

# LE DEMENZE: ATTUALITA' E PROSPETTIVE

Dal piano nazionale e regionale al fondo per l' Alzheimer

**25 SETTEMBRE 2023**



## L'importanza degli interventi psicosociali nella cura delle demenze

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# Indice

- ▶ Introduzione
- ▶ Il percorso
- ▶ Gli interventi psicosociali
- ▶ L'importanza



**Alzheimer's Disease  
International**

*The global voice on dementia*

# World Alzheimer Report 2023

Reducing dementia risk: never too early, never too late

Chapter 6:

## Post-diagnosis risk reduction

*Life isn't over after a diagnosis*



# Un buon percorso di cura

Buona prevenzione

Riduzione  
rischio

Buona diagnosi

Tempestiva  
Accessibile  
Comunicazione  
della diagnosi  
Pianificazione  
cura  
Follow-up

Buon supporto

Accesso  
a interventi  
di alta  
qualita'  
e sicuri

Vivere bene

Le persone  
Possono  
Vivere bene  
In sicurezza  
E in  
Una  
comunita'  
accogliente

Morire bene

Rispetto  
Dignita'  
Luogo  
desiderato

Durata in anni variabile

## Buon supporto

- ▶ Quando una persona riceve una diagnosi di demenza dovrebbe essere supportato a rimanere il più indipendente possibile, di continuare a godere le attività usuali e le proprie occupazioni e a mantenere il più a lungo possibile le sue capacità
- ▶ **Dovrebbe essere supportato ad utilizzare strategie di coping adeguate:**
  - **Strategie pratiche**- supporti mnemonici, stimolazione cognitiva, pianificazione anticipata della cura
  - **Strategie sociali**- ricevere un aiuto familiare, ricevere supporto spirituale, partecipare ad attività di gruppo
  - **Strategie emotive**- Humor, godere i momenti di piacere, riconoscere gli aspetti positivi
  - **Strategie per la salute fisica**- esercizio fisico, dieta, alcol, fumo

Adattata da Alz.  
Soc.

## Buon supporto

Il senso di identità

Il comportamento,  
i bisogni e le sfide  
della persona con  
demenza

Le relazioni  
interpersonali

Le relazioni sociali

Il ruolo sociale



## Buon supporto

- ▶ Supporto ai familiari che curano
- ▶ Supporto ai professionisti che curano
- ▶ Modifiche ambientali
- ▶ Disponibilità delle tecnologie



# Vivere bene con la demenza

Living well with dementia: What is possible and how to promote it (Quinn et al., 2021)

TABLE 1 Summary of responses to the question 'What does living well mean to you' by 1339 people with dementia in the IDEAL cohort

Category	Number of references coded
Engaged and active lifestyle	979
Positive relationships with others	636
Good living situation and environment	408
Having security	388
Getting on with life	318
Being able to get out and about	250
A positive outlook on life	236
Being able to cope	194
Having independence	155
Having a purpose	112
Unsure	25

- ▶ Stile di vita attivo e partecipe
- ▶ Relazioni positive con gli altri
- ▶ Buone condizioni di vita e buon ambiente
- ▶ Sicurezza
- ▶ Essere in grado di andare in giro
- ▶ Vivere la propria vita
- ▶ Una prospettiva positiva
- ▶ Essere in grado di gestire e fare fronte alle situazioni
- ▶ Avere autonomia



# Interventi psicosociali: la confusione sotto il cielo

- ▶ Psicosociale
- ▶ Bio-psicosociale
- ▶ Non farmacologico
- ▶ Riabilitativo
- ▶ Abilitativo
- ▶ Eco-biopsicosociale
- ▶ Etc.

Non-farmacologico: non utilizza farmaci

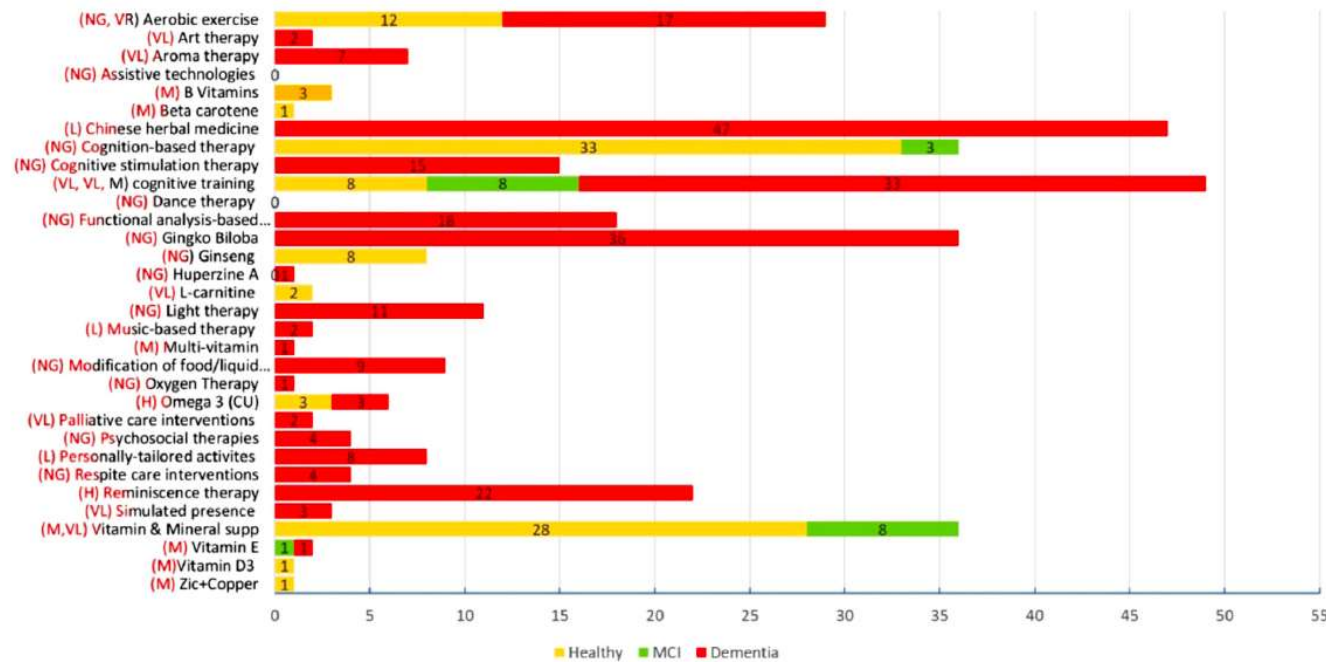
Psico-sociale: affrontare le conseguenze psicologiche e sociali, della malattia, le relazioni e il contesto

Interventi e impatto psicologico e sociale

Cornice teorica di riferimento

## Toward a theory-based specification of non-pharmacological treatments in aging and dementia: Focused reviews and methodological recommendations

Cochrane Reviews on NPTs in older people on the spectrum from health to dementia 2009-2019



# Ecopsychosocial Interventions in Cognitive Decline and Dementia: A New Terminology and a New Paradigm

John Zeisel, PhD, DSc (Hon)<sup>1,2</sup>, Barry Reisberg, MD<sup>3</sup>,  
Peter Whitehouse, MD, PhD<sup>4,5</sup>,  
Robert Woods, MA, MSc, FBPs<sup>6</sup>, and Ad Verheul, MA<sup>7</sup>

American Journal of Alzheimer's  
Disease & Other Dementias®  
1-6  
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sagepub.com/journalsPermissions.nav  
DOI: 10.1177/1533317516  
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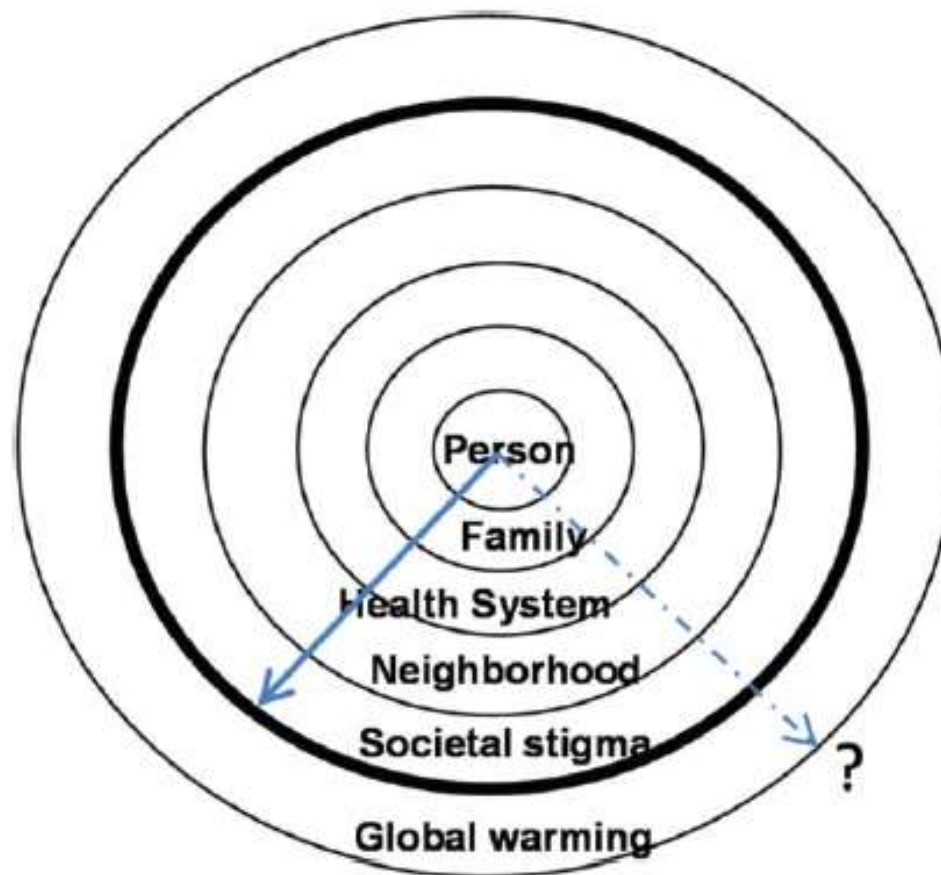


Figure 1. Environmental range of ecopsychosocial interventions in dementia.

# Interventi psicosociali e Piani nazionali in Europa (Chirico et al., 2021)

**Table 2.** Overview of National Dementia Plans and Strategies across Europe.

Country	Name and Year of Publication	Source				Categories		
		AE (n = 15)	ADI (n = 8)	Google (n = 2)	Available on Request (n = 1)	Treatment (n = 26)	Education (n = 12)	Research (n = 7)
Austria	National Dementia Strategy: Living well with dementia (2015)		X			X		
Belgium	Flanders Dementia Strategy (2016-2019)	X				X		
Cyprus	National strategic Plan for Dementia (2012-2017)				X	X		
Czech Republic	National Action Plan for Alzheimer's disease and other related diseases (2016-2019)	X				X	X	
Denmark	A safe and dignity life with dementia: National Dementia Action Plan (2017-2025)		X			X	X	
Finland	National Memory Program: Creating a 'Memory friendly' Finland (2013-2020)	X				X	X	X
France	National Plan for neurodegenerative diseases (2014-2019)	X				X	X	X
Germany	National Dementia Strategy (2020)		X			X		X
Greece	National Action Plan for Dementia-Alzheimer's disease (2015-2020)		X			X		
Iceland	Action Plan for services for people with dementia (2020)	X				X		
Ireland	The Irish National Dementia Strategy (2014)	X				X	X	X
Israel	Addressing Alzheimer's and other types of dementia: Israeli National Strategy (2013)	X				X		
Italy	Italian National Dementia Strategy (2014) Final report of the Steering Committee on the development of a National Dementia	X				X	X	
Luxembourg	Action Plan (2013)	X				X		
Malta	Empowering change: National Dementia Strategy in the Maltese Islands (2015-2023)	X				X	X	X
Netherlands	Dementia Delta Plan (2012-2020)		X			X	X	X
Norway	Dementia Plan: A more dementia-friendly society (2015)	X				X	X	
Portugal	Action Plan and Budget (2018)			X		X	X	
Slovenia	Dementia Control Strategy within 2020 (2016)	X				X	X	
Spain	Comprehensive Plan for Alzheimer's and other dementias (2019-2023)		X			X	X	X
Sweden	National Strategy for caring for people with dementia (2018)			X		X		
Switzerland	National Dementia Strategy (2014-2019): Achieved results (2014-2016) and priorities (2017-2019)		X			X		
United Kingdom-England	Living well with dementia: National Dementia Strategy (2009)	X				X		
United Kingdom-Northern Ireland	Improving dementia services in Northern Ireland: A regional Strategy (2011)	X				X		
United Kingdom-Scotland	Scotland's National Dementia Strategy (2017-2020)		X			X		
United Kingdom-Wales	Dementia Action Plan for Wales (2018-2022)	X				X		

Notes: Alzheimer Europe (AE) members. Retrieved from [33]. Abbreviations: ADI, Alzheimer Disease International. Bosnia Herzegovina, Bulgaria, Croatia, Estonia, Hungaria, Jersey, Montenegro, North Macedonia, Poland, Romania, Slovakia, and Turkey do not have a National Dementia Plan/Strategy.

# The Integration of Psychosocial Care into National Dementia Strategies across Europe: Evidence from the Skills in Dementia Care (SiDECAR) Project

Ilaria Chirico <sup>1\*</sup>, Rabih Chattat <sup>1</sup>, Vladimíra Dostálová <sup>2,3</sup>, Pavla Povolná <sup>2,3</sup>, Iva Holmerová <sup>2,3</sup>, Marjolein Niels Janssen <sup>4</sup>, Fania Dassen <sup>4</sup>, María Cruz Sánchez-Gómez <sup>5</sup>, Francisco José García-Peñalvo <sup>5</sup>, Manuel A. Franco-Martín <sup>5</sup> and Giovanni Ottoboni <sup>1</sup>

**Table 1.** List of psychosocial interventions.

Interventions	Definition/Examples
Carer interventions	Psychoeducation, cognitive behavioral therapy, counselling
Physical activities	Seated exercise, walking, strength training
Reminiscence	Therapy based on the use of human senses to help people with dementia remember events, people and places from their past
Multisensory stimulation/Snoezelen	Non-directive therapy aimed at providing a multi-sensory experience or single sensory focus, by adapting the lighting, atmosphere, sounds, and textures to the person's needs
Massage/touch	Regular massage forms (i.e., a touch with some pressure is applied in a moving way on parts of the body); therapies focused on finger pressure on specific points; 'therapeutic touch' (i.e., interventions where the therapist's hands may be held at a short distance from the person's body)
Behavior management	Techniques based on the ABC model where the focus is on identifying the A (antecedent or activating event), that lead to the B (challenging behavior), and examining the C (consequence) of the behavior. The aim is to improve carer's ability to identify and reduce triggers for behavioral and psychological symptoms of dementia
Cognitive-behavioral therapy	Talking therapy that helps people to understand links between their thoughts, feelings and behaviors, and use this understanding to make positive changes
Recreational activities	Scrapbooking activities, housework and daily tasks, gardening activities
Environmental design	Use of natural light; providing good tonal contrast between flooring, skirtings, walls and doors; minimizing noise sources and ensuring good acoustics by construction and sound absorbent materials, such as floating floors and decorative acoustic wall panels
Cognitive stimulation	Program of themed activities (e.g., discussion of past and present events and topics of interest, word games, puzzles) designed to increase people with dementia's cognitive and social functioning, and ultimately, their quality of life
Music therapy	Therapy aimed at stimulating different brain areas thus helping the person to express feelings and connect with past memories (e.g., playing music that is significant, listening to favourite pieces of recorded music, singing)
Aromatherapy	Therapy based on the use of aromatic plants or essential oils to reduce symptoms of anxiety and depression. The mechanism consists of the activation of the olfactory receptors and, consequently, of the brain areas associated with emotional regulation
Animal-assisted therapy	Supportive goal-oriented intervention based on human-animal interaction. It allows people with dementia to initiate a social interaction with an animal (dog, horse) in a controlled manner. It is associated with decreased loneliness and agitation, and increased motivation, pleasure and relaxation
Reality orientation	Therapy aimed at increasing cognitive stimulation by orienting people with dementia to the present (e.g., talking about orientation, including the day, time of day, date and season; using people's name frequently; discussing current events)
Memory training	Program designed to improve people's attention, concentration, and working and long-term memory (e.g., number mnemonics, story mnemonics, the method of loci)
Validation	Therapy aimed at promoting carer's ability to listen attentively and respond respectfully to the person with dementia, who can struggle to express basic needs (e.g., use of a clear, low-pitched, and loving tone of voice; eye contact; avoiding to argue)
Emotion-oriented care	Care including different approaches (e.g., validation, reminiscence, sensory integration) designed to increase people with dementia's emotional and social functioning and, ultimately, their quality of life. Focus is on supporting them in the process of coping with the disease, by linking up with individual functional possibilities, and the person's subjective experience

## 5.2 Fase di Diagnosi e Cura

### h) Pianificazione dei trattamenti non farmacologici(riabilitativi) e degli interventi psicosociali (PSI), tra cui:

- *Interventi di stimolazione cognitiva/memory training (individuale o di gruppo);*
- *Interventi di terapia occupazionale secondo lo schema riportato nella DGR 990/2016;*
- *Gruppi psico-educativi e di sostegno rivolti ai familiari o altri caregiver;*
- *Gruppi di sostegno ed auto-aiuto;*
- *Consulenze individuali e famigliari;*
- *Interventi a bassa soglia.*

**Monitoraggio??**

## 5.2 Fase di Diagnosi e Cura

PERCORSO  
DIAGNOSTICO-TERAPEUTICO-ASSISTENZIALE  
NELLE DEMENZE

### La gestione dei disturbi del comportamento

In termini di sanità pubblica, gli interventi di prima linea per la prevenzione e la gestione dei BPSD dovrebbero essere gli **interventi psicosociali (PSI)** ed in particolare, il primo livello dovrebbe essere rappresentato da programmi psico-educazionali incentrati sulla informazione e **formazione sui BPSD** rivolti ai familiari/caregiver oltre che agli operatori dei servizi. Con l'ausilio

## Monitoraggio??

## Le conseguenze della disabilità cognitiva: psicologiche

Accettazione  
della diagnosi

Adattamento al  
cambiamento

Bisogno di  
contrastare la  
perdita

Preservazione  
dell'autonomia  
e del controllo

Sofferenza  
psicologica

Stima di sé

Pensare il  
futuro



# Le conseguenze della disabilità cognitiva: salute sociale

Stigma

Isolamento

Ritiro

Perdita di  
relazioni

Perdita di  
attività

Perdita di ruolo  
(Young Onset  
Dementia)

Mancata  
partecipazione  
sociale

# Le conseguenze della disabilità cognitiva e il ruolo di



vicinato



comunità



servizi



contesto urbano



diritti

# Obiettivi degli interventi psicosociali

- ▶ Mantenere e migliorare il funzionamento personale
- ▶ Migliore le relazioni interpersonali e sociali
- ▶ Favorire adattamento (persona, familiari, staff, ambiente)
- ▶ Migliorare coping con la perdita
- ▶ Sostenere la possibilità di vivere bene con la demenza

**Buon supporto**

**Vivere bene**

# Focus

- ▶ Difficoltà delle persone con demenza
- ▶ Bisogni delle persone con demenza
- ▶ Interazione tra persona e contesto (famiglia, staff, ambiente)



# Strumenti



Personalizzazione



Diagnosi psico-sociale



Piano di attività personalizzato




Monitoraggio e cambiamento



Condivisione con la persona



# Interventi psicosociali e carers

- ▶ Formazione
  - ▶ Psico-educazione
  - ▶ Costruzione di competenze: comprensione e comunicazione
  - ▶ Gestione dello stress
  - ▶ Cura delle relazioni
  - ▶ Tecniche di rilassamento
  - ▶ Meditazione
  - ▶ Partecipazione sociale
  - ▶ Sollievo
  - ▶ Burn-out e compassion fatigue
- 

# Interventi psicosociali e carers



Il benessere del curante



La competenza comunicativa del curante

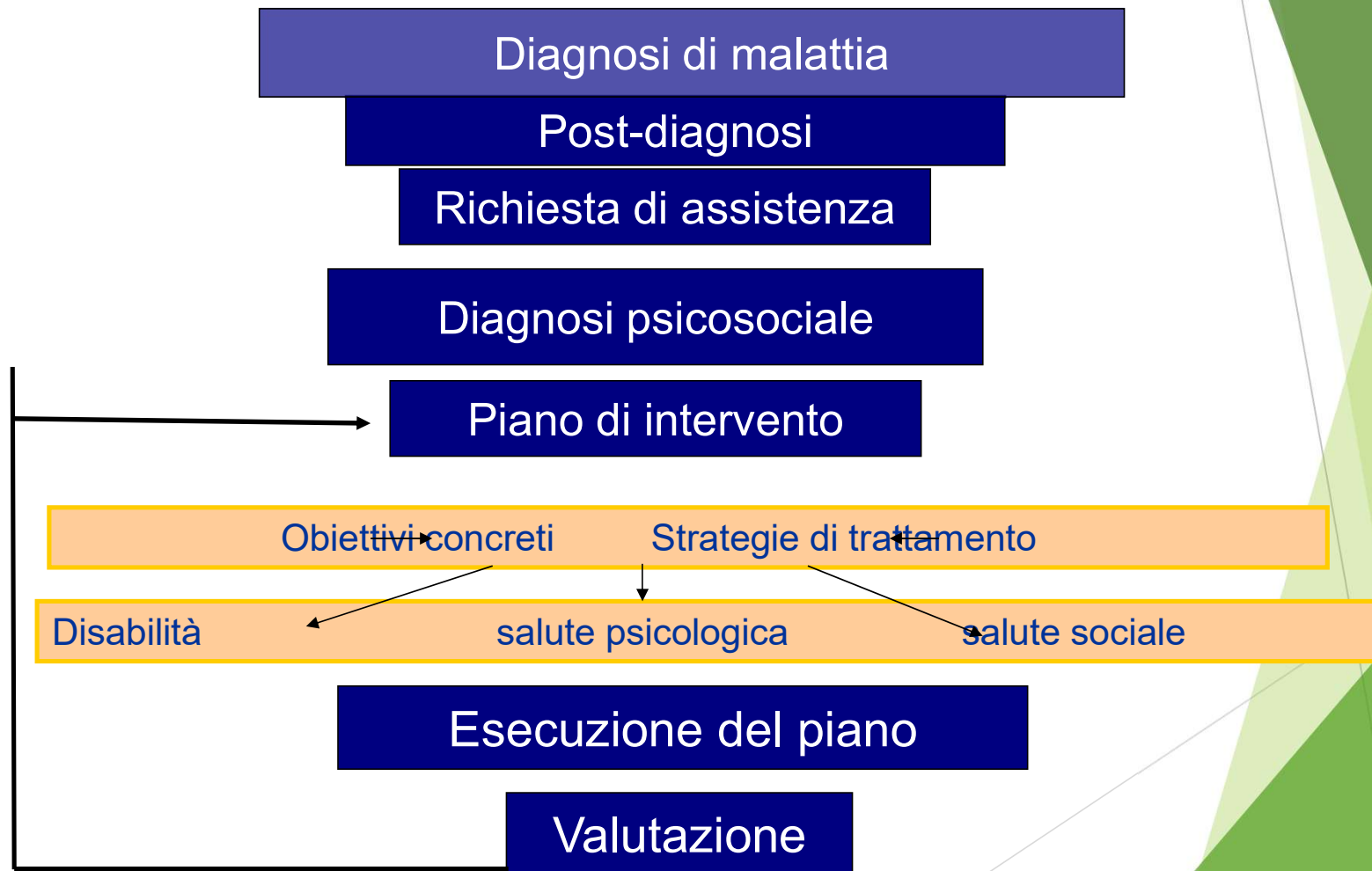


La competenza relazionale



La collaborazione nella cura

# L'approccio dei centri di Incontro





# Gli strumenti: Diagnosi psicosociale e piano di attività'

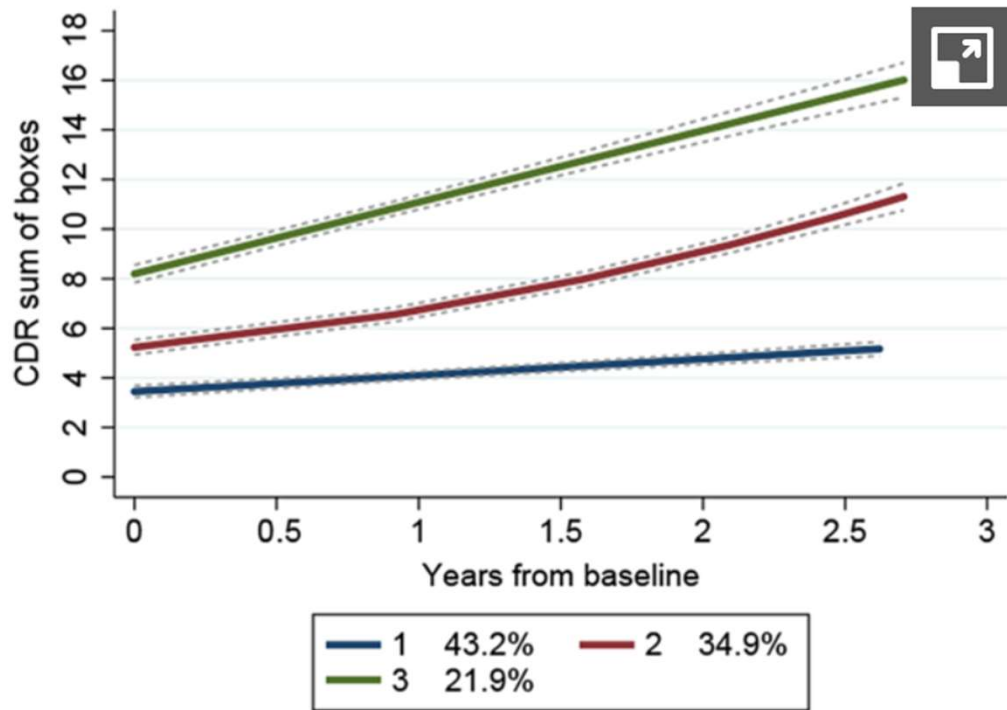


# Perché importante

- ▶ Benessere della persona, dei familiari e dei curanti
- ▶ Mantenimento autonomia
- ▶ Qualità di vita
- ▶ Diritti
- ▶ Inclusione sociale

Impatto sulla velocità di  
progressione???

# Traiettorie di progressione (Edwin et al., 2021)



**Figure 1.** Three trajectory groups based on change in CDR sum of boxes over time. Note. Trajectory groups, using GBTM, with the trajectory shapes 1 2 1 (1 = linear, 2 = quadratic). The proportions (%) are based on the maximum probability assignment rule. Group 1 (blue); number of patients ( $n$ ) = 195 (43.2%), posterior probability of group membership = 0.92, and OCC = 14.7. Group 2 (red);  $n$  = 153 (34.9%) posterior probability of group membership = 0.88, and OCC = 13.4. Group 3 (green);  $n$  = 94 (21.9%), posterior probability of group membership = 0.94, and OCC = 62.6. CDR, clinical dementia rating scale. Production: File format TIFF, using Stata/IC 15.1 StataCorp LLC 2018 on Windows 10 Pro.

## Fattori di modulazione: stato di salute

- ▶ Stato di salute durante il corso della malattia (instabile o compromesso (fast progressor))
- ▶ Trattamento adeguato delle condizioni di salute: slow progressor
- ▶ Disturbi cardiovascolari durante il corso della malattia (fast progressor)
- ▶ Uso degli AntiAch e e memantina non influenza il tasso di progressione.
- ▶ Differenze di genere

## Non-pharmacological interventions and neuroplasticity in early stage Alzheimer's disease

*Expert Rev Neurother.* 13(11), 1235–1245 (2013)

**Molte attività stimolano la neuroplasticità e possono influire sulla velocità di progressione**

- While early stage mild cognitive impairment seem to benefit most from targeted cognitive training (e.g., memory training), Alzheimer's disease patients benefit from stimulating interventions (including arts and music) with social interaction and involvement of caregivers, especially with regard to psychosocial aspects and management of the disease.
- Cognitively and physically challenging activities provide the most efficient stimuli to induce neuroplastic changes, and complex activities like making music, juggling and dancing provide promising avenues for effective intervention.
- Strategies combining complex cognitive training with physical activity, electrophysiological stimulation or pharmacological treatment might be the most promising avenue for slowing neurodegeneration. They should be investigated in future studies, ideally with monitoring of functional and structural brain plasticity by brain imaging.

**Training cognitivi, stimolazione cognitiva, arte, musica, danza, interazioni sociali, coinvolgimento dei familiari, attività stimolanti. La combinazione sembra promettente**

# Fattori modulanti: Ambiente di cura



# Fattori modulanti: la relazione con il familiare

## La forza della relazione

- Relazione positiva con il caregiver
- Accettazione da parte del caregiver
- Adattamento del caregiver

## Buona salute del caregiver

## Differenze tra coniugi e figli

Norton, M.C., Percy, K.W., Rabins, P.V., Green, R.C., Breitner, J.C.S., Oshby, T., Corcoran, C., Welsh-Bohmer, K.A., Lyketsos, C.G., & Tschann, J.T. (2009). Caregiver-recipient closeness and symptom progression in Alzheimer disease: The Cache County dementia progression study. *Journal of Gerontology: Psychological Sciences*, 64(5), 560-568, doi:10.1093/geronb/gbp052. Advance Access publication on June 29, 2009.

Caregiver-Recipient Closeness and Symptom Progression  
in Alzheimer Disease. The Cache County Dementia  
Progression Study

**Conclusion:** A more rapid progression of dementia was found in a group of patients with increasing depressive symptoms.

Duan et al. *BMC Geriatrics* (2018) 18:175  
<https://doi.org/10.1186/s12877-018-0864-6>

BMC Geriatrics

RESEARCH ARTICLE

Open Access

## Psychosocial interventions for Alzheimer's disease cognitive symptoms: a Bayesian network meta-analysis



Yuting Duan<sup>1†</sup>, Liming Lu<sup>1†</sup>, Juexuan Chen<sup>1</sup>, Chunxiao Wu<sup>1</sup>, Jielin Liang<sup>1</sup>, Yan Zheng<sup>1</sup>, Jinjian Wu<sup>1</sup>, Peijing Rong<sup>2\*</sup> and Chunzhi Tang<sup>1\*</sup>

**Conclusion:** Our study confirmed the effectiveness of psychosocial interventions for improving cognition or slowing down the progression of cognitive impairment in AD patients and recommended several interventions for clinical practice.

*International Psychogeriatrics* (2017), 29:2, 195–208 © International Psychogeriatric Association 2016  
doi:10.1017/S1041610216001654

REVIEW

## Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis

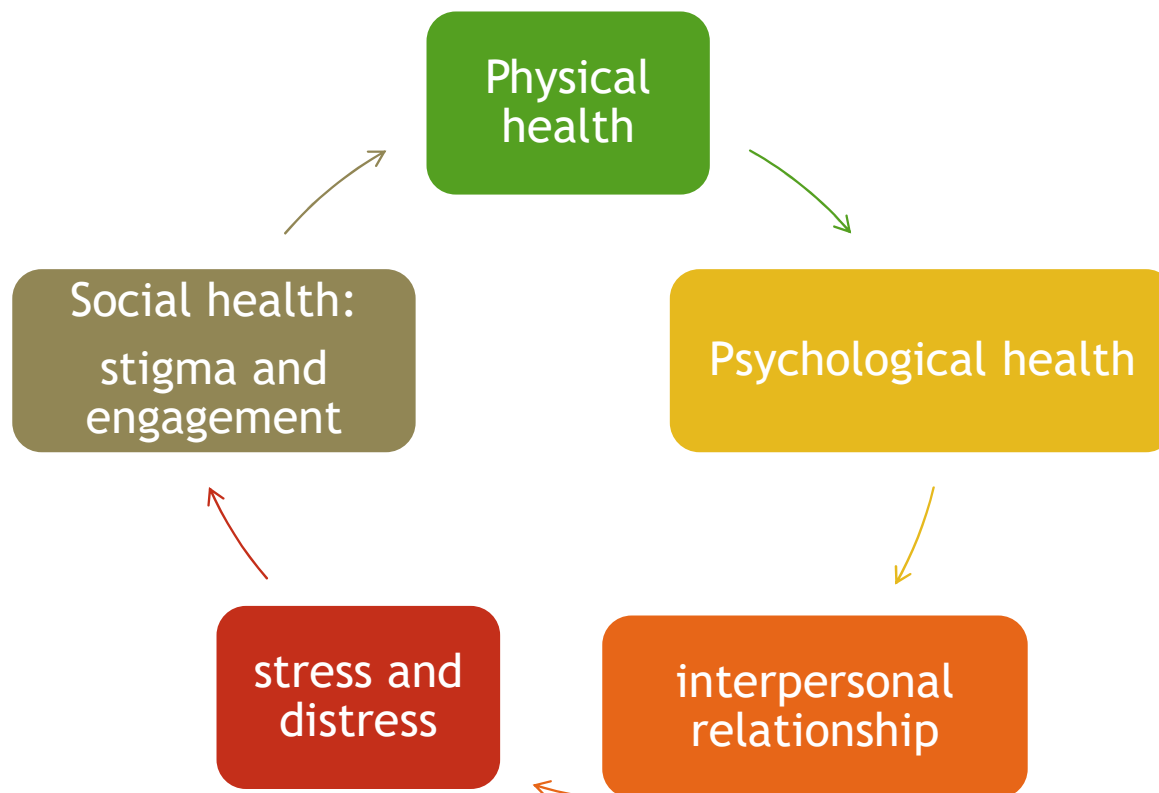
Sandeep Toot<sup>1</sup>, Tom Swinson<sup>1</sup>, Mike Devine<sup>2</sup>, David Challis<sup>3</sup> and Martin Orrell<sup>4</sup>

**Conclusion:** We recommend focusing on cognitive enhancement strategies, assessment and management of BPSD, and carer education and support to delay nursing home placement.





# Una interazione di fattori modulano la progressione



# Prospettive

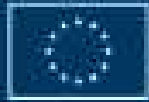
Rendere disponibili gli interventi a tutti



Formazione e educazione dei curanti



Promuovere inclusione sociale



Finanziato  
dall'Unione europea  
NextGenerationEU



Ministero  
dell'Università  
e della Ricerca



Italiadomani  
GOVERNATO DA LEONARDO



# Programma di Ricerca Age-It Ageing well in an ageing society



CARE SUSTAINABILITY IN AN AGEING SOCIETY - CASAS

WP5.

TRAINING PROFESSIONAL AND INFORMAL  
CAREGIVERS



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Thanks for your attention



**INTERDEM**