

We Care - Do You?

The Triangle of Care
– Domiciliary Care for
Older People



EQUAL

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We Care - Do You? is a transnational partnership between Estonia, Italy, Latvia, the Netherlands and the United Kingdom funded through the European Social Fund's EQUAL Community Initiative Programme. This toolkit is one of the products of this partnership incorporating the experiences of two of the partners.

WHO IS THE TOOLKIT FOR?

“Toolkit” is an English term, commonly translated as “cassetta degli attrezzi”. A tool is something concrete used in everyday working life. Its Italian equivalent is ‘strumento’ (instrument). However, this document will use the English word, as the term ‘tool’ not only suggests something concrete and useful, but also something simple and practical, which this aims to be.

The toolkit is aimed not only at social workers, but also community workers, paid care workers and unpaid carers for the elderly. It is designed to help older people remain at home by providing a framework for their support by their families and/or carers, and paid or domestic care workers. Welfare policies in Italy and in the UK are different, as are the resources allocated to them and the services provided by them. What is common to both are the needs of service users, families and carers, and paid care workers.

WHAT IS A CARER?

Carers provide unpaid care, outside a professional framework and within a personal relationship, for family, partners or friends in need of help because they are ill, frail or have a disability.

Carers give much to society yet they can experience ill health, poverty and discrimination because they provide care.

INTRODUCTION

Demographic changes across Europe are seeing an increase in the older population, with a corresponding increase in the number of years older people can expect to live in poor health. This makes it imperative for new models of eldercare to be developed, targeting health needs and promoting independence, with individual programmes designed to support older people at home. While health and social care systems are reconfigured to meet this challenge, the caring role is increasingly falling to families, and very often women

Both Italy and the UK are seeking to develop more community based services to meet this need, but it is currently met largely by residential and home care services, in a market which, although critical, can suffer low levels of investment and labour market shortages.

In Italy, older people requiring care can count on free health care from the National Health System (NHS), means-tested social care from Municipalities, and State welfare benefits –(means-tested) disability pensions and (non-

means-tested) care allowances – as well as from local authorities (Regions and Municipalities, generally means-tested). Under to this system, which is undergoing a process of decentralisation and transfer of responsibility to the Regions, free health care is now actually limited to primary care by GPs (who reach the whole population) and to hospital acute care, while long term care costs in residential and nursing homes are covered only partially.

Older people and their carers access local services through the social board (sportello sociale). A case manager is appointed to the older person, who can in turn involve a multi-agency team to evaluate the psychological and - physical condition of the user and/or draw up a a personalised care plan. Local support and services can be described as follows:

Services supporting independent living and participation (Centro risorse anziani, social centres, involvement in voluntary activities)

Residential and semi-residential services (residential care for dependent older people and sheltered housing or day care for independent or partially independent older people)

Domiciliary care services (home care, welfare benefits, respite services, intermediate care services, support for people affected by dementia and their families)

There is currently, a trend towards increased use of market-led care services. Increasingly, families are resorting to the use of foreign immigrants (the so-called “badanti”, often unregulated, untrained, unprotected, and illegal) to provide home care to their dependent elderly relatives.

In the UK, there are possibly higher levels of domiciliary care services available for older people. These can be provided (and funded) directly by the state, sometimes by external agencies, or bought by individuals or families either through state funding such as Attendance Allowance or privately. Within the state provision of care, the system of Direct Payments can be used to employ Personal Assistants who do not have to be trained or registered. Local Authorities and private care providers are increasingly using migrant workers to meet staff shortages in domiciliary care, and although the use of ‘badanti’ is not an identified issue in the UK, there is anecdotal evidence that families sometimes rely on informal arrangements with migrants to manage the care of an older person. There is also an example of one agency which recruits migrant workers in Europe and acts as an agency for their placement, offering them training and registration.

THE FACTS – UK

- There are 3 million working carers in the UK. Of these 1.4 million are men and 1.7 million are women.
- Carers are not a static group - more than 2.3 million in the UK people move in and out of caring situations each year.
- The majority of carers in the UK look after older people. 70% of those cared for are aged 65 or over
- 38% of carers care for their parents, 18% for their spouse

- Research tells us that 3 out of 5 people will care at some stage in their working lives.
- Many carers find themselves forced to give up work due to a lack of care services or flexible employment. A recent survey by the Equal Opportunities Commission found that 1 in 5 carers gives up work to care

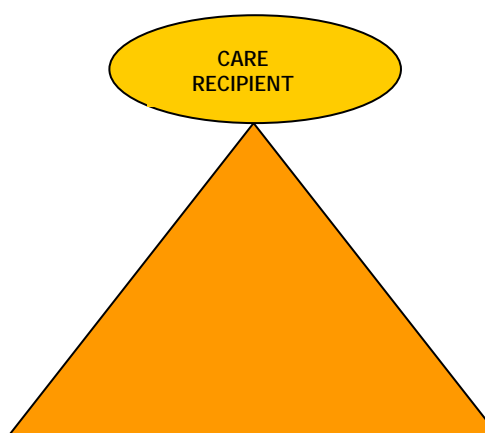
THE FACTS – ITALY

- 70 % of carers are women, with the majority employed in temporary jobs in the service sector, characterized by greater flexibility
- 17% of economically inactive women of working age and 13% of retired women in Italy consider that caring has had a significant negative impact on their professional status, resulting in failure to access the labour market, giving up work to care, or early retirement.
- Working women face significant difficulties in combining work and care, with more than half reducing their working hours.
- National data indicate that the categories of people most frequently involved in caring for older people are their children (68%), their spouse or other relatives living with the family (48%) and other relatives who do not live with the family (26%)
- A survey conducted in 2002 (IREF-ACLI in collaboration with Eurisko) estimated that 950,000 families use immigrant workers to care for older people or for children because they find state services unsatisfactory, unreliable and incompatible with working hours and family needs

THE COMPLEXITY OF CARE WORK

Caring for someone - assisting, supporting, nursing – takes place either in a professional framework, or within a personal relationship, when the person being cared for is a family member – a frail elderly parent, a disabled child, a mentally ill partner - or a friend.

However, when care is provided in a home setting, in particular in a co-resident relationship – whether paid or unpaid – or when care is delivered very flexibly, it involves often complex relationships of dependence and interdependence. The diagram below represents the key players in the framework of care provision.



THE TRIANGLE OF CARE

CARER

CARE WORKER

In this context, what might be sought by an individual or family is not a trained care worker but someone who has the personal qualities and commitment to 'engage' with a family in a care situation, implying a degree of control or management of that situation, often mirroring the role of the unpaid carer. There is then the potential for conflict between care worker and carer, as their roles overlap and the distinction between them blurs. This can be the case not only for 'badanti' who more often than not live with the person they are providing care for, but for Personal Assistants who provide flexible care solutions and often enter very particular caring relationships with their clients,

DESCRIPTION

The toolkit consists of three checklists, each applying to one of the players in the triangle of care: the service user (in this case frail elderly), the primary carer (often a family member), and the care professional (in this case a domiciliary care worker, co-resident, migrant, Personal Assistant or otherwise).

Each checklist covers a range of general issues or needs relating to each player. These have been identified through consultation with care professionals, service users and carers, domiciliary care workers (including Personal Assistants, and informal migrant care assistants or 'badanti'), and through the specialist literature. Each identified area of need is then broken down into specifics through a series of questions. The list of questions is not exhaustive: they are drawn from professional and practical experience. They should be used sensitively – for example, as the basis for a face-to-face interview – and integrated into everyday practice.

OUR INTENTIONS

The toolkit is designed to support a range of activities associated with the triangle of care: the work of care professionals in identifying the needs of the service user, involving the user in that process; the work of care professionals in helping carers to identify not only the needs of the person they are caring for, but their own needs; the provision of care by migrant workers in a context which offers protection to all parties.

The tool does not seek to cover all existing issues or to identify new ones. The items in the three lists relate to the daily experience of professionals in this field. What is new, if anything, is the attempt to represent the complexity of relationships within the provision of care – the triangle - and 'join up' its

different elements, recognising that that complexity increases when paid care is provided by foreign domestic paid care workers (in Italy), or Personal Assistants (in other European countries).

POSSIBLE USE

There are different ways in which care professionals can use these checklists. Above all they can act as a guide to the complex network of needs and demands of people in caring relationships, paid or unpaid.

In the case of Italy, the tool might be used to identify the complementary or conflicting needs when care is provided by 'badanti', for example:

1. In terms of complementary needs, the service user and carer's need for round-the-clock care at home and the migrant care worker's need to work and have accommodation
2. In terms of conflicting needs, the demand for round-the-clock care versus the migrant care worker's need for protection in terms of employment conditions

In the case of the UK, the tool might be used to identify the complementary or conflicting needs of the carer, for example:

1. In terms of complementary needs, the service user's need for care to enable them to remain independent and the carer's psychological need to maintain relationships.
2. In terms of conflicting needs, the service user's need for flexible round-the-clock care and the carer's need to continue a life outside caring.

The checklists can be used as interview guidelines for each one of the three identified players. Helping people to gain awareness of their own role within the care dynamic, and supporting them to understand other points of view within it are the most effective ways to minimise potential conflict and develop better relationships between the service user and carer, the carer and care worker, and between all of these and the service provider.

Last but not least, the tool is meant to raise awareness among service providers and citizens of the role of carers.

Carers have been recognised in the UK since the mid-90s as significant players in the delivery of social care. In Italy, this recognition has yet to take place.. Service providers and policy makers, and even families themselves, do not appear to be aware of the fundamental role they are playing within the welfare system framework. When assessing the needs of the service user, the relevant family member or carer is often perceived as their spokesperson or representative, or at best identified as needing or receiving support services themselves. The three grids presented here are designed to identify the carer not only as having distinct needs, but significant resources. In this last respect, carers and family members can be seen as partners in the delivery of care and critical allies for caring professionals. It is for this reason that they should be recognised and supported - in crisis situations, for example, when the condition of the person they care for deteriorates, in decision making, for

example identifying the most appropriate service to support the needs of all parties in the caring relationship, in coping emotionally, for example, in dealing with changed relationships and ultimately with the loss of the person they care for, and finally, and most importantly, in maintaining a meaningful life outside caring.

Contacts

www.arcopolis.it/elsa

www.regione.emilia-romagna.it/wcm/ERMES/Canali/servizi_sociali.htm

www.comune.cesena.fc.it

www.comune.forli.fo.it

www.comune.savignano-sul-rubicone.fo.it

Contacts

www.acecarers.org.uk

www.carersuk.org

www.theparliament.com

www.employersforcarers.org.uk

Carer's needs check list

Do you think you have enough information about:

1. Condition/impairment/general health of the person you care for
2. Care and support services available for the person you care for

**Access to
information and
services**

<p>3. Any welfare benefits or incentives available to carers and/or users</p>	
<p>How long have you been providing care to the person you care for? Do you think the person you care for is aware of his/her condition? What kind of help are you currently providing? How much time do you devote to caring tasks on average each day? How is your daily life affected by these caring tasks? Are you in paid work? Does your caring role prevent you from doing things you did previously, e.g., working, studying, accessing leisure or social activities? Do you have other care or childcare responsibilities e.g., for children, grandchildren, other disabled family members? How does your caring role affect your other family responsibilities?</p>	<p>Balancing life and caring</p>
<p>What would you need to provide better care to the person you care for? What do you think are the most significant needs of the person you care for? Would the person you care for agree? Are there other family members or friends involved in the care of the person you care for? Does the person you care for receive health or social services? Do you employ a paid care worker or domestic assistant? Is there anyone you can turn to for advice or support? Do you have any health problems e.g., back pain, stress, anxiety, sleeping problems that could be associated with your caring role?</p>	<p>Practical support</p> <p>Emotional support</p>
<p>Do you manage to find time for yourself? Can you combine your caring role with a life outside caring? Do you receive health or social services in your own right? Do you think you will ask for these services in the future? What do you expect from health or social services?</p>	<p>Respite</p>
<p>Have you ever felt you need some guidance or training for your caring role?</p>	<p>Guidance and training</p>
<p>What satisfaction do you gain from your caring role? Do you have someone you can delegate your caring role to when necessary? Do you think your role is acknowledged by the person you care for, by other family members and by social services? How do you see your future? What is your main worry for the future?</p>	<p>Personal aspirations</p>

Private domestic assistant's needs check list

<p>What country do you come from?</p> <p>What expectations did you have before leaving? Have they been fulfilled? To what extent?</p> <p>Do you intend to stay for a long period in Italy?</p> <p>Do you have other childcare or caring responsibilities, e.g., children, elderly parents, a disabled family member, in your Country?</p> <p>Do you manage to keep a regular relationship with your family of origin?</p>	<p>Personal history</p>
<p>Do you think you have enough information about:</p> <ul style="list-style-type: none"> - immigration legislation - employment legislation for domestic assistants and careworkers - social and health issues in relation to aging and the specific condition of the person you are providing care for - health and social services available to the person you are providing care for - health and social services available to you personally 	<p>Access to information and services</p>
<p>Are you currently employed?</p> <p>How did you find your job?</p> <p>What are your working hours?</p> <p>What are your caring tasks?</p> <p>What kind of contract do you have?</p> <p>Do you have free time and/or a free day?</p> <p>Is it easy for you to access the nearest urban area from the house you are working in?</p>	<p>Current employment status</p>
<p>Do you live with the person you are providing care for?</p> <p>Are there other family members living in the same household?</p> <p>Do you have your own room in the house?</p>	<p>Residential status</p>
<p>What is your education history?</p> <p>Have you had a previous job in Italy?</p> <p>Did you have a previous job in your own country?</p> <p>Have you had any previous experience of paid care work or unpaid caring?</p> <p>If you have had experience of paid care work, please give details, including type of job, duration of job and reason for leaving.</p> <p>Have you ever undertaken training in care work, in Italy and/or in your country?</p> <p>Would you like to undertake training in care work?</p> <p>Would you like to change your job?</p>	<p>Education and previous work experience</p>
<p>Are you satisfied with your job?</p> <p>What satisfies you most in your care work?</p> <p>Do you think your work is acknowledged by the person you are providing care for, by other family members and by social services?</p>	<p>Personal and professional aspirations</p>
<p>Do you think you need supervision and/or assistance in your job?</p>	

<p>Is your cooperation with other people providing care, e.g., family members, doctor, health and social care workers, satisfactory?</p> <p>Is there anything you need to help you do your job in a safer and more skilled way?</p>	<p>Guidance and training</p>
<p>Is there anyone you could turn to for advice and support?</p> <p>In the case of an emergency, e.g., conflict with the person you are providing care for, death of the person you are providing care for, illness, immediate need to return to your Country, who do you think you would turn to?</p>	<p>Emotional support</p>
<p>What demands of the person you are providing care for and their family do find most difficult to cope with?</p> <p>How do you cope with them?</p> <p>How would you describe your relationship with the person you are providing care for?</p> <p>How would you describe your relationship with the primary carer , i.e., family member with most care responsibility, and with the other family members?</p>	<p>Care relationships</p>
<p>Are you satisfied with the way you spend your leisure time?</p>	<p>Social life and leisure time</p>

Older person's needs check list

<p>Do you live alone?</p> <p>Is there any family member taking care of you?</p> <p>Is it difficult for you to take care of your house?</p> <p>Is your diet suitable?</p> <p>Is it difficult for you to take care of yourself?</p> <p>Do you take care of someone else?</p> <p>If so, how do you manage to cope with this task?</p> <p>How do you spend your days?</p> <p>Is it difficult for you to manage your money?</p>	Everyday life
<p>Do you think you have enough information about:</p> <ul style="list-style-type: none"> - your condition/impairment/general health - care and support services available to you - any welfare benefits or incentives available to you and/or your primary carer 	Access to information and services
<p>How is your general health?</p> <p>Do you have any problems with memory?</p> <p>Do you have any problems with sight and/or hearing?</p> <p>Do you suffer from incontinence?</p> <p>Do you have any problems taking medication and/or in following specific treatments?</p> <p>Do you have stress or anxiety problems</p> <p>Do you ever have accidents at home, e.g., falling?</p> <p>Do you have problems with alcohol?</p>	Health
<p>How do you get around inside and outside your house?</p>	Mobility
<p>Do you meet regularly with friends, relatives, or neighbours?</p> <p>Are you satisfied with your social life?</p>	Companionship
<p>What is your relationship with the your primary carer?</p> <p>What is your relationship with other family members?</p> <p>Is there anyone else taking care of you?</p> <p>Do you feel satisfied with your care?</p> <p>What would you need to feel it was better?</p>	Care relationships
<p>Do you think your housing is appropriate to your needs?</p>	Household
<p>Do you think you have had a role in making decisions and choices that have affected you?</p>	Independence and dignity
<p>Do you ever feel in danger or at risk?</p>	Safety

ACENational
action for carers and employment
led by **CARERS** UK



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Empowerment of care
worker migrant women



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