



# S.IN.CA.L.A.



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## NEWSLETTER

### THE PROJECT

The stress of a chronic health condition or disability in a family member can impact on families as a whole, particularly if the different caregivers within the family attempt to deal with his or her feelings alone and without support. The ability to communicate effectively is a critical aspect of healthy functioning families.

A primary threat to communication is the repression of affect, when family members suppress negative feelings like being overwhelmed, guilt, uncertainty, conflict and confusion within relationships associated with their situation. Being able to openly express these feelings and share emotions can build care givers' resilience.

The S.IN.CA.L.A project will meet common need of all EU countries: to address the challenge of providing care and support to an ageing population, particular

among the older old (80+). In all countries, there will be a need for an increasing number of families to provide care. To achieve this, policy and supports for family carers will be imperative. S.IN.CA.L.A will provide an intervention programme that can be used by professionals working with family carers to support them build resilience to maintain capacity to care.

### THE TARGET GROUPS ARE:

Informal carers which includes all members of households with caring responsibilities for older adults – spouses, adult children, grandchildren.

Adult Educators and Professionals including psychologists, nurses, social workers, community workers, home care workers.



# FOCUS GROUPS

## IRELAND

### *Co-Creation Support CLG*

Seventeen participants took part in the three focus groups in Ireland, eight spouses/ partners, five adult daughters and four grandchildren respectively. Initial findings from the focus groups indicate that while the majority of participants are struggling to cope with the demands caring for a loved one places on them, any opportunity for time for themselves sustains them. Having support from other family members, neighbors or formal carers that allows the carer to do things like go for a swim, meet friends, get out to the garden contributes to carers' emotional well being.

Another contributor is being able to talk about inner feeling such as frustration, anger at the situation, in a safe non-judgement environment where others had similar experiences or understood what it is like to be providing care for a loved one. All of the groups perceived this as essential in building resilience.

## SLOVENIA

### *Spominčica*

Alzheimer Slovenia carried out all 3 focus groups in the beginning of March 2019 in Alzheimer Center in Ljubljana. First Focus group was performed among spouses with 3 females and 1 male. Spouses perceived their role as a carer with tremendous love for the closest one. Most of the care was provided on their own but occasionally they got some additional help from their children. The biggest concerns were facing emotional and financial issues. They stated, the professional entities, should offer more different and financially accessible services in community. Second focus group was held among 3 adult children and one adult child-in-law. It consisted of 2 females and 2 males. Adult children understood their role as a carer as a duty for their parents or parent-in-law. Some of them who have family on their own frequently experience guilt, because they do not have enough time for children due to responsibilities for their parents. They agree, the services must address their needs at different levels and

definitely be personalised to each individual. The last focus group was carried out among 6 adult grandchildren, all were females. They pointed out that they soon accepted their new role in family dynamics. As other participants in focus groups they were positive on necessity for modified services. Closing remarks from all focus group showed that the family relationships became stronger or at least remained the same.





# GREECE

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*Greek Association of Alzheimer's Disease and Related Disorders*

The first focus group took place on 4/3/2019 and the participants were 4 daughters of patients with dementia. The second one took place on 17/4/2019 and the participants were 4 wives and one husband of patients with dementia.

On the same day, 17/4/2019, 3 grand-daughters of patients with dementia took part in the third and last focus group. All three focus groups took place at the day center of GAADR – Alzheimer Hellas and were coordinated by SINCALA implementation manager, Mahi Kozori.

# ESTONIA

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*MTÜ Eesti Omastehooldus.*

In March 2019, 2 rounds of focus group interviews were conducted in Estonia in the cities of Tartu and Võru. Both of them focused mainly on the adult children of the person in need of care. In a way, this illustrates the average caring relation and predominantly the responsibility is carried by the daughters.

Altogether, 10 participants were included in the 2 rounds of focus groups, 9 adult children and 1 spouse taking care of family member being 60+. Unfortunately, grandchildren taking care of the elderly remained unreachable, which indicates the caring culture of Estonia. The caring is mainly done by one generation downwards or upwards and other relatives are usually included on as needed basis. In some cases, the support network is limited due to the family history or choices made by family members of different generations. A lot is depending on the awareness and the willingness of the primary carer.

During the focus groups, an effort was made to understand the role of different family members from different generations and how the primary caregiver identifies the value and support provided by them. Different patterns of care management and coping skills of carers were drawn out. The level of resilience is dependent on the length of the care responsibility and support provided in course of the care relation.

For more information contact Ivar Paimre, NGO Estonian Carers, [ivar.paimre@omastehooldus.eu](mailto:ivar.paimre@omastehooldus.eu)



# ITALY

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*Anziani e non solo Società cooperativa sociale*

Twentyone participants took part in the three focus groups in Italy during the February and March sessions: 8 sons and daughters, 6 spouses/ partners and 4 grandchildren.

From the analysis of the responses from the 3 target groups, there emerged 3 different way of approaching caregiving and the management of related emotions. In the focus group of the spouses the common thread is the pain and concern for the condition of the partner and the correlated consequences, on the same partner and on the family. From the focus group of the children, in particular, the burden of the care responsibility on them selves emerges; taking care of the parents is mostly lived as an obligation. From the focus group of the grandchildren, which are secondary caregiver, the concern for the parents, the primary caregivers, is the main theme come to light.

# PORTUGAL

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*CASO50+*

In Portugal, thirteen participants took part in the data collection proccess developed by CASO50+, namely four adult children, four spouses, and five grandchildren.

Data analysis reveals that, in general, all participants perceived their role as carer as a natural one in face of a disease or health condition of a loved one. Being a carer of a family member is understood as a way to reciprocate and show gratitude.

The most highlighted challanges related to the carigiving activities were: lack of support from other family members, friends or neighbours; the negative impact on carers' professional activities (which may aggravate or lead to financial problems), as well as on their social lives; and physical and emotional consequences – burden, tiredness, feelings of guilt and helplessness.

# THE WEBSITE

The web-platform features news in English and national languages, blogs, project resources and updates, such as reports, policy briefs as well as opportunities for engagement e.g. events, workshops and face to face training sessions.

**[WWW.SINCALA.EU](http://WWW.SINCALA.EU)**