

We Care - Do You?

Balancing Work and Care - A Professional's Guide



WE CARE - DO YOU?

Balancing Work and Care – A Professionals Guide

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 the partnership incorporating the experiences of all of the partners.

WHO IS THIS TOOLKIT FOR?

- **Service providers – care workers, professionals in rehabilitation and education, primary health care and palliative care service providers, disability organisations, etc**
- **Governmental bodies in partner countries, responsible for the provision and coordination of social services in the community, will also benefit from information included in this toolkit.**

We invite people who can make a difference to use this document to develop services and support for families and carers to improve their quality of life and help them to continue in employment whilst managing their care responsibilities.

What is a carer?

Carers provide unpaid care, outside the 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 so much to society yet they often experience ill health, poverty and discrimination because they provide care.

Carers often juggle other demands such as family and a job with their caring role. For many, this becomes a difficult situation with significant consequences such as having to give up work or study. This toolkit does not attempt to provide a comprehensive picture of all of the activities undertaken by partners but, by highlighting experience and best practice, aims to offer practical solutions and guidance to help overcome difficulties faced when attempting to reconcile work, care and family life.

DEFINITION OF TERMS

Care worker: a person, professionally trained, who provides paid care, including personal care, and usually in the community.

Volunteers: a person who provides unpaid services on a voluntary basis.

Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being, and which limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.

Respite Care: the system whereby families and carers can have a break from their caring responsibilities whilst the person being cared for spends time with other trained staff either within their own family setting or in another family setting or institution.

EFFECT OF CARING ON THE QUALITY OF LIFE

Family members are affected by the person's disability or illness, and, often, become co-managers of the everyday care. They may experience many changes as a result of the permanent caring needs within the family and can be affected psychologically by the disability or illness of the person being cared for. Family members often join the person being cared for in a period of grief caused by a loss of function. Severe injury, chronic disease, or disability may mean a change in family roles. For example, a non-working partner may need to return to work and become the breadwinner; a son may need to adjust his work schedule to help care for an elderly parent. These changes can cause stress and conflict within the family. Financial problems due to additional costs or unemployment can occur, placing more pressure on the family. Changes in living arrangements, childcare issues, and relationships within the community can all pose new problems for the family and often have a negative impact on the ability of carers to continue in or return to employment.

By working together with the social care providers, the client and family can help reduce some of the adverse effects of caring responsibilities. This can be accomplished by:

- identifying the adverse effects of caring within the family.
- working together on realistic solutions.
- participating in carer education, counselling and support services
- liaising with relative agencies to ensure adequate carer support

Demographic changes and an ageing population, together with an increasing demand for care, make it necessary for policy makers, government and health and social care providers to pay attention to this situation. Although it is evident from forecasts across the 5 countries (see Eurostat table below) that people will be living longer in the future, these extra years many not necessarily be in good health resulting in an increased demand for care, both from unpaid carers and from paid care workers.

	Population ¹		Fertility ²		Life expectancy ³				Old Age Dependency ⁴	
					Men		Women			
	2005	2050	2004	2050	2004	2050	2004	2050	2004	2050
Estonia	1.3	1.1	1.4	1.6	65.5	74.9	76.9	83.1	23.8	43.1
Italy	58.5	52.7	1.3	1.4	77.3	83.6	83.2	88.8	28.9	66.0
Latvia	2.3	1.9	1.3	1.6	64.9	74.3	76.2	82.5	23.6	44.1
Netherlands	16.3	17.4	1.8	1.8	76.2	80.2	80.8	83.6	20.5	38.6
United Kingdom	60.3	64.3	1.7	1.8	76.4	82.9	80.9	86.6	24.3	45.3

Source: EUROSTAT, 2004

Notes:

1 Population in million on January 1st (2050: trend scenario)

2 Number of children per woman (2004: estimate; 2050: trend scenario)

3 Life expectancy at birth in years (2050: trend scenario)

4 Number of people aged 65+ as percentage of people aged 15-64 (2050: trend scenario)

Further comparative data can be found on the Red Cross website:

<http://www.bfs.admin.ch/bfs/portal/en/index/international.html>

The following real life stories provide examples where support has enabled carers to balance their caring responsibilities with their employment and family life.

An increasing number of older workers have care responsibilities for elderly parents and face the dilemma of choosing residential or home care which can often lead to the carer giving up their own employment. Ellen's story from **The Netherlands** highlights the difficulties faced when choosing to care for your parent in your own home.

Ellen is the CEO of a national organisation with 230 employees. She works full time and is a carer, taking care of her mother who is 94 and has Alzheimers disease.

A year ago Ellen's mother was discharged from the hospital and came to live with her. The doctors estimated that she would live for some 12 weeks but, after a year, she is still alive and living in her daughter's home. Ellen is one of many women who struggle to combine caring for a parent with a career. She finds it difficult.

The health insurance organisation in the Netherlands does not consider it efficient to nurse her mother at home: a nursing home with people around for 24 hours is less expensive than using a personal budget to employ people on a one to one basis at home. However, although Ellen has the choice over whether to admit her mother to a nursing home, she is determined to look after her at home. She hires a nurse for 13 hours a day. The personal care budget she is entitled to is only enough to pay for 6 hours and so Ellen has to

meet the shortfall from her own money. She provides the care for her mother during the remaining 11 hours when there is no nurse employed.

Ellen's house has needed adaptations to cope with her mother's needs e.g. a special bed, toilet seat, lowering of door thresholds and for every single item she has had to struggle with social services for assistance. Needless to say, this has caused her a lot of time and trouble.

In order to get one night's undisturbed sleep a week, Ellen hires a careworker for the night. Fortunately, she has sufficient income to do this.

In a recent article in a national newspaper Ellen described her situation and made a plea for better arrangements for working carers including more home help from professional careworkers, support for carers together with respite care and options for leave from work as well as financial compensation. Ellen pointed out that this is particularly relevant considering the ageing population and the need for citizens to remain economically active.

Caring for a partner can bring great changes within a relationship and the following story from **Italy** stresses the importance, not just of service provision for the client, but also of self-help groups for the carer.

Maria was only 56 when her story began to change, although her husband realised that there had been many small signals before this time. Although Maria is the person with Alzheimer's type dementia, her husband's life as her carer has also changed dramatically.

In view of her young age, the family felt the need to find a treatment to halt the process but the doctor did not want to give them false hope. It was hard for Mario to pretend nothing was happening and he had no-one with whom to share his anger and pain. Mario was put in touch with the local Social Services. He joined a support group and attended carers' training courses. This helped him come to terms with what he would have to cope with. The group also encouraged Mario not to give up his leisure activities and to make time for himself away from the caring situation without feeling guilty. This was helped once Maria accepted some external domestic assistance within the house thus giving Mario the opportunity to go to the pub to meet friends and socialise.

Mario has now started volunteering with the CAIMA Association (Italian Alzheimers Association). Although his life as a carer is very busy he feels he has a duty to help others who are still experiencing sad and confusing times.

Maria will soon start attending a dementia day centre. This decision did not come easily for Mario but it was felt best for both of them. Mario realises that, as his wife's most important and main support, he must stay strong for both of them. The services provided for Maria have enabled her husband to care for her whilst still remaining an active citizen within his local community.

John's story from the **United Kingdom** shows how flexible service provision tailored to individual needs can bring great benefit to both client and carer.

A Direct Payment is money given to you by the Social Services Department. As the client, you are then able to use this money to purchase services that are appropriate to your particular needs, thus enabling choice, flexibility and greater control over clients' and carers' lives. Some areas have promoted the use of Direct Payments to carers and provided a support network of Personal Assistants (PAs) to maintain a reliable system.

John was diagnosed with progressive multiple sclerosis (MS) whilst his wife was pregnant with their first child. They had been running a successful business together and they had planned to share the childcare responsibilities whilst both remaining involved with the business. However, John's health deteriorated much more quickly than expected and, by the time the baby was 6 months old, he was no longer able to continue contributing to the family business. John felt very guilty that his wife was coming home from work each day tired yet still having to start on the household chores.

To deal with this situation, Direct Payments were set up so that they could employ help with the baby and also help with maintaining the household during the day whilst John's wife continued to work full time.

After this had been put in place, John felt relieved that the house was now cleaner than it had ever been and that his wife no longer had to struggle with the chores after a long day at work. He was also really happy as he now had the opportunity, with the help of his personal assistant (PA), to take his child – now a toddler – to the park during the day. He had been able to watch his child run around safe in the knowledge that the PA was there to support him.

Direct Payments have greatly benefited this family by taking pressure off the main family carer whilst, at the same time, removing guilt from the client.

Parents of young adults with learning disabilities can experience a sudden shortfall in the support they receive once their son/daughter moves from children's to adult services. The need for continued support is highlighted in the following account from **Estonia**.

The right to work is everyone's inalienable right. Work as a phenomenon of human life is far more than simply going to work and making money. The meaning of work is the same for people with special needs as it is to anyone, but work is especially important for them as it is a key to their independence, social environment and human relations. Having a pleasant job maximises the possibility of self-esteem.

In some EU countries there are very few services for young adults with learning disabilities once they have reached school leaving age. This, in turn, places a new burden on the family carers as they are once again faced with difficult decisions on whether to continue in employment or leave their son/daughter for long hours alone. In recent years sheltered workshops have been developed in Estonia but they can have a negative image as the pay is low or non-existent, there is little integration with outside society and by working there, the clients can be seen as identifying themselves as 'incapacitated for work'.

However, the Tallinn Training Centre 'Juks' aims to reverse this image and provides worthwhile on the job training with promotion prospects and life skills courses. The parents and family members welcome the increased independence and self esteem gained by the young people. Many remark that their son/daughter has started to communicate more and to help around the house. Instead of being someone who needs care they want to help with household chores such as shopping and preparing meals. This often leads to supported employment for the son or daughter enabling parents to continue with full life beyond care including work or training.

Some families face such sad and traumatic situations affecting every family member that they desperately need support to assist them through extreme times. The Children's Palliative Care Service in **Latvia** seeks to support the whole family throughout care and bereavement and on to life and hope for the future as seen in the story below.

The parents of two daughters with a rare genetic disorder were able to continue working as the girls' grandmother and her sister (the girls' great aunt and godmother) had provided caring support during the working week. The girls had developed normally until the age of 3 when they began to regress and lose skills previously gained. After several years' illness and intense caring need, both girls died within less than a year of each other.

During this time the parents were finding it hard to cope and the effect of their daughters' illness had the following results:

- poor health due to permanent stress and overwork trying to combine work and care with frequent sleepless nights;
- deteriorating marriage relations, each blaming the other and with little time to spend together;
- a decreased circle of social contacts as the girls' needs took all their time.

The family was referred to a psychotherapist and, although this was first viewed with mistrust, gradually the attitude of the family changed. Support was provided within the family home which provided the opportunity to:

- talk about the ups and downs of the illness and the frustration for the family;
- grieve for the elder daughter who died first;

- anticipate the grief which would be experienced on the death of the second daughter;
- support the grandmother and great aunt;
- final support in coping with the death of the second child.

By the provision of this service, the family was able to stay together to provide care throughout for the girls, with the parents having the fortitude to continue in their employment thus maintaining hope for the future.

WHAT CARERS NEED

Although legislation and levels of carer awareness differ across the five countries, a general theme emerges which shows that:

- most value the opportunity to have a part of their life away from caring;
- for most, their income from employment is very important;
- flexible working and supportive managers are crucial;
- tiredness and stress are especially difficult problems;
- mentoring or the facility to talk through problems can make all the difference

Demographic predictions make it imperative that carers are put firmly at the centre of governments' agendas. Governments must recognise that supporting individuals who take up caring is an essential part of the solutions needed for the challenges ahead. This can be done by:

- 1 Better recognition of carers by professionals to ensure that carers' needs are always considered when health and care plans are made for the person being cared for;
- 2 A realistic carers' allowance and financial compensation to cover additional costs of caring such specialist equipment and higher transport costs;
- 3 Carer-friendly employment practices enabling carers to combine work and care coupled with flexible service provision to accommodate the needs of the person being cared for;
- 4 Support for carers' health by providing regular health checks to assess their needs resulting from the physical and mental strains of caring together with the provision of respite care to provide breaks for carers;
- 5 The recognition by governments that, due to the often isolating experience of caring, carers are at risk of social exclusion and that resources need to be targeted to enable carers to be included in society.

FURTHER INFORMATION

Further information relating to each of the five countries can be found on the following websites:

UK:

www.carersuk.org

www.acecarers.org

ITALY:

www.arcopolis.it/elsa

LATVIA

<http://www.palliative.lv/>

ESTONIA

<http://www.tartukoda.ee/?sisu=7>

THE NETHERLANDS

www.mantelzorgenwerk.nl

www.mezzo.nl

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



This toolkit is part funded by the European Social Fund
under the EQUAL Community Initiative Programme