A MODEL OF INTEGRATED CARE FOR DEMENTIA:
THE “Emilia-Romagna Project”

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In 1999 the Regional Government of Emilia-Romagna deliberated the “Regional Dementia Project” (Regional Act 2581/1999).

This act provided funds for the organization of Health And Social Welfare Services in the community for people with dementia and collaboration with Family Alzheimer Associations.
Why a Regional Dementia project?

- Emilia Romagna is one of the oldest Regions in Europe
- Limits of pharmacological treatments
- Prolonged duration of dementia
- Caregiver’s burden and patient’s distress
- Social and health impact

- Currently 60,000 people with dementia in Emilia Romagna
- Numbers likely to double in the next 30 years
- Costs likely to treble in next years
  - Dementia is one of the main causes of disability later in life
  - 40% of older people admitted to hospital suffer from dementia
  - At least 50% of long term care residents suffer from dementia

Resident population on 12/31/2010:
4,432,439 inhabitants

986,845 Inhabitants are over 65 years
Main strategies and main tools of the Regional Dementia Project

- Ensure good and timely diagnosis
- **Global approach** (social and health services integrated)
- **Qualify existing network service** (not only separate net for people with dementia)
- **Improve and support caregivers** (=family & professional) and family associations
- **Training and education** (courses for GPs and nursing staff)
- Good staff (quality, number and different skills)
- Environment
- Therapeutic agreement with families
- **Global care plane, follow-up, continuity of care**
- Modify **hospital approach** when patients with dementia need hospitalization
Priorities in implementing the project:
the regional documents to diffuse common tools and a shared model to approach dementia

§ **Guidelines** for diagnosis and evaluation,

§ **Directory** of assessment instruments

§ **Protocol of care**: How to approach main therapeutic and nursing problems

§ **Protocol of education and training**: specific for different level of staff and caregivers

§ **Guidelines for providers of services**: how to improve quality of life and care

§ **Design Handbook**: criteria for designing and adapting the environment (domestic and nursing home)

§ **Caregivers’ Handbook**: what is dementia, how to cope with it.

More than 50,000 copies distributed!
The general organisation

REGION
Regional board committee for dementia

General decisions, guidelines, financial support

Monitoring of actions and Annual Regional Report of the Project

Local Health Agency (AUSL)

According to general lyshared strategies

Each AUSL has a manager for the project

Receiving financial support from the Region to implement the project

Expert center (each having a manager)

Municipalities, Associations..

Integration: HEALTH AND SOCIAL

According to regional decisions

Annual report to the Region

DEDICATED FUNDS:
About 8 MLN Euros from 2000 to 2010

ORDINARY FUNDS:
By social and health funds
Correct and early diagnosis, the expert center: a network that has been consolidated

**A TOTAL OF 53 Center all over the Region**

**Various PROFESSIONAL STAFF OF MORE THAN 270 individuals**
(geriatricians, neurologists, psychologists, nurses, rehabilitation therapists, sociale workers etc)

**HIGH CONTACT CAPACITY**
about 18,000 new contacts per year with 14,000 people taken into care system *

**DIAGNOSTIC ACTIVITY**
about 10,000 new diagnosis of dementia per year *

* Data year 2010
General approach to suspected dementia according to regional guidelines

- **visit by GP**

- **Suspecting dementia?**
  - **Doubt?**
    - **Other Diagnosis**
      - **No**
      - **Yes**: M.M.S.E.c < 26/30

- **administer MMSE**
  - **Doubt?**
    - **Yes**: Patient referred to the Dementia Expert center with screening tests
    - **No**: Deeper Evaluation (2nd level) Based on standardized criteria

- **Activation**
  - Evaluation of family resources, identification of the caregiver, medical advisor
  - Information to caregivers on dementia services
  - Referral to the social worker based on standardized criteria
  - Follow-up of clinical status and drug therapy through the various stages of the disease
  - Activation, when required of Integrated Home care (ADI), or other services (Day Care, Nursing Home, Respite Care, ...); Supporting caregivers (self-help, advices, etc)

- **GP administers a Dementia CHECKLIST**
The diagnosis is only the starting point... and not the target

..We can not cure the disease but we can care the people with dementia..

The patient
The family
The professionals

People with dementia & their carers must be helped to live well with dementia, no matter what the stage of their condition or where they are in the health & social care system

ACCORDING TO PEOPLE’S PREFERENCES AND NEEDS
The opportunities for people with dementia

- Pharmacological and health care
- Psychological support in the early stage of dementia
- Cognitive, motor and sensorial stimulation
- Occupational therapy, socialization activities
- Right to live at home as long as possible by helping family and caregiver (i.e. private assistants)
- Right to receive qualified care through services (not only special services)
The family: an important resource of care to be helped

- **Education and Training**
- **Information seminars**
- **Support and self-help groups**
- **Specialist advices: psychological, nursing and care, legal, technique for home adaptations**
- **Economic support and work permission**
- **Support to keep demented people at home** (i.e. psychological support, respite care, flexible homecare, ecc)
- **Caffè Alzheimer, Meeting centers**

From 2002-2010: More than 52,000 Caregivers involved, given more than 102,000 specialist’s advice; n° 45 “Alzheimer Càfé “activated in 2010 (more than 2000 PWD involved) at a cost of about 1,5 milion in this year (FRNA)
Collaboration with Family associations

Associazione di Ricerca e Assistenza delle Demenze Bologna ONLUS
viale Roma 21, 40139 BOLOGNA
Tel. 051/465050 ; fax 051/463000
Site: www.aradbo.org e mail: aradbo@interfree.it

Gruppo Assistenza Familiari Alzheimer
GAFA - CARPI - Associazione di Volontariato ONLUS
c/o Casa del VOLONTARIATO
Via Peruzzi 22 - 41012 Carpi
cell. 349 5928342 - Site: www.gafal.it Email: info@gafal.it

Associazione Ama-Amarcord
Castello D’Argile ONLUS
Via Matteotti 158 – 40050 Castello d’Argile (Bo)
Tel. 346 5884000
e-mail ama.amarcord_argile@libero.it

CAIMA Cesena Care-givers Associazione Italiana Malati di Alzheimer ONLUS
Via Gadda, 120 - 47023 Cesena
Tel/fax: 0547/646583
Site: www.caima.it - e-mail: associazione.caima@virgilio.it

Associazione Malattia Alzheimer Ferrara ONLUS
Via Ripagrande, 5 – 44100 Ferrara
Tel. 0532/792097 - fax 0532 799552
Site: www.amaferara.it, email: amaferara@amaferara.191.it

"La Rete Magica" - Associazione Amici per L’Alzheimer e il Parkinson ONLUS
Via E. Curiel 51 - 47100 Forli
Tel/Fax 0543.033765
Sito: www.laretemagica.it Email: info@laretemagica.it

ASDAM - Associazione Sostegno Demenze e Alzheimer Mirandola ONLUS
Via Castelfidardo, 40 – 41037 Mirandola (Mo)
Tel. 0535.611588 - Cell. 331 6309109
Email: asdam@libero.it

Associazione Familiari malati di Alzheimer “G.P. Vecchi” Pro senectute et dementia ONLUS
Viale Vittorio Veneto 9 – 41100 Modena
Tel 059 436546 - Tel 059 283918 – cell 3355323021
sito: www.gpvecchi.org email: econcari@inwind.it

Associazione Italiana Malattia di Alzheimer - Reggio Emilia ONLUS
Via Papa Giovanni XXIII 16, 42020 Albinea (RE)
Tel. 0522 348813 - Fax 0522 348816
Sito: www.alzheimer-ama.it Email: ama.re@libero.it

Associazione Ama-Amarcord
San Pietro in Casale ONLUS
P.zza Calori n° 7 - 40018 San Pietro in Casale (Bo)
Tel.3332225965
e-mail: ama.amarcord@libero.it

Associazione "Per Non Sentirsi Soli" un sostegno a chi convive con L’Alzheimer ONLUS
Via Bontempelli, 375 - 41058 Vignola (Mo)
Tel. 059 4731724 - Cell. 333 1315870
sito: www.pernonsentirisoli.org - pernonsentirisoli@email.it
Little brochure for foreign family assistants
7 different topics - 9 different languages

1. Relationship
   "The relationship with the elderly person"

2. Hygiene
   "Ensuring personal and household hygiene and safety"

3. Eating
   "Eating: help during meals"

4. Movement
   "Assisting the elderly person with movement"

5. Dementia
   "Caring for persons affected by dementia"

6. Services
   "Services network orientation"

7. Rights
   "Foreign family assistants: rights, opportunities, and obligations"
Improve patients’ and caregivers’ quality of life

Supporting the professional staff

- Life long learning
- Common program for all staff (a shared knowledge)
- Equipe (team work)
- Prevent and reduce burn-out and turnover rates
An important effect of the global approach in dementia care: decreasing in drug therapies

In Italy people prefer to stay at home. We have good reasons to believe that a global and integrated approach reduces the risk of premature institutionalisation, with a consequent cost reduction. In a public system this means guaranteeing care to a bigger number of people.
Qualify and specialise existing services: not only separated services

Special units for demented people (specialist level)

NURSING HOMES
n° 15 Alzheimer Special Care Unit – 244 beds

Eligibility criteria, not for all demented
Not permanent

DAY CENTERS
N° 18 Alzheimer Day Center – 252 places

All the services

Each service has to set up a plan to improve quality of care for people with dementia, following the regional act n.514/09

With the new regional system “Accreditation” more equity and quality will be guaranteed throughout the public services system for the elderly and disabled people
Future developments

- Analysis of memory clinics (in order to spread and adopt models of best practice)
- Increasing and qualifying the psychosocial interventions and developing/implementing research
- More personalised and flexible services
- New solutions

XVIII World Alzheimer’s Day 2011

A particular day..

DVD-Cartoon on how to cope at home with behavioural symptoms associated with dementia

http://sociale.regione.emilia-romagna.it

Subtitles in 6 different Languages

ITALIAN
ENGLISH
FRENCH
SPANISH
ROMANIAN
RUSSIAN
integrated care program for dementia: the «network»

- **Social Welfare Service**
- **Memory Clinic**
- **Hospital**
- **Nursing Homes, Day Centers**
- **Primary Care**
  - GPs, social workers, nurses
- **Home Care Services**
- **Families, volunteers**
Thank you for attention

www.emiliaromagnasociale.it

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