



Informal Carers and Volunteering in the Community





The Project



SOS Malta received Small Initiatives Support Scheme 2011 funding from MCVS.

Project Aim: To begin a dialogue between relevant stakeholders within Malta on the need for wider recognition of the role and contribution of informal carers in society, their need for support to carry out their role and the role of the voluntary sector in supporting them.

Main activities

- 1) Initial Research: Good practice across Europe and the situation in Malta
- 2) Conference: To discuss the role of the volunteer sector in supporting informal carers; discuss good practice; suggest initiatives

- An increase in awareness of the role of informal caring in the community and the support required
- Potential initiatives for volunteering in the community in support of informal carers identified
- Increased collaboration among volunteers and volunteering organizations for responses to the needs of informal carers

Definitions

Informal Care: Care provided by informal care givers such as spouses/partners of family members or friends with an already existing relationship with the cared for person. The provision of informal care is unpaid.

Formal care: provided by professional care assistants who are paid for providing the care in the form of an employment contract. For example. Nursing homes, professional carers in the home.

Caring duties Personal care or routine- daily living activities (bathing, dressing, eating); Household work (cleaning, cooking, shopping); Company and emotional support

- 1) Desk Research on good practices in Europe and the situation in Malta**

- 2) Online and printed survey in Maltese and English:**
 - i) for NGOs in Malta**
 - ii) for informal carers in Malta**

Why?

- Caring roles are demanding and can have negative effects on the care giver physically and mentally
- Financial burden also an issue
- Decrease in social well being
- Few nationwide comprehensive schemes /policies to support informal carers

- Informal caring traditionally been carried out by family networks
- The majority of informal carers are between 40-59 years old and female
- Changing roles in society providing greater burden (Troisi and Formosa):
 - Decreasing number of children in the family
 - Increasing life expectancy and the ageing population
 - Dispersion of families
 - Changing role of women

- Services in Malta predominantly focus on the cared for person themselves rather than the carer
- There is social assistance for females taking care of relatives
- No formal measures such as those to grant leave or flexible working
- No formal register of carers in Malta or organisation for carers

Initiatives from government

- **Day centres:** priority given to elderly living alone
- **Handyman service**
- **Incontinence service**
- **Meals on wheels** for elderly living alone
- **Home help:** to enable older people to remain at home longer such as shopping, errands laundry.
- **Telecare service**
- **Grant** of €300 per annum for elderly over 80 living at home
- **Removal of VAT** on private care services

Initiatives from Civil Society

- **Caritas Malta:** Good neighbourhood scheme for elderly living alone. Provides info on services; training schemes for family carers including on stress management, time management, dealing with guilt. Provides group workshops where people can exchange experiences. Valuable for emotional support.
- **Cana Movement:** training on care for carers dealing with isolation and basic care
- **MMDNA:** Nurse visits for: 1) general care; 2) surgical dressings; 3) injections; 4) diabetic care
- **Malta Hospice Movement:** provides support to terminally ill and their families through 1) home care- respite, physiotherapy etc; 2) day care; 3) hospital support; 4) loan of equipment
- **Jean Antide Foundation:** Community outreach to support care givers in the community with a special focus on the family and the most vulnerable.
- **Richmond Foundation:** Provides community mental health services, promotes mental wellbeing, provides support for good quality of life.



Harnessing Volunteers



- European Year of active ageing and solidarity between generations- aims to encourage people to do what they can to create a society where older people can play their part (Healthy older people and Young people)
- Can provide a key role in improving quality of life and improving the “social well being aspect”
- Idea of a friend and someone acting in solidarity rather than being paid to be there.



Gaps, Needs and opportunities



- Promoting more community based responses through volunteers such as respite, befriending etc
- There is a need for an association/organisation of carers to provide a better support network
- Increase availability of training for informal carers
- Identify gaps in service provision and collaborate to find initiatives to address challenges.



Cases of Good Practice of community support in Europe



- **UK:** <http://www.carers.org/> - online support forum providing comprehensive information on for carers including initiatives for support at local level.
- <http://www.carersuk.org/> campaigning organisation where you can find out about rights as carers. Provides training.
- **Denmark:** DaneAge – volunteer respite services for families with elder people suffering from dementia
- **Ireland:** carers association a national voluntary organisation provides home respite services, training, information, support and counselling, advocacy, information operating 16 carers resource centres across Ireland

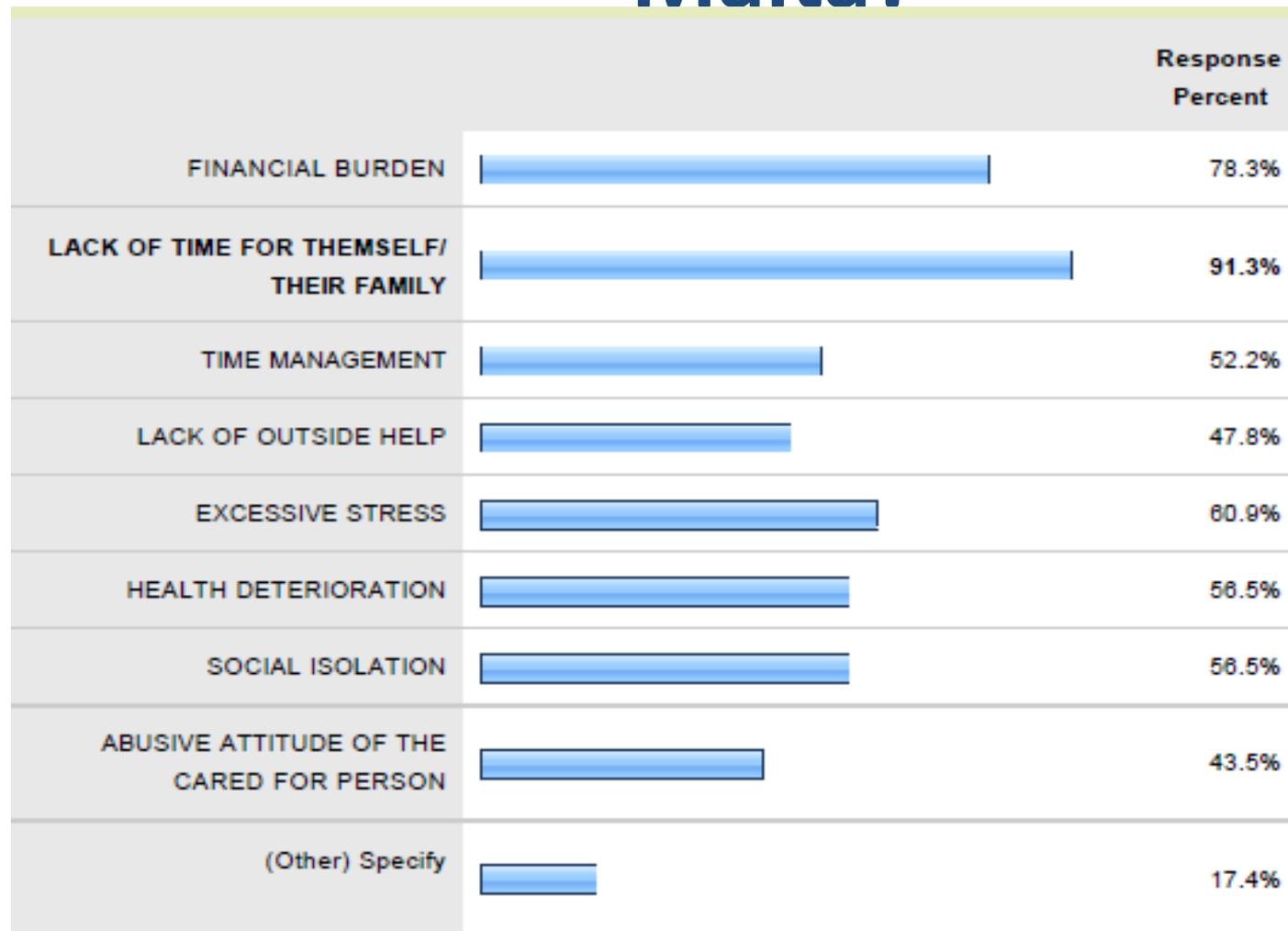


Research Results

Responses From NGOs

- 40 Responses
- 70% of respondents would be interested in participating in a project to support informal carers
- Of NGOs working in the field they provide services such as: support to day to day caring needs; training for volunteers and carers; support to low income families in the form of clothes, food medicine, support groups
- NGOs named initiatives such as good neighbour schemes; training for carers; support to carers psychologically; recognition of carers; support networks as potentially important for carers.

In your experience, what are the main challenges faced by Informal Carers in Malta?



**Which
Services
would be
most
beneficial
for carers in
Malta?**

	Response Percent
COUNSELLING FROM SOCIAL WORKER/PSYCHOLOGIST	65.2%
HOSPITAL/NURSING HOME FOR RESPITE CARE	52.2%
IN-HOME RESPITE CARE	52.2%
SUPPORT GROUPS	60.9%
HOUSE/YARD MAINTENANCE	30.4%
OFFICE WHERE TO ASK QUESTIONS ABOUT THE SERVICES AVAILABLE AND ASK FOR ASSISTANCE	47.8%
INTERNET PAGE/ NEWSLETTER/ SOCIAL MEDIA WHERE TO FIND INFORMATION	21.7%
PHONE HELP LINES	56.5%
HELP IN DEALING WITH AGENCIES/ BUROCRACY TO GET SERVICES	52.2%
SUPPORT BY VOLUNTEERS OR PSYCHOLOGIST AFTER THE LOSS OF THE CARED FOR PERSON	60.9%
FINANCIAL SUPPORT	65.2%
TAX BREAK, STIPEND, GOVERNMENT SUBSIDY	65.2%

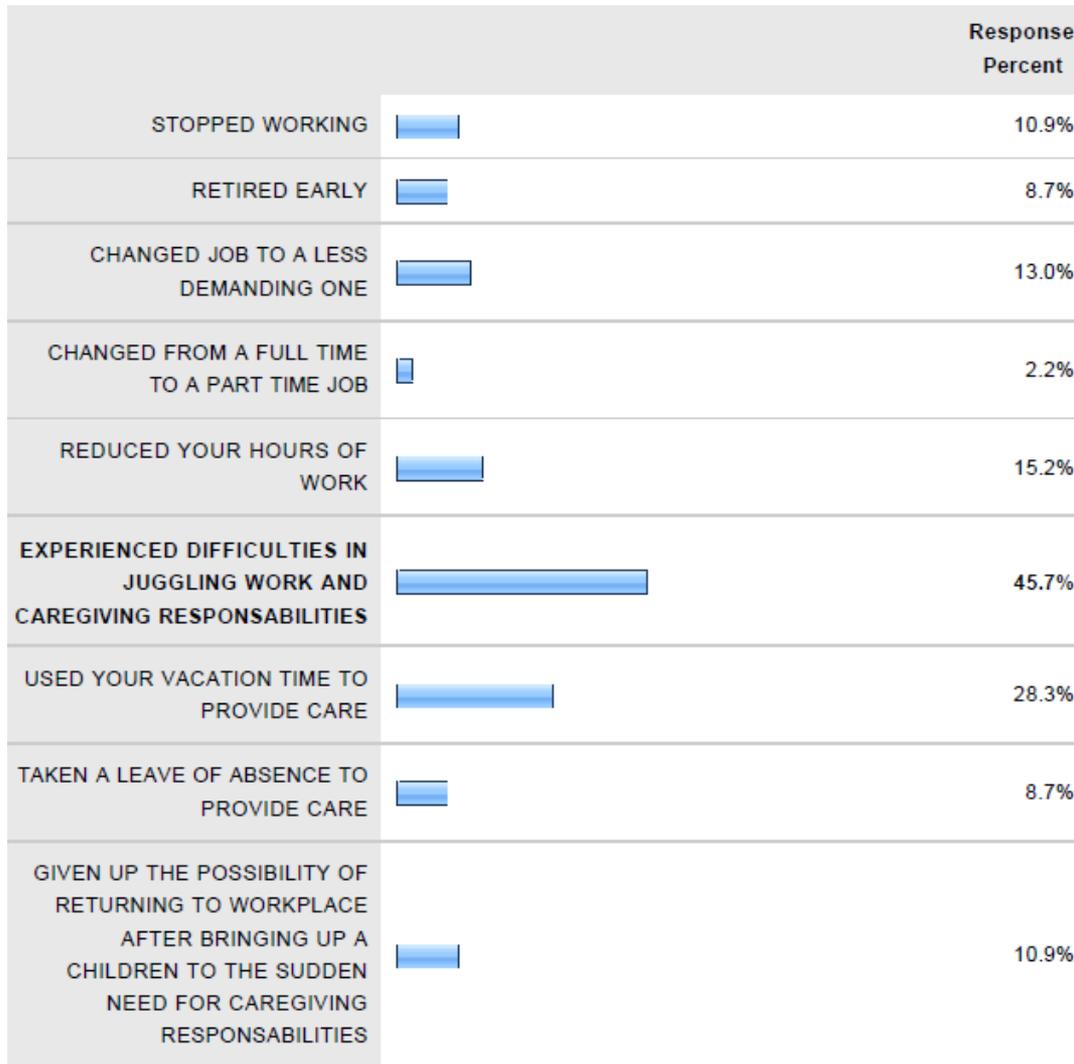
Responses From Informal Carers

- 113 respondents of whom 83.2% had previously considered themselves as an informal carer
- The majority (79.6%) were caring for a member of the family.
- The majority were providing care because the person was a member of their family (50%), it was expected of them (13.8%) or they wanted to help out (17%)
- Positive aspects of care giving were cited as helping your family (52.5%), the caring itself (37.3%) as well as companionship, a sense of accomplishment and a sense of meaning.
- 92.7% of respondents have never been offered a carer's assessment of their needs.
- 61% of those interviewed were not aware of the availability of the carers pension
- 44.1% of respondents answered that their quality of life had deteriorated since becoming a carer.

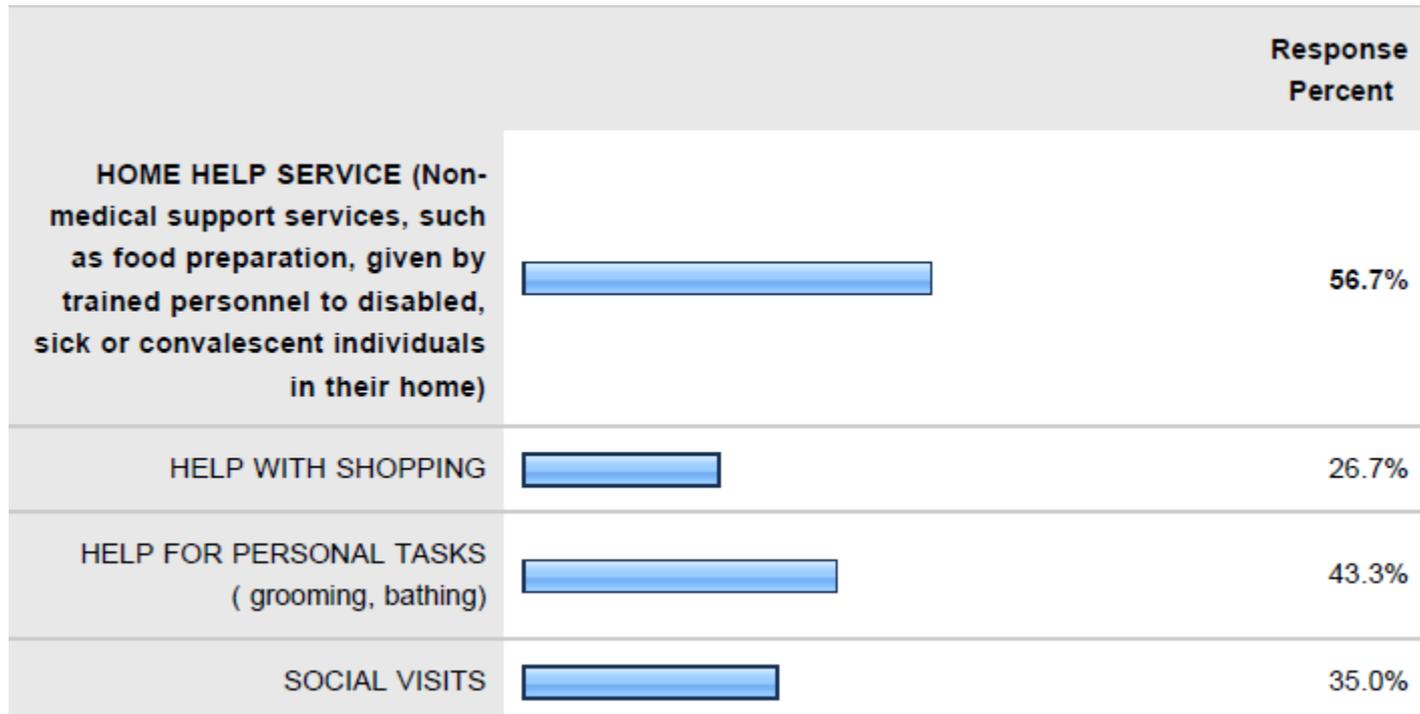
Which of the following have been the biggest difficulties in care giving?

	Response Percent
FINANCIAL BURDEN	20.3%
LACK OF TIME FOR MYSELF/ MY FAMILY	40.7%
TIME MANAGEMENT	28.8%
LACK OF OUTSIDE HELP	18.6%
EXCESSIVE STRESS	42.4%
HEALTH DETERIORATION	16.9%
SOCIAL ISOLATION	15.3%
ABUSIVE ATTITUDE OF THE CARED FOR PERSON	5.1%
UTTER DEPENDENCE ON SELF	13.6%
OTHER RELATIVES REFUSE TO SHARE THE BURDEN OF CARE; THUS I BECAME THE PRIMARY CAREGIVER	22.0%

Employment: Because of your role as informal carer have you:



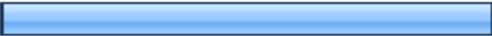
Which services for the cared for person would you be most likely to use if available?



Which services would you be more likely to use if available?

	Response Percent
HOSPITAL/NURSING HOME FOR RESPITE CARE	31.7%
IN-HOME RESPITE CARE	46.7%
HOUSE/YARD MAINTENANCE	28.3%
OFFICE WHERE TO ASK QUESTIONS ABOUT THE SERVICES AVAILABLE AND ASK FOR ASSISTANCE	36.7%
INTERNET PAGE/ NEWSLETTER/ SOCIAL MEDIA WHERE TO FIND INFORMATION	46.7%
PHONE HELP LINES	43.3%
HELP IN DEALING WITH AGENCIES/ BUROCRACY TO GET SERVICES	28.3%
TAX BREAK	43.3%

Would you prefer to benefit from these services and the ones being offered...

		Response Percent
UPON PAYMENT, IF CARRIED OUT BY PROFESSIONALS		31.7%
FOR FREE, IF CARRIED BY TRAINED VOLUNTEERS		68.3%



Suggestions on how volunteers could support informal carers

- Social network; create groups for people to exchange experience and help each other
- Respite care and help in the home
- Being trained and informed on different cases and situations (such as dementia) to be able to caring out support roles effectively.
- Access to information about different services

Conclusions

- Care giving should not be assumed to be a natural part of family life
- All stakeholders play an important role in supporting informal carers (state, family, private sector, community)
- Community initiatives should come hand in hand with government policies to ease burden on carers
- Volunteers can play an important role especially in improving the “quality of life” aspects of caring.
- Civil society organizations should find ways of collaborating to ensure joined up initiatives in support of informal carers such as a carers association or a national level information service
- Training for both Volunteers and Informal carers is key to ensure the cared for persons receives high quality care and the Carer feels adequately supported.

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