

(a) **Purpose;**

CARE Rights (Caring & Reaching Elders' Rights, Seoul, South Korea) aims to ensure the well-being of elders and family caregivers, working to strengthen older persons' rights with emphasis on autonomy, independence and dignity in terms of Quality of Care and Quality of Life. All projected projects aim to implement programs in collaboration with the UN NGO Committee on Ageing, N.Y. as of 2012.

CARE Rights works to address and cover a 'normative gap,' known as the lack of provision in human rights law, and promotes the reduction of an 'implementation gap,' or the lack of protection for elders' rights through the existing human rights system<sup>1</sup>. CARE Rights is currently communicating with a UN Special Rapporteur in New York to facilitate activities, as well as working to collaborate with coalitions from other UN Member States in planning for the International Convention in 2014 and 2016.

(b) **General Principles;**

CARE Rights takes into account on-going efforts to achieve the three fundamental principles of the MDGs (Millennium Declaration Goals)<sup>2</sup>: human rights, equality and sustainability. Under these fundamental principles, CARE Rights operates with three goals which target the specific situations of elders and their family caregivers. All strategies are multi-facted, people-centered and sustainable approaches in line with international standards.

1. The first goal is to promote and facilitate opportunities for legal action in the context of elderly patients' rights in End-of-Life (EOL) decisions under the principle of human rights. The rights of elderly patients in terms of their autonomy, dignity, and independence in the processing of EOL decisions must be protected by an international legal subsystem.

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<sup>1</sup> Strengthening Older People's Rights: Towards a UN Convention. DESA (2010)

<sup>2</sup> Report to the Secretary-General, Realizing the Future We Want for All. DESA (2012)

2. The second goal is to educate and support family caregivers, and to build social and cultural support systems for these individuals, the majority of whom are elderly females or unpaid spouses/partners, under the principle of equality. Public and private sectors must address the fragility and limitation of the target group, many of whom are affected by financial, physical and psychosocial difficulties.
3. The third goal is to raise public and professional awareness of human rights in regards to one's EOL decision, as well as for the protection of female elderly spouses and/or partners caregivers. CARE Rights is involved in areas of policy and social strategies with effective and sustainable responses.

### **(c) Definitions: Issues faced by the Ageing Population**

#### **i) Lack of awareness and other EOL decision limitations**

The population of older persons is dramatically increasing, and this phenomenon of rapid, global ageing heralds various challenges related to human wellbeing<sup>3</sup>. Consequently, these changes have led to an unprecedented surge in the cost of EOL care. Additionally, almost half of all Medicare expenditures for EOL care in the U.S., and a third of those within the South Korean population, are incurred in the last two months of EOL care, predominantly due to the use of life-sustaining treatments and drugs to prolong lives.<sup>45</sup> Within a lifetime, minorities in the U.S. accrue the most medical expenditures within their last six months due to more time spent in intensive care units and numerous aggressive and unnecessary procedures undergone. Such issues stem from a lack of clear and culturally-sensitive information as well as a deficit in legislation regarding EOL decisions.<sup>6</sup>

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<sup>3</sup> Ageing in the Twenty-First Century: A Celebration and A Challenge. UNPF, NY & HelpAge International, London (2012)

<sup>4</sup> Statistics for Long Term Care Services. Korea National Health Insurance Cooperation (2012)  
Retrieved from <http://www.nhic.or.kr/static/html/wbd/g/a/wbdga0101.html>

<sup>5</sup> End-of-Life Decisions. NHPCO(2005). Retrived from [www.caringinfor.org](http://www.caringinfor.org)

<sup>6</sup> Reverse racial and ethnic disparities in EOL costs. Hanchate, A.D., Kronman, A., Young-Xu, Y., Ash, A., & Emanuel, E. Archives of Internal Medicine, 169(5), 480-488 (2009).

These problems extend outside of the U.S. where legislation and/or information are(is) not instituted or widely recognized by elders and their family caregivers, thus excluding and/or causing disadvantage to them in the EOL process and with ‘Advance Directives.’ Cultural ideas and expectations also play a role. For example, discussions regarding a parent’s death prior to its occurrence are perceived as taboo in South Korea. As such, legislation and information to guide and outline the rights of an older person is minimal. In recent data, only 6.3 percent of Korean elderly patients were admitted to hospices in the country, as opposed to a 38 percent admission rate in the U.S.<sup>7</sup>

Awareness of information and options is also limited by the global population migration generated by approximately 214 million international migrants and an estimated 740 million internal migrants, totaling almost one billion people living away from their place of origin or residence.<sup>8</sup> In 2011, 95,234 American Nationals aged 60 years or older entered Korea; 14,708 of them remained in the country at least three months or longer with registered foreigner status from the U.S.<sup>9</sup> Such individuals, including those who have completed their ‘Advance Directives for Health Care’ in their home country, are at a higher risk for misconduct or limitations in their EOL decision making process within Korea (as opposed to one’s native country) due to differences in legal and cultural systems.

## **ii) Elderly female spouse/partner caregivers and increasing population of elders with dementia**

U.S. national data showed that 38.4 percent of primary caregivers are unpaid elderly spouses/partners. 67.6 percent have no secondary caregiver in their care, receiving less assistance from other family members or friends than adult children.<sup>1011</sup>

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<sup>7</sup> Analysis of Health Care Expenditure before the Death. Lee, S., Lee, H., Kim, J., & Kang, S. . Health Insurance Policy Institute (2011).

<sup>8</sup> International Migration Report 2009: A Global Assessment . Department of Economic and Social Affairs (2011)

<sup>9</sup> Korea Immigration Service Statistics 2011. Korea Immigration Service, Ministry of Justice (2012)

<sup>10</sup> Caregivers of Frail Elders: Updating a National Profile. Wolf, J.L., & Kasper, J.D. (2006).*The Gerontologist*. 46(3), 344-356.

<sup>11</sup> Through The Eye of the Caregiver. Family Association of America. (2011). Retrieved from caregiver.org/caregiver/.../FCA\_2011YearInReview\_Report.p...

In Korea, 65.6 percent of all unpaid, informal family caregivers are women aged 75 years or older, 62 percent of whom spend 20 or more hours caring for elderly spouse/partners/relatives on a weekly basis.<sup>12</sup>

The dementia rate among Korean elders is projected to increase to up to 13 percent of the total ageing population by 2035.<sup>13</sup> However, Korean family caregivers who are caring for elders with dementia are seeking less outside or professional help due to a lack of information for social support, as well as a fear of social stigma fuelled by cultural expectations of filial piety.<sup>14</sup> Both Korean elders with dementia and their elderly spouse/partner caregivers suffer from social, cultural, and financial difficulties and require legal and health care assistance and information.

Elder abuse and neglect are complex problems that combine elements of family arrangements, carer issues and socio-cultural issues<sup>15</sup>. In Korea, the number of elderly domestic violence cases increased almost seven-fold between 2007 and 2011<sup>16</sup>. Physical abuse between elderly husband and wife partnerships was shown to result in increased physical and/or mental difficulties.

#### **(d) Introduction of Programs Based on Equality and Human Rights as Applied to Elders;**

CARE Rights works to develop two main programs targeting the specific situations of elders and their family caregivers within the community and areas of LTC (Long Term Care); i) “The Program of Protection for Elders’ Rights in End-of-Life Decisions”, ii) “The Program of Empowering Elderly Spouses/Partners Caregivers”

##### **i) The Program of Protection for Elders’ Right in End-of-Life Decision**

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<sup>12</sup> National Survey of Profile of Elderly Life and Welfare Needs. Ministry of Health & Welfare(2012). Retrieved from [http://english.mw.go.kr/front\\_eng/index.jsp](http://english.mw.go.kr/front_eng/index.jsp)

<sup>13</sup> Predictors of Caregiver Burden in Caregivers of individuals with Dementia. Kim, H., Chang, M., Rose, K., & Kim, S.(2012). *J of Advanced Nursing*, 68(4), 846-855.

<sup>14</sup> Korean Elder Protection Agency, Annual Report 2011. (2012). Retrieved from [http://www.noinboho.or.kr/board2/bbs/board.php?bo\\_table=zine&wr\\_id=32](http://www.noinboho.or.kr/board2/bbs/board.php?bo_table=zine&wr_id=32)

<sup>15</sup> Report of the Expert Group Meeting “Rights of Older Person” UN DESA 5-7 May, Bonn, Germany (2009)

<sup>16</sup> Korean Elder Protection Agency, Annual Report2011. Korean Elder Protection Agency (2012)

- Target population
  1. Elderly patients and their family caregivers in hospitals, LTC services for institutional and community programs, and community mental health clinics
  2. Elders with dementia and their family caregivers
  3. Elders who are interested in making their ‘Advance Directives’
  4. Elderly foreign travellers and foreign national residents with immigration status in South Korea
  5. Health care staffs, social workers, care managers, religious organization’s leaders and members, and community activity centers, etc.
- Service areas
  1. Hospitals and LTC services for institutional and/or community-based care settings
  2. Active Ageing Centers and Communities
  3. Internal and International services for Korea, U.S., other parts of Asia, and further UN member countries
- Activities
  1. Education
  2. Translation of UN reports/materials
  3. Research & Data collection
  4. Advocacy for public awareness & Legislation
  5. Developing materials for an education manual, a website, and other media

**ii) The Program of Empowering Elderly Partner/Spouse Caregivers**

- Target population
  1. Elders with dementia and their family caregivers in hospitals, LTC services for institutional & community programs, and community mental health clinics
  2. Elders and their unpaid, elderly spouse/partner caregivers

3. Long distance family caregivers for foreign national residents with immigration status in Korea
- Service areas
    1. Hospitals and LTC services for institutional and/or community-based care settings
    2. Community Family Service Centers, Active Ageing Centers and Community-based mental health clinics, etc.
    3. Internal and International services for Korea, U.S.
  - Activities
    1. Education
    2. Care Management
    3. Developing material for media and website
    4. Research & Data collection
    5. Advocacy for public awareness & Legal legislation for enactment
    6. Social Action for Family caregiver's Association

### **(e) National and International Supervisory Mechanisms.**

CARE Rights understands and agrees with the report of the General Assembly Resolution 67/139 of 20 December, 2012. CARE Rights also understands that all programs will be in collaboration with the UN NGO Committee on Ageing, N.Y. since 2012. CARE Rights is not prepared to become a relevant UN Non-Governmental Organization (NGO) at this time. However, it does believe that targeted solutions for the specific situations of elders and their family caregivers needs immediate attention at both internal and international levels. CARE Rights calls upon national and international instruments to promote and protect the rights and dignity of elders through the agency's plans and activities for supervisory mechanisms.

- i) **CARE Rights aims to become a rapporteur, and/or to encourage existing rapporteurs to address the rights of elders and their family caregivers.**

- Planning & Activities
  1. Evidence and data collection
  2. Collaborating with internal and international academic and civic resources
  3. Research with evidence-based approaches & material development
  4. Contribute to the UN NGO Committee on Ageing, N.Y.

ii). **CARE Rights works to prepare for various International Conventions for the rights of elders and their family caregivers**

- Planning & Activities
  1. Official IAGG meeting for Elder's Rights in EOL decision in 2013; CARE Rights and Gerontological Society of America, Asian Interest Group will host an official meeting to discuss Asian culture and Elder's Rights in EOL decisions in Seoul (confirmed)
  2. Convention for Elder's Rights in EOL decision in 2014; CARE Rights and Gerontological Society of America (Dr. Jillan Chen) will initiate an international convention involving the Asia-Oceania area in Seoul (planning)
  3. Convention for Empowering Elderly Female Spouses/Partners Caregivers in 2016; CARE Rights and Korean National Social Work Association will initiate an international convention in Seoul (planning)