

# INFORMAL CARERS' SKILLS AND TRAINING – A TOOL FOR RECOGNITION AND EMPOWERMENT

Informal carers gain a wealth of skills and experience while performing their caregiving tasks. These skills and competences are generally undervalued even though they could potentially be an important instrument to improve the caring experience both for carers and their carees. Recognising and developing informal carers' skills is also a sound investment for society as a whole since these are key to secure carers' crucial contribution to long-term care systems. Even more so, valuing and strengthening informal carers' skills may prove a promising tool to counter their social exclusion and to improve their chances to maintain an active life or re-enter the labour market.

Recognising and developing informal carers' skills is therefore not only useful to improve the quality of life of carers and their carees, but also to contribute to the sustainability of our care systems and to the EU (female) employment objectives.

## Informal carers got talent!

Because they often care for people affected by severe health condition or multiple diseases, informal carers handle a range of skilled home care on a daily basis. These include personal care (bathing, washing, feed, dressing, managing incontinence...), as well as specific medical care (such as home-based dialyses, management of oxygen/nebulisers, monitoring of blood and insulin levels in the case of diabetes, tracheotomy patient care, blood pressure monitoring, colostomy bag management, administering medication, diet and eating monitoring, etc.)

In addition, carers also demonstrate and develop specific communication skills with people affected by dementia or other mental illness, and often have to deal with challenging

behaviours in this context. Besides, informal carers develop important transversal skills, as they tend to organise and manage care arrangements for their loved ones, involving a range of health and social care professionals, while also managing their own professional and family responsibilities. Planning, managing competing priorities, organising, sharing information, coordinating, using digital tools are some of the skills they apply in their everyday life.

## Informal carers lack recognition of their skills

While caring for a loved one can be an important source of personal satisfaction, informal carers suffer from the lack of awareness of the value of their unpaid work. Informal carers who are not included in the labour market may feel isolated and undervalued. For those in employment, being an informal carer can be a source of stigmatisation and is associated with limited professional opportunities, lower salaries and pension entitlements especially when they are compelled to opt for part-time work. This is particularly the case for women having to combine work and caring responsibilities but also for young informal carers, who face stigmatisation at school/university and difficulties to follow a standard educational curriculum. Being an informal carer can also have a negative impact on their educational

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achievements as many young carers tend to leave school early.

Furthermore, many informal carers do not recognise themselves as such, which reflects the little value associated with this role. Training pathways that build on the experience of informal carers can effectively help informal carers to become more aware of their skills, to gain self-confidence and motivation in order to develop their competences even more. Training can help informal carers both to improve their caring experience and to enter professional training pathways likely to support their social inclusion and their integration on the labour market.

## The multiple advantages of training for carers and for their cares

Research demonstrates the usefulness for the carers to be equipped with specific skills in order to be able to deliver quality care, notably:

- Disease-specific knowledge,
- Skills required to maintain the health status of the patient and, if possible, facilitate his/her rehabilitation,
- Skills dealing with the management of symptoms,
- Skills related to daily life activities (for example, transferring, bathing and dressing, feeding),
- Management of emergency situations,
- Ability to take care of oneself, manage stress and protect one's own health.

Authors insist on the importance of sharing 'factual information' related to the health status of the patient as well as on developing relevant strategies to improve 'communication with people affected by dementia', building on the 'expertise of health professionals', and to help carers manage the stress attached to caring. It was established that training carers does have a clearly measurable positive impact on their quality of life, skills and self-reported burden, as well as on their ability to cope and resilience to depression. Carers' experience channelled by carers' organisations across Europe confirm these analysis.

Training can also contribute to prevent mistreatment by raising awareness about Human Rights issues related to caregiving, but also because they help informal carers break their isolation and pay attention to their own well-being and life satisfaction.

## The added value of training informal carers for the society

The preventive aspects of well-trained and well-supported informal carers in avoiding or delaying hospital admission and long-term institutional care is well documented. Training, especially in core caring skills e.g. manual handling, coping with caring, knowledge of conditions and in situations where carers need to manage and monitor complex medication prescriptions, coordinate and implement complex medical procedures is essential in this respect. Training in stress-management techniques is also useful to prevent informal carers' burn-out and therefore unwanted and unprepared institutional care. The provision by informal carers of 80% of long term care in our societies is in itself a treasure that should be safeguarded, notably in the interest of our public budgets. Ensuring adequate training to informal carers will contribute to maintaining their contribution.



## Validating and developing informal carers' skills: supporting informal carers' inclusion in the labour market

### Training for carers as a tool to combat social exclusion

The quality of life of carers is generally poorer than society's as a whole. Being a carer is often associated with poverty and carers of working age face tremendous difficulty to access or retain work. When at work, they are more likely to be employed part-time and their career prospects are reduced. Informal carers, and especially women, have been found to be at higher risk of poverty, reflecting a weaker attachment to the labour force and hence the accrual of lower pension entitlements. Viitainen, in a study of 13 EU countries in 2005, found that single women with care responsibilities for older people incur a greater risk of old-age poverty. Intensive carers tend to have lower income than non-intensive carers: 60% of them are in the first and second income quintiles compared to 40% of non-intensive carers. Unless there is good access to formal care support and policies enabling people to combine work and family responsibilities, as in some Northern European countries, care can entail substantial economic sacrifice. Carers may be forced to cut down their working time or leave paid employment altogether. Obligations to look after elderly relatives can

also cause poverty when informal carers reach pensionable age, unless arrangements have been made to help them to reconcile family and care responsibilities and (as in Germany and Slovakia, for example) to build up pension rights.

Besides reduced income from work, caring for a dependent person often implies a range of expenses linked to the products needed to provide care and assistance, out-of-pocket cost of healthcare services, which have been on the increase in recent years due to austerity policies, and costs linked to the necessary adaptation of the home.

**42% of non-working carers are in the lowest income quartile (compared to 24% of non-carers), 59% of non-working carers have difficulty making ends meet (compared to 46% for non-carers).**

**Besides, informal caring is often associated to social isolation and frustration, ill health and depression.**

Recognising the contribution of carers, as well as the value of their skills and competences, can have a very positive impact on their wellbeing and self-confidence, both as carers and as citizens. Projects aimed at empowering informal carers from disadvantaged background, building on the recognition and the development of their skills are often a first step towards their inclusion in the community, the continuation of further training and inclusion in the labour market, if compatible with their caregiving responsibilities.

**Exploiting a vast untapped pool of skills to address the needs of the labour market**

Europe is ageing and this leads to a growing incidence of age-related diseases, a growing demand for care and a real sustainability challenge for our social and health care systems. A potential shortage of health and care workforce is one of the crucial challenges facing Europe's healthcare systems. Several Member States, experience difficulties in recruiting long-term care workers.



Foreign-born workers often play an important role, making up some 70% of LTC workers in Italy. A Peer Review organised by the European Commission in 2013 discussed the use of migrant workers to bridge this gap. Major challenges in this regard include the need to ensure that such international recruitment drives benefits for both the host and the sending country, and to discourage active recruitment of health personnel from developing countries facing critical shortages of health workers.

In this context, validating the skills of informal carers and taking stock of their experience as part of pathways to achieve recognised professional qualification in the field of care, would incidentally contribute to addressing this shortage in the care workforce and opening opportunities for informal carers who wish to return to the labour market.

In the context of the EU's free circulation of workers, achieving mutual recognition of validated skills for informal carers would support the mobility of those carers who are willing to have their experience and training recognised or wish to go and work in another Member State.

## Informal carers and professional care workers: building bridges

The objectives of training for informal carers may differ sensibly from the objectives pursued by training aimed at professional care workers. However, developing common elements in both training pathways could be particularly useful in order to develop common references, mutual recognition and understanding. Indeed, professional care workers and informal carers need to cooperate very closely in the interest of the caree, which does not necessarily happen smoothly in every context. In this respect, training can ensure a positive contribution to the development and implementation of integrated community-based care.

## What kind of training do carers need the most? What is working well and why?

### Informal carers lack accessible training opportunities

Learning opportunities are highly valued by informal carers and are recommended by health and vocational training professionals as well as academic research. Yet, the development of initiatives aimed to increase and adapt training opportunities for informal carers remain globally insufficient, extremely fragmented and uneven in the European Union. As it is also the case for other support services, the availability of training opportunities varies a great deal across countries, regions and even municipalities – with very limited opportunities in Bulgaria and Slovakia, and more developed training opportunities available in Finland, Germany, Italy, Sweden and the UK. Civil society organisations play a major role in the provision of available support services, together with public authorities and the private sector.

Besides the lack of training opportunities, informal carers face a multiplicity of obstacles to access training, including a lack of geographical accessibility, lack of information, organisational difficulties (most carers find it extremely difficult to free themselves up from their caregiving responsibilities, as well as from their other family and professional commitments, in order to take part in training courses), or a lack of self-awareness as a carer. Even in countries where a diversity of training opportunities exists, the low take-up of these remains a major concern.

### Existing training – what do carers need the most?

Among existing training opportunities, one can identify the following types:

1. Professional vocational training, also open to informal carers willing to obtain a formal qualification;
2. Training developed within the health sector with the aim to equip carers with the necessary skills to maintain the health status of a patient discharged at



home, as well as to maintain his/her own health;

3. Training developed by Civil Society Organisations in the continuation of their role as information providers, generally free and open to all carers in a flexible way;
4. Training developed by Civil Society Organisations, specifically targeted at female carers at a disadvantage on the labour market, with the view to improve their situation, characterised by intense support and the willingness to provide certification.

Contents and pedagogical approaches may differ sensibly from one initiative to the other. However, stakeholders all agree on the need to develop some categories of competence in particular: health-specific skills related to emergency situations and illness management, transversal care competencies including communication, forward planning and decision making; and training to help carers manage their own health condition.

## What works best and why?

Building on the literature and exchange of experience, Eurocarers has identified the following learnings regarding the design of a successful training pathway.

- Training is most efficient when personalised and adapted to the specific profile, needs and preferences of the carer;
- Co-design and participative approaches are needed to ensure that the needs and preferences of carers are actually met and training is taken up;
- Embedding training in a package of various support services (awareness raising, counselling, peer network, respite care) can help overcome obstacles and reach out to carers;
- Some active pedagogical approaches (multi-component training, including group work, online support, active training on skills, information, support,

etc.) can be an efficient approach for specific target groups;

- Combining online (for accessibility) and face-to-face training seems to be the best approach. The use of online features can be extended to carers who may not be very familiar with this tool, provided that technological support is offered to them;
- Enshrining training in a human rights approach is a prerequisite for ethical reasons but has also proved an efficient tactic, especially in relation to supporting active living.

## How can the European Union support progress in this area?

In 2014, the European Commission and the Social Protection Committee acknowledged the need to recognise the contribution of informal carers and the need to support them efficiently through financial and in-kind support including training. While supporting informal carers as part of the organisation of long term care system remains the prerogative of EU Member States, the European Union can provide convincing incentives and lead the way towards a carer-friendly society, notably through:

- Policy guidance, including policy recommendations, peer exchanges, promotion of good practices, monitoring based on targets and indicators;
- Support to transnational projects in the areas of training and education aimed at informal carers (through the Erasmus+ programme and others); and
- Support training programmes targeted at informal carers as a group at particular risk on the labour market through the European Structural and Investment Funds, notably through the European Social Funds.





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