cause children and young adults to have infections that come back frequently or are unusually hard to cure. Lack of awareness of these signs means the majority of PID sufferers in Europe are undiagnosed. This leads to persistent suffering, anxious concern by parents and unnecessary healthcare costs. If you or someone you know is affected by two or more of the following warning signs, speak to a physician about the possible presence of an underlying PID.

Eight or more new ear infections within 1 year

Recurrent, deep skin or organ abscesses

Two or more serious sinus infections within 1 year

Persistent thrush in mouth or elsewhere on skin, after age 1

Two or more months on antibiotics with little effect

Need for intravenous antibiotics to clear infections

Two or more pneumonias within 1 year

Two or more deep-seated infections

Failure of an infant to gain weight or grow normally

A family history of primary immunodeficiency

On 5 October 2006 European doctors, nurses, patients, parents and health policy makers united to launch a *Call to Action*, urging EU Governments to combat the suffering caused by Primary Immunodeficiency diseases (PIDs) - suffering mainly caused by misdiagnosis and thus inappropriate treatment.

Developed with the support of the European Commission's Public Health Programme, the *Call to Action* is contained within a Consensus Statement, Recommendations & Report developed by the attendees of the European PID Consensus Conference held at the Paul Ehrlich Institute in June 2006. This conference was attended by representatives from patient and clinician groups, as well as health policy makers, journalists and industry representatives.

All information about the EU PID Consensus Conference, including the EU PID Consensus Statement, Recommendations and Report in ten languages can be found at the conference web site: [www.eupidconference.com](http://www.eupidconference.com).



These Warning Signs were developed by the Jeffrey Modell Foundation Medical Advisory Board © 2006 Jeffrey Modell Foundation

# Members news

—**PRINCESS ROYAL TRUST FOR CARERS IN SCOTLAND**

Two seminars on the Scottish Executive's forthcoming NHS Carer information Strategy (CIS)

—**EXTRA CARE [NORTHERN IRELAND]**

Wins an award for its family-carer training programmes

### THE PRINCESS ROYAL TRUST FOR CARERS

The London-based Trust is the largest provider of comprehensive carers' support services in the UK. The organisation also manages a separate Glasgow-based Scottish division. This Princess Royal Trust for Carers in Scotland administers a network of centres which, in collaboration with key partners, collectively drives the carers' agenda in Scotland.

<http://www.carers.org>

### ABOUT THE SCOTTISH NHS CARER INFORMATION STRATEGY

In February 2006, Scotland's governing body, the Scottish Executive, published *The Future of Unpaid Care in Scotland*, a 48-page report that produced "a bold new vision for unpaid carers in Scotland".

Recommendations included carers' rights to flexible employment, financial and practical support, information, housing, transport, healthcare, and regular respite.

An 81-page November 2005 report from the Scottish Executive, *Delivering for Health*, committed NHS Scotland to giving systematic support to carers and the people for whom they care.

On April 24th 2006, the Scottish Executive Health Department placed a legal requirement on Scottish NHS Boards to prepare an NHS Carer Information Strategy, to be implemented in April 2007. Consultation processes for the Strategy are currently in train.

## INITIATIVE ON CARER INFORMATION IN SCOTLAND

Ahead of Scotland's NHS Carer Information Strategy (due to be implemented in April 2007), the Princess Royal Trust for Carers hosted two half-day seminars, 'Scottish NHS Carers Information Strategy', in Edinburgh and Inverness during August 2006. The meetings were aimed at senior executives of Scottish Health Boards, and were intended to discuss means of engaging and supporting Scotland's 60,000 or more carers.

The seminars concluded that any effective carer information strategy (CIS) needed to effect "a culture change across all levels of health, ensuring that carers are truly included as partners in their charge's care". The seminars specified that any such strategy should take account of the personal situation of individual carers (including gender, age, and locality), so that carers can get information appropriate to their needs.

Numerous barriers to progress were foreseen by seminar attendees, not least the presence of "inadequate resources (especially time), and the practical difficulties of releasing staff to take part in carer-awareness training. Moreover, the 'pathway' from diagnosis to discharge can be as short as 2-3 days. If the emphasis is on getting patients out of hospital as quickly as possible, the information process for carer and the cared-for needs to start as early as possible in the patient journey. This requirement means joined-up thinking between primary and secondary care".

The Princess Royal Trust for Carers believes that further lobbying will be necessary to convince the Scottish Executive to release more funds to enable the Strategy to be fully implemented.

<http://www.carers.org/data/files/august-06-health-seminar-report-1809.doc>

**EXTRA CARE**

Founded in 1935, the local, voluntary, Belfast-based Extra Care "aims to enable dependant adults to live with dignity in their homes". Extra Care offers respite, and trains family carers in the home.

<http://www.extra-care.org>

**NORTHERN IRELAND CARER GROUP WINS AN AWARD FOR ITS FAMILY-CARER TRAINING PROGRAMMES**

Extra Care is one of the world's oldest carer organisations. The Northern Ireland-based voluntary organisation provides services that help dependent adults to continue to live at home. In 2003, Extra Care launched its Family Carer Training Programme to give respite to family carers. The scheme trains carers in their own homes, enabling the carers to fulfil their caring role and minimise any health and safety risk to themselves or their dependents. The programme, which includes elements such as moving and handling, personal care, and stress management, has benefited 170 carers since 2003.

The Programme's excellence was recognised when Extra Care won a 2006 National Training Award (a major UK government-backed accolade awarded to a few dozen of the country's businesses and organisations that can demonstrate the achievement of success through training and learning).

<http://www.delni.gov.uk/index/press-releases/press-releases-oct-dec-2006/best-year-on-record-for-northern-ireland-national-training-award-winners.htm>

# Research

—COFACE [BELGIUM]

Embarks on a trans-European project, 'Help the Carers'

**COFACE**

Founded in 1958, the Confederation of Family Organizations in the European Community (COFACE) is a non-political, non-religious, not-for-profit, voluntary organisation that links general and single-issue national family organisations. COFACE has 60 member groups, and gives voice to millions of parents and children.

<http://www.coface-eu.org>

**COFACE UNDERTAKES A CARERS PROJECT**

The COFACE Handicap project was born out of an initiative presented to the European Commission in 2004. The Commission decided not to fund the project, but its 11 partner groups [see below] retained so much confidence in their joint initiative that they decided to press on without the European Commission. The project was further refined at a meeting between the partners in Brussels in October 2005. There, the 11 groups resolved to gather evidence on the degree of recognition given to carers by their respective countries of Belgium, Cyprus, France, Greece, Italy, Luxembourg, and Portugal. The project has two immediate aims:

- The production of a guide to the needs of family carers (as expressed by carers themselves).
- A statement of carers' rights and a record of the support measures for family carers implemented by national authorities (or organised by support associations) in the various European countries under study.

The key long-term goal of the Handicap project is to obtain official recognition at European Commission level of the status of the family carer. Research has been ongoing throughout 2006.

**Partner groups in the COFACE Handicap project:**

- **Belgium:** Association des Parents et Professionnels autour de la Personne Polyhandicapée (AP3).
- **Cyprus:** Pancyprrian Organisation for Large Families (POP).
- **France:** Association des Paralysés de France (AFP); Union Nationale des Associations Familiales des Traumatisés Crâniens (UNAFTC); Union Nationale des Associations des Parents d'Enfants Inadaptés (UNAPEI); Union Nationales des Associations des Parents d'élèves de l'Enseignement Libre (UNAPEL).
- **Greece:** Κέντρο Μεριμνας Οικογενειας και Παιδιου [Family and Child Care Center (FCCC)].
- **Italy:** Associazione Italiana Per l'Assistenza Agli Spastici (AIAS); Unione Famiglie Handicappati (UFHA).
- **Luxembourg:** Association des Parents d'Enfants Mentalement Handicapés (APEMH).
- **Portugal:** Liga Portuguesa Dos Deficientes Motores (LPDM).

## **HEALTH and SOCIAL CAMPAIGNERS' NEWS INTERNATIONAL**

THE WORLD'S ONLY INDEPENDENT PUBLICATION THAT KEEPS YOU IN TOUCH  
WITH THE OPINIONS OF HEALTH ADVOCATES  
—THEIR HOPES, THEIR FEARS, AND THEIR PLANS FOR THE FUTURE

### **MOST RECENT BACK ISSUES OF HSCNEWS**

#### **Issue 18 (May 2005)**

✓ Hospital-acquired infections: an *HSCNews* global survey commissioned by the Irish Patients' Association (IPA).

#### **Issue 19 (June 2005)**

✓ From market-driven to needs-driven drug research: Médecins Sans Frontières (MSF) drafts a strategy to promote the development of drugs for neglected diseases.

#### **Issue 20/21 (Summer 2005)**

✓ Users' perspectives of national healthcare systems: an *HSCNews* global survey.

#### **Issue 22 (October 2005)**

✓ Clinical trials registration: the views of three key health campaigners.

#### **Issue 23 (November 2005)**

✓ Users' views of electronic medical records: an *HSCNews* global survey.

#### **Issue 24 (December 2005)**

✓ New initiatives on patients' rights.

#### **Issue 25/26 (January/February 2006)**

✓ Annual review of health campaigners' activities worldwide.

#### **Issue 27 (March 2006)**

✓ Medical litigation.

#### **Issue 28 (April 2006)**

✓ Health campaigners and the future of medical research.

#### **Issue 29 (May 2006)**

✓ Health advocacy in 2006: a global profile.

#### **Issue 30 (June 2006)**

✓ Children's health campaigners: a global profile.

#### **Issue 31 (August 2006)**

✓ Global survey on patient information.

#### **Issue 32 (September 2006)**

✓ The patients' rights' movement in Eastern Europe: an overview. Plus interviews with four campaigners from the region.

