



*The role of social media  
(Facebook)  
for building resilience of  
family carers*

Resil4Care (RESILience FOR informal  
CARE givers)



INŠTITUT ANTONA TRSTENJAKA  
za gerontologijo in medgeneracijsko sožitje



*ERWG, Ancona, 30.11-1.12.2023*

# FACEBOOK SUPPORT GROUPS

4 Facebook support groups moderated by 4 organizations that support informal carers in Greece, Italy, Slovenia and Spain:

- Purpose: to support carers through social media (identifying and addressing needs)
- Regular and thematically diverse posts.
  - Post formats: text, image, video, audio, etc.
  - Content of posts:
    1. Educational/informative content.
    2. Practical/technical content.
    3. Stories/personal experiences.
    4. Taking care of one-self (*"I'll take care of you, while taking care of me"*).
    5. Cultural content (suggestions for books, films, theatre performances, etc.)

# RESIL4CARE MODEL

## Parallel groups:

- **Online support group for family carers on Facebook**
- **Core group** (around 4 members): care professional, family carers
  - Monthly meetings of core group leaders
  - Regular (2 times per month) meetings of core groups
  - Working with Worksheets following the same methodology
  - Task: preparation of Facebook posts



### DELOVNI LIST 11: Skrb zase je pomembna - zame in za osebo, za katero skrbim

1. Oglejte si spodnje tabelo. Skupaj jo preberite in se ustavite pri vsaki človeški razsežnosti ter se pogovorite o tem, kaj konkretno že počnete (vsil člani osnovne skupine) zasa. Vse vaše izkušnje zberite v desnem stolpcu.

ČLOVEŠKA RAZSEŽNOST	PREDLOGI ZA ZDRAVE NAVADE	KONKRETNI PRIMERI TEGA, KAR ŽE POČNEMO.
<b>FIZIČNA</b> (telesna)	<ul style="list-style-type: none"> <li>Poskrbite za zdravo in uravnoteženo prehrano.</li> <li>V največji možni meri vodite reden ritem (pri tem vam lahko pomagajo vsakodnevne rutine).</li> <li>Redna telesna dejavnost! Izbirajte tisto, ki jo lahko izvajate in v kateri uživate.</li> <li>Zagotovite si dovolj spanja, redno telesno vadbo in sprostitvene vaje.</li> <li>Izogibajte se prevelikim količinam nikotina, alkohola in kofeina.</li> </ul>	
<b>PSIHOLOŠKA</b> (duševna)	<ul style="list-style-type: none"> <li>Sprostite se in si vzemite čas za vsakodnevni mir.</li> <li>Odkrijte, kaj vam povzroča napetost, in bodite pozorni na svoje odzive.</li> <li>Poskrbite na popolnost.</li> <li>Gojite svetle in pozitivne misli.</li> <li>Zmislite se!</li> </ul>	
<b>DUHOVNI</b> (prepričanja in stavi, ki nas presenjajo)	<ul style="list-style-type: none"> <li>Znati reči NE, kadar nečesa ne morete storiti, ne zmorete ali nimate storiti.</li> <li>Ko se znajdete v stabi situaciji, se vprašajte, kaj bi lahko bilo še slabše. V mislih sprejmite najslabši možni scenarij, nato pa poskusite najti točko.</li> <li>Nekatere stvari so nesprejemljive ali niso odvisne od vas, ne gledajte na to, kako zelo si to želite. Sprejmite okoliščine, ki jih ne morete spreminjati.</li> <li>Sprejemajte odločitve, ki so urenjujive, sicer je boljše, da jih sploh ne sprejemate!</li> </ul>	
<b>SOCIALNI</b> (odnosi)	<ul style="list-style-type: none"> <li>Prilijte tuko - poskusite aktivno iskati pozitivno v drugih!</li> <li>Ne krivite drugih za svojo napetost.</li> <li>Gojite naklonjenost do vseh ljudi.</li> <li>Pogovorite se z svojih tesnivih.</li> <li>Izogibajte se konfliktom z drugimi ljudmi.</li> </ul>	
<b>RAZVOJNI</b> (tisto, kar nas podpira in nam pomaga rasti)	<ul style="list-style-type: none"> <li>Uravnotežite delo, prosti čas in zabavo.</li> <li>Bežite dobre knjige.</li> <li>Pri gledanju televizije bodite izbirčni.</li> </ul>	
<b>EKZISTENCIALNI</b> (kaj nam daje smisel)	<ul style="list-style-type: none"> <li>Počinite smisel v stvareh, ki jih počnete.</li> <li>Čenite, kar ste vi in vaši bližnji ustvarili in naredili dobro.</li> </ul>	



**Inštitut Antona Trstenjaka**  
Skrbnik Najboljši soustvarjalec · 7. november ob 16:00 ·

V eni izmed oktobrskih oddaj Svetovalni servis na Radiu Slovenija je bila gostja predsednica Zdruzjenja Spominčica Alzheimer Slovenija, **Štefanija Lukič Zlobec**.

September je bil mesec, posvečen demenci, ki jo gospa Lukič Zlobec poimenuje tudi: "tihan epidemija današnjega časa". V tokratni oddaji pa je sogovornica predstavila predvsem pomoč svojim in skrbnikom oseb z demenco.

Vabljeni k poslušljanju!

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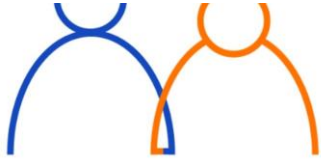
**Spominčica - Alzheimer Slovenija**  
2. oktober ·

Gostja v oddaji Svetovalni servis je bila predsednica Zdruzjenja Spominčica Alzheimer Slovenija, **Štefanija Lukič Zlobec**.

Svoji oseb z demenco doživljajo velike... **Prikaži več**

RTVSLO.SI

**Štefanija Lukič Zlobec: Demenco naj sprejmejo za svojo tudi svojci**  
Svoji oseb z demenco doživljajo velike obremenitve. Ker bolezen napreduje in traja več le...



**SLOVENSKO ZDRUŽENJE**

Uredi

Družinski oskrbovalci

Povabi

Razprava Vodniki Predstavljeno Dogodki Večpredstavne vsebine Datoteke Osobe

Napiši kaj...

Vizitka  
Skupina je namenjena družinskim oskrbovalcem, torej tvojcem, prijateljem, sosedom in drugim, ki doma tedensko...  
Anonimous Post Fotografija/video Anketa

zdravstvenim poslušateljcem za pomoč pri aktiviranjem pozitivnih vzorcev.

Tukaj je nekaj nasvetov, kako obvladati apatijo/depresijo:

- Ohranite redni dnevni umik, ki vključuje veliko telesne dejavnosti čez dan in miren spanec ponoči. Vključite jih v dejavnosti, kot so hišna opravila, pri katerih se počutijo koristne, ali druge dejavnosti, kot je obisk prijatelja. Ljudem z apatijo in depresijo pogosto primanjkuje motivacije in pobude, zato jim pomagajte, da se lotijo naloge.
- Dejavnosti časovno prilagodite razporeditvi svoje ljubljene osebe čez dan. Morda bo ob določenem času dneva bolj sodelovala in bila bolj pripravljena na določene dejavnosti, kot je na primer kopanje.
- Za sodelovanje uporabite pozitivne spodbude, na primer obisk pri ljubljene restavracije po obisku pri zdravniku.

Spremljajte prihajajoče objave v skupini. Prihodnji teden bomo z vami delili naslednji posnetek, ki bo obravnaval tema halucinacij.



YOUTUBE.COM  
Caregiver Training: Depression/Apathy | UCLA Alzheimer's and Dementia Care Program

<https://www.facebook.com/group/s/druzinskioskrbovalci>



»Odkar smo prenovili kopalnico imamo vse – tuš, banjo in bide in to nam danes zelo prav pride. Ob prenovi 15 let nazaj smo imeli pravo slavnostno otvoritev nove kopalnice s šampanjcem in trakom! Pripravila sem kosilo, ki nas je čakalo na mizi, vnuki pa so me najprej »krstili« v novi banji. Vesela sem, da smo se takrat odločili za prenavo. Sedaj mi je veliko lažje, ko v kopalnici lahko bolj enostavno in varno uredim moja, pa tudi meni pride prav.«



družinski oskrbovalci



GAWANDE

Minljivost

PREDLOG  
ZA BRANJE



neformalni oskrbovalci



SOSEDJE

Ali veste?

V Sloveniji brezplačno in nekaj ur tedensko svoje znance in prijatelje oskrbuje več kot 20.000 sosedov, kar je visoko nad evropskim povprečjem.



NI SMRT TISTO, KAR NAS LOČI,  
IN ŽIVLJENJE NI, KAR DRUŽI NAS.

SO VEZI MOČNEJŠE. BREZ POMENA  
ZANJE SO RAZDALJE, KRAJ IN ČAS.

VEKOVEČNA DRAGIH JE BLIŽINA.  
SMRT JE LE ZDRUŽITVE NÁVEČER.

ZEMLJA SKUPNO JE PRIBEŽALIŠČE  
IN POSLEDNJI CILJ VSEH NAS JE MIR.

MILA KAČIČ



**IZBIRA PRIMERNEGA  
PRIPOMOČKA ZA HOJO**

bergle?



hodulja?



rolator?



fotografije: Soča oprema

družinski oskrbovalci

IDEJE ZA SKUPNE PROSTOČASNE AKTIVNOSTI



**VIRTUALNI OGLED MUZEJEV**

# RESULTS 1

- 4 Facebook groups:
  - Greece (closed group): 194 members, Italy (closed group): 127 members, Spain (closed group): 103 members, all with 80-120 posts
  - Slovenia (open group): 507 members (153 during the last year), 119 posts, 80 comments, 1149 reactions
- 12 core group leaders' meetings (learning methodology, exchange of good practices, of difficulties, common search of solutions)
- Around 24 core groups meetings in 4 countries (to learn, exchange, support each other and generate content)
- 4/4 groups leaders found the methodology and results useful for their organization and meaningful and useful for carers, due to working together with informal carers they feel they understand the needs of family carers and way to approach them better, they connected inside their core groups and they want to continue working with them
- 3/4 the meaning was recognized by organizations, and they plan to continue the work after the end of the project

## RESULTS 2 - FOCUS GROUPS WITH MEMBERS OF ORGANIZATIONS WHO HAVE CONTACT WITH FAMILY CARERS :

- Online support group was recognized as: “a good tool with which family caregivers could strengthen their knowledge, while at the same time taking good care of themselves”
- Main identified **positive effect** of online support groups was empowerment of family carers through:
  - diverse information,
  - quick access to information,
  - by addressing important topics
  - construction of community and formation of platform for experience sharing,
  - reminder that self-care is important.

Positive aspects were also: being a new option to reach family carers, possibility of anonymity, engagement tailored to the participant (I take what I want, I respond to what and when I want), good cost-benefit for organizations, possibility to bring closer and get feedback on professional work and knowledge.

- Perceived **barriers** were: attitudes towards Facebook (and social media), danger of non-respectful or violent communication, lack of physical contact, not accessible to all, issue of trust.
- **Almost half of focus group participants favored personal approach** while supporting resilience of family carers (especially formal carers), **nonetheless they perceived the benefits of this form of online support group for certain family carers, especially due to the growing dependence on and familiarity with digital solutions**: "I find the idea very interesting, especially in this digital age. In our case, we would need to find out who in the health center is doing the most work in this area and we could introduce a support group like this for additional support."

## RESULTS 3 - FOCUS GROUPS WITH MEMBERS OF ORGANIZATIONS WHO HAVE CONTACT WITH FAMILY CAREERS

- participants discussed the **participation in such groups** and shared experience: “We already have such a support group in our organization. It is very welcome, but I notice that people are not very responsive. I regularly post various contributions in the group (supporting videos, informative materials) and I see that people notice them, but rarely does anyone comment or react otherwise. **There is much more communication and interactivity between members of this support group when someone asks for advice or experience in person.** That's when the debate develops more.”
- **trust, intimacy and safety issues were emphasized:** “...it's important to maintain intimacy, trust. If people are embarrassed, it should be done in such a way that it is not seen. Then, over time, people open up.”
- **about the leadership of such group, people found it important, that people running such support groups have experience of care, participation of the professionals from the field was seen as an advantage:** "I think it is very important that the person who runs the FB group also has the experience of providing care. It is important that he/she realizes that he is not the person giving professional advice, but only directing people to this advice and information. ...It is very good that the group is supported by an expert who can answer more professional questions. This person must be a skilled communicator, definitely with some additional knowledge, especially communication skills - how to communicate with a difficult topic, how to communicate with people who have a lot of problems, anger, disappointment, sadness due to helplessness, because they want to help, but they can't.”

# ANTON TRSTENJAK INSTITUTE OF GERONTOLOGY AND INTERGENERATIONAL RELATIONS

- informal care in LTC framework
- informal care on local level (as part of AFCC program: understanding of local situation and possibilities for support)
- tele-care and its role in home and institutional environment and connection with carers
- relationship between informal and formal care (focusing on human resources aspects)
- informal care and knowledge transfer (training, courses, other forms)
- abuse prevention in setting of informal care
- understanding of informal care and carers in Slovenia

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