



**Observatory for  
Sociopolitical Developments  
in Europe**

# **Counselling services for family carers in Europe**

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## Abstract

This working paper provides an overview over counselling services and counselling structures in the field of age and care in the EU member states Sweden, Austria, France and Scotland (as part of the United Kingdom). The research focuses on measures and offers for the target group of 'family carers'. There is a short introduction to the care system of each individual country as well as one example for good practices. Following that, the working paper is structured alongside to the following types of counselling: first, the provision of information and (psychosocial) counselling and, second, training and education offers for family carers. The offers and measures aim at relief for the carers by providing them with needs-oriented information and counselling as well as by strengthening their competences.

Overall, the following aspects can be highlighted:

- Supporting family carers is part of policy-making in all four countries.
- There is a vast range of information, counselling and training services.
- The existing services are highly diversified and fragmented across different political levels and different stakeholders/actors.
- Civil society groups, authorities/institutions and self-help organisations play an important role in providing such services.
- In Scotland and Sweden, municipalities are required by law to provide counselling and support for family carers.
- In Austria, the nationwide services of home visits and family carer interviews stand out.
- In France, the platforms for support and relief as well as the CLIC contact points constitute important counselling structures.
- There are hardly any significant digital service offers.
- Dominating in the field of training are the – usually free – service offers of the self-help organisations and welfare associations.
- Central networking and coordination structures are mostly lacking.

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# 1 Introduction

## The role of informal care work

80 percent of care work in Europe continues to be performed by informal carers<sup>1</sup>. These carers thus constitute the backbone of the European care systems. Dependent persons often favour being cared for at home and by a close person (Hoffmann & Rodrigues, 2010). In the coming decades, the number of elderly people in need of care will continue to increase. Reasons for this are the generally growing number of elderly people as well as the increase in average life expectancy. With the increasing numbers of people in need of care, the demand for long-term care work, and particularly for home-care, will rise as well. The growing amount of elderly people who are in need of care and support is mismatched by a decreasing amount of people of working age. This means that the number of potential (professional) carers decreases, too. Currently, there are four persons of working age for each person aged 65 years or above. In 2050, this ratio will have shrunk to two persons of working age (Genet et al., 2013). In addition to this development, urbanisation, the increase in female employment and the greater spatial distances between the generations will also lead to gaps in care. These changes in need and societal circumstances call for new concepts and services in the health and social sectors. Safeguarding family care capacities is thus of particular importance (Colombo et al., 2011).

The group of family carers is diverse regarding their age, relationship with the person in need of care and their employment. On the one hand, about 40 percent of informal carers in the European Union are “working carers”, meaning they have a (gainful) employment besides the care work. On the other hand, there is a major part of family carers who are considered part of a vulnerable group with low integration into the labour market, higher risk of poverty and higher susceptibility to mental diseases. Women account for about two thirds of informal carers – they are mostly partners/spouses or daughters (in law) of the person in need (Hoffmann & Rodrigues, 2010).

## Counselling services for family carers

Caring for someone is a challenging mental and physical activity that can burden the health and psyche of carers if no adequate support is offered. Counselling of family carers can make an important contribution to protection against overload, burnout and possibly aggressive behaviour (Colombo et al., 2011).

The [European Charter for Family Carers](#) states that family carers should be informed about their rights and obligations. Moreover, they should have access to all information that could support them in their role as carers. This also includes access to special training programmes and courses designed to improve family carers' knowledge of needs, support services and awareness of the challenges of care work. The charter calls in particular on public authorities to establish comprehensive training for family carers (COFACE, 2017).

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<sup>1</sup> In this working paper, the term “family carer” is used meaning informal carers in the immediate vicinity of the family of the person in need of care.

In practice, focus is put on counselling and information services, especially for family carers. Counselling issues are, among others: financial benefits, organisation of care, relief from care, quality of care, preventing health problems, adaptation of living spaces, aid and practical care. Counselling is an individual support service and is to be adjusted to the needs of the people in need of care as well as their (caring) relatives. It serves to ensure and organise good caring practices, self-determined decisions, prevention of health problems of relatives, and it is to determine potential support services. Counselling is thus not only a source of information, but also aims to develop and implement good and stable care conditions at home (ZQP, 2016).

### **Aims and contents of this working paper**

This working paper describes counselling services and counselling structures in the field of age and care in the EU member states Sweden, Austria, France and Scotland (as part of the United Kingdom). This selection of countries was determined based on the preparatory work<sup>2</sup> performed by the observatory<sup>3</sup> as well as on expert interviews. The existence of particularly progressive and expanded care counselling and/or innovative structures was used as selection criterium.

On EU-level, France, Austria and Scotland are countries with a slightly above-average importance of informal care. Sweden has a highly developed public care system. Informal care is therefore rather less widespread than on EU-average. This holds true for both the number of informal carers as well as the scope of care (see fig. 1). In Sweden, there are not only less informal carers than in France, but they also allocate less hours for care work. Whereas in France three quarters of all informal carers provide care work on a daily basis, this is true for less than two thirds of informal carers in Sweden (OECD, 2015).

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<sup>2</sup> Reinschmidt, L. (2018): [Reconciling Work and Care. Experiences from Different European Countries](#). Documentation of the European Expert Meeting on 4th/5th September 2017 in Berlin. Observatory for Sociopolitical Developments in Europe.

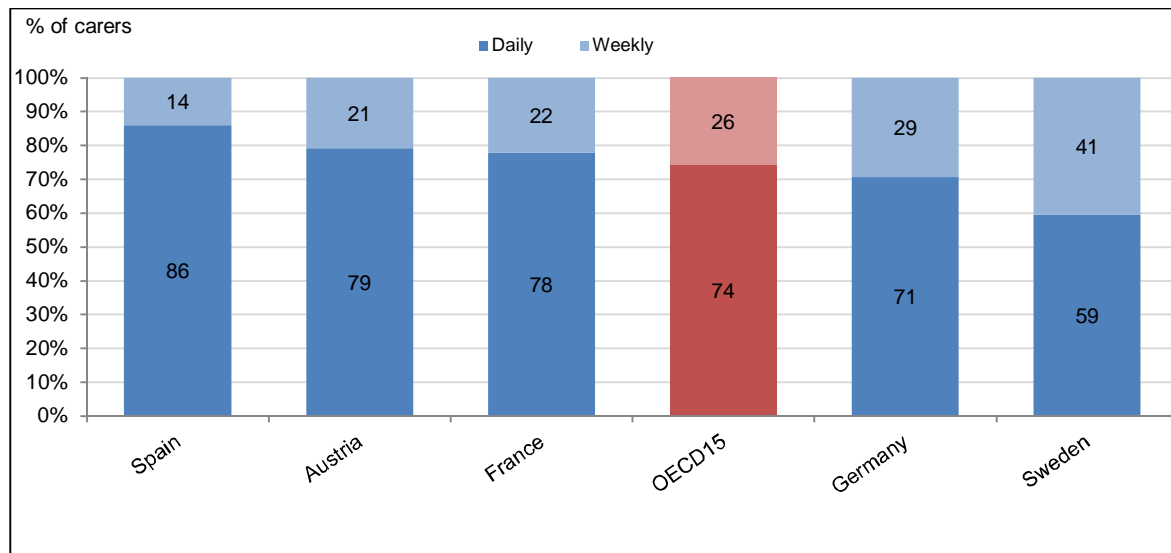
<sup>3</sup> Counselling is one aspect of support for family carers. The Observatory has already published several publications on the compatibility of care and occupational work as well as exemption models for family carers in home care, which can be accessed online:

Reinschmidt, L.; Pieper, J. (2017). [How Do European Countries Support Family Carers? A Look at Worklife Balance Policies in Germany, Austria and Belgium](#). Newsletter No. 1/2017;

Reich, N.; Reinschmidt, L.; Hoyer, S. (2017). [\(Wie\) Kann häusliche Pflege im Angehörigenkreis aufgeteilt werden? Freistellungen und finanzielle Leistungen für die häusliche Pflege in ausgewählten europäischen Staaten](#). Study.

Hoyer, S.; Reich, N. (2016). [Leave and financial support for family caregivers in EU member states](#). Report.

Reinschmidt, L. (2014). [Care Leave Models: Comparison of Leave Models for Reconciling Care and Work in Germany, Austria, Belgium and Sweden](#). Expertise.



**Figure 1: Share of care that is provided by informal carers** Source: OECD, 2015. Revised illustration.

This working paper is divided into chapters describing the single countries. These chapters are structured according to the types of counselling. The following types of counselling in the field of age and care have been identified in the individual countries:

- **Information and counselling:** Providing information on, among other issues, available social services, contact points for counselling, including counselling on social law regarding benefits in kind and cash benefits. This also includes psycho-social counselling that is to reduce the burdens and support a good handling of the role of carers.
- **Training** (courses, training offers): Carers are trained in the areas of occupation, nutrition, personal hygiene, mobility and support aids etc. with the aim of strengthening their skills.

According to a classification of support measures for informal carers in Europe, these types of counselling are specific and direct measures that use a cognitive approach (Triantafillou et al., 2010: 9).

In a next step, the structure of services is assessed. This includes in particular the dimensions “level” of the counselling services (i.e. national, regional, local) as well as the “service providers” or “competence” of the services (private, public, non-profit, interest/advocacy groups). Particularly innovative or outstanding services are presented as “examples of good practices”.

In addition to the various forms of counselling, the research also concentrates on existing networks and coordination of counselling services, e.g. in the form of coordination offices.

This working paper aims to provide an overview on the different counselling structures in the selected countries. The working paper does not aim to provide a complete presentation of all existing counselling services in the four countries.

## 2 Scotland

### 2.1 Short introduction to the care system

Scotland has a publicly financed healthcare system, named *NHS Scotland*<sup>4</sup>. Health and social policy as well as funding are the responsibility of the Scottish government's Health and Social Care Directorates. Between 2008/09 and 2016/17, the Scottish government has allocated close to 39 million pounds for direct counselling of family carers and Young Carers to the NHS Boards. These funds contribute, among other things, to the financing of care centres around Scotland offering information and counselling as well as other services.

In Scotland, there is a national strategy for carers ([National strategy for carers 2010-2015](#)) in which various measures on the subject of counselling have been enshrined. On regional level, there is a [strategy](#) (2013-2018) in the county of Lanarkshire aiming at the needs of and support for family carers.

On 1st April 2018, the Carers Act ([Carers Act 2016](#)) entered into force. The act is to support the health and well-being of carers. Among other measures, it specifies that all local public authorities must set up, maintain or safeguard the presence of an office for information and counselling services for carers.

The local authorities are legally required to assess the individual needs and support family carers of all age groups. However, local authorities have discretionary powers with regard to the levels and types of services they finance. Therefore, services may vary in terms of scope. The entitlement to an assessment of the specific individual needs of carers is to be put into practice by the local council's social care departments. There, the family carer receives an appointment with a social worker for the [assessment interview](#). These interviews aim to facilitate the access to support as well as better networking and interlinking between support services.

Those measures on the level of the Scottish national government reflect recognition of the role of informal carers.

The political support measures for carers in Scotland are also strongly influenced by the self-help and representation of the interests of family carers. Self-organisation and representation of family carers has a long tradition in Scotland. Such organisations partially take on counselling tasks for the public care system as well. The lobbying activities of the Alzheimer's disease organisations are particularly strong.<sup>5</sup>

Since 2012, Carers Scotland has been organising an annual Carers Parliament for carers from all over Scotland on behalf of the Scottish Government and in partnership with national carers' organisations. The Carers Parliament is a forum offering family carers the opportunity to discuss their experiences and needs jointly with ministers and other political decision-makers.

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<sup>4</sup> NHS is the abbreviation for "National Health Service".

<sup>5</sup> Amongst others, there is a "[Charter of Rights for People with Dementia and their Carers in Scotland](#)".

## 2.2 Information and counselling services

On national level, there is the online platform [Care Information Scotland](#) (CIS), which was launched by the Scottish government in 2010. CIS offers help and counselling via telephone and chat. The website offers information on various topics around the field of care. CIS also lists contact centres and information on local services and offers which can be passed on if required. The platform is maintained by NHS 24. The government's website [NHS inform](#) provides information on access to health and care service providers in Scotland. This also includes information on care services, rights and support.

All local councils' social care departments in Scotland offer services and partially also contact centres for information and counselling. The services of the single councils can be accessed via the website of [Care Information Scotland](#). These offices are also responsible for the above-mentioned assessment of carers' needs (see 2.1).

With regards to the third sector and self-help, the following service providers are particularly noteworthy:

[Carers Scotland](#) offers counselling, information, support and training for carers. The organisation has a hotline for carers but also offers contact via email. Moreover, an online forum has been established in which carers can share their experiences, counsel each other and connect.

[Carers Trust Scotland](#) offers counselling in the fields of finance and legal rights, support in caring leave and leave of absence, reconciliation of care and work as well as support services. The organisation also offers a database to search for service offers. Carers Trust Scotland cooperates with a network of independent Carers' Centres in all of Scotland in order to improve support, services and recognition of carers in the Scottish counties.

[Carers' Centres](#) are independent charities that provide local support, counselling and information on issues like services/benefits, relief, support and assistance for family carers. Emotional support by trained staff is offered as well. The centres also offer (free-time) activities and leisure from care work for family carers. The [MECOPP Carers' Centre](#) in Edinburgh provides multi-lingual information and counselling for ethnic minorities. Another good example is the VOCAL Carers' Centre (see 2.4).

## 2.3 Training

Training for carers was included in the national strategy for caregivers and supported with concrete measures and financial resources<sup>6</sup>. It is also included in the new Carers Act 2016. There are numerous trainings and courses to support family carers in their role as well as to train them in handling the care work and providing knowledge on the diseases or disability.

Many of the Carers Centres, but also self-help organisations, offer trainings free of costs. Carers Scotland provides trainings and e-learning courses which can be completed online.

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<sup>6</sup> In the years 2010/11, the Scottish government has allocated 281.000 £ to support and provide trainings for carers.



The [Open University](#) offers courses free of charge as well, some of which focus on the reconciliation of care and work. VOCAL (see 2.4) also provides free trainings.

## 2.4 Example: Good practices

### **Good Practices: Voice of Carers Across Lothian (VOCAL): an innovative approach on local level**

- VOCAL is a contact point in the county of Midlothian and in Edinburgh, offering counselling and the development of a support plan with each carer individually. Besides training, information and counselling on legal issues and services, this can also include a referral to the VOCAL Carers Counselling Service.
- The Carers Counselling Service was developed by VOCAL in the year 2000.
- The offer includes a combination of counselling and psychotherapy.
- Contact can be established via telephone, email or a personal visit by the counsellors at home or close to the place of residence.
- The aim is to reduce the emotional stress and impact of informal care, to understand and reflect on one's own role within the care relationship and to learn to handle and cope well with one's own feelings.
- The services are coordinated by experienced personnel.
- The qualified counsellors have completed professional trainings and offer at least three counselling sessions a week.
- The costs for these sessions are calculated depending on the individual circumstances of the carer.
- More [information](#).

## 2.5 Networking and coordination of services

The [Coalition of Carers in Scotland](#) (COCIS) is a network of more than 80 autonomous local interest groups, centres and projects. They inform and support each other mutually. The members of the coalition meet every three months to share information and discuss problems.

Carers Trust Scotland cooperates with a network of independent Carers' Centres in all of Scotland in order to improve support and services in all Scottish counties (see also 2.2).

Moreover, the Scottish Young Carers Service Alliance has been founded by Carers Trust Scotland. This alliance comprises a network of organisations supporting Young Carers and providing information. The alliance also advocates for the interests of Young Carers in national policy-making and thus aims to ensure that the needs of Young Carers are recognised.

## 3 Sweden

### 3.1 Short introduction to the care system

Formal care is the backbone of the Swedish care system. This can be traced back to the establishment of the welfare system in the post-war period: The citizens were granted a high degree of individual independence from the family; areas of responsibility that used to lie with the family before the creation of the welfare state were then transferred to the state level. However, since the mid-1990s, family carers have returned to the focus of policymakers and civil society. Johansson et al. speak of a “re-discovery” of the family in elderly care. Informal care is an important part of long-time care work (Johansson et al., 2011).

With the “Ädel reform” in 1992, the local municipalities became responsible for inpatient long-term care and care for the elderly. The reform aimed at positioning medical and social services on one level. As there was a lack of care capacities, hospitals were overburdened with patients who did not require medical care. Since the municipalities had to reimburse the costs for these hospital stays to the regional authorities after implementation of the reform, the reform was at the same time an incentive for the expansion of care facilities. In 1994, the municipalities took over care responsibilities for persons with disabilities; and for persons with mental diseases as of 1995. With these three reforms, about 20 percent of healthcare spending on regional level were transferred to the municipal level (Gerlinger & Reiter, 2014).

The responsibility for the planning of care services is shared between the national, district and local level. The major share of care-related services is borne by the municipalities. The Social Services Act of 2009 obliges municipalities to offer support services for family carers. Regarding the specific implementation, types and standards of services, the municipalities enjoy far-reaching autonomy. This autonomy leads to major differences in the design and quality of support services, though (Fukushima et al., 2010). In the end, however, this obligation has led to a situation in which almost all municipalities provide a wide range of services for informal carers. Many municipalities also offer dialogue opportunities for family carers. The obligatory offering of counselling by the municipalities has been financed by the national government by means of start-up financing. Today, the municipalities have to finance their services themselves (Reinschmidt, 2018).

In Sweden, care is primarily understood as a task performed by the public sector. Public services and providers play a major role in Sweden. However, since the late 1990s, attempts have been made to involve welfare organisations – that were previously mostly active in the fields of culture and sports – to a greater extent in the provision of social services (Jegermalm, 2005).

### 3.2 Information and counselling services

The National Council for Health and Social Affairs, through the Ministry of Health and Social Affairs, has in 2008 tasked the Swedish Family Care Competence Centre ([Nationellt Kompetenscentrum Anhöriga](#)) with the following tasks: Research and transfer of scientific results into practice, information, public attention for family carers, support and advice with

technical expertise to municipalities, districts and private providers of health and care services. The work of the competence centre is dedicated to all carers – independent of their age and the diseases or disability of the person in need of care. In particularly complex cases, the Competence Centre also offers direct counselling for family carers.

As a basic service, most communities offer direct support for family carers. This can include information, counselling as well as short-term care at home. Local support centres also serve as contact points for informal carers and offer information and counselling by professional care workers.

The *anhörig konsulenter* “family carer advisors” (see 3.4) play a major role in counselling informal carers in Sweden. In 80 percent of the 290 municipalities, there is now at least one full-time employee developing support services for carers (mainly coordination of public services and the civil society sector), providing information and offering psychosocial support. The family carer advisors visit carers at their home and offer emotional support. They also inform and give advice on existing services and additional services offered by the municipality.

“A good place” (*En bra plats*) is an online forum for family carers which is coordinated by the family carer advisors of the municipalities. By now, this internet-based service is available in 29 municipalities.

The Family Support Portal (*Anhörigstödsportalen*) by the municipality of Gävle offers online support for working carers in order to improve the reconciliation of work and care. The portal offers counselling via email and an online portal on which family members can connect and also contact employees of the municipality that can help in coordinating support services.

With regards to the third sector, there are for instance Carers Sweden and the Swedish Dementia Association offering helplines and internet-based information and counselling. They also have services enabling peer-to-peer exchange between affected persons.

### 3.3 Training

In Sweden, there are various temporary courses on different topics, often aimed at relatives of people with a particular disease such as stroke, dementia and diabetes, offered by the health sector. In some municipalities, there are also courses and trainings focusing on strengthening the self-confidence. Care and patient organisations offer a range of different trainings for family carers both in person as well as online (Eurocarers, 2016: 17).

**ACTION** (*Assisting Carers Using Telematics Interventions to Meet Older People’s Needs*) is an IT<sup>7</sup>-based service for elderly people living at home but being dependent on support. ACTION offers a range of internet-based pedagogical care programmes for carers. ACTION enables direct contact to other users via a video-telephone-installation at home as well as to medical professionals via a call centre. At the start, the user is trained in using the computer and a special software tool. The multimedia information and training programmes cover,

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<sup>7</sup> IT is an abbreviation for information technology.

among others, the following topics: Care in daily life, nutrition: food and drink, dementia<sup>8</sup>, end-of-life care, available support services, aids, relaxation and physical training. The aim is to provide elderly people and their relatives with up-to-date information on care that helps them making their daily lives easier and more comfortable. The pedagogical approach is based on an empowerment model aiming to support family carers and elderly people living at home in gaining control over their care situation by providing relevant training, information and support. ACTION is a project financed by the European Union (Eurocarers, 2016: 27ff).

Another example from the field of information and communication technology (ICT) is Apps for Carers ([A4C](#)). This is a two-year project funded by the European Commission under the Erasmus+ programme. The coordination of the project is done by Linnaeus University Sweden. The project's objective is to contribute to the well-being of family carers by offering mobile solutions and applications.

A study by Blusi et al. in the field of internet-based support for family carers has shown that the use of ICT services contributes to competence building and helps in regaining or promoting a sense of security and independence (Blusi et al., 2013).

### 3.4 Example: Good practices

#### **Good Practices: family carer advisors (*anhörig konsulenter*)**

- Family carer advisors visit the family carers at their homes.
- Tasks: providing emotional support, counselling and information about existing services and offering municipal support programmes, but also direct referral to other services, offering psychosocial support and developing support services for carers.
- The family carer advisors have a networking and coordinating function for public and private providers of social services and counselling services.
- In about 80 percent of all municipalities, there is at least one full-time family carer advisors.
- Family carer advisors are employed by the municipalities.
- Approximately one third of all municipalities work with a systematic assessment in order to identify the needs of carers and to provide support in the best possible way. The offered support is evaluated.

### 3.5 Networking and coordination of services

In general, the coordination of services is performed on municipal level, see family carer advisors under 3.4.

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<sup>8</sup> For people with dementia and their relatives, there is a specific programme within ACTION, named "Living with Dementia".

An innovative practice are the [Blended Learning Networks](#) (BLN). These networks aim to enable elderly people, their families and service providers as well as municipality officials to share their knowledge and experiences, to learn from each other and to include carers in the development of counselling services as well as to raise awareness for this issue. A BLN is a heterogeneous network in which people with different backgrounds and experiences have a common interest and work together to achieve the common goal of improving care for elderly people. The regular meetings of the networks take place with focus on various topics and are comprehensively documented to ensure that these documentations become available as a collection of teaching and learning materials. The networks are coordinated by the Swedish Family Care Competence Centre. Since the start of the project in 2008, more than 150 of such networks have been established. BLNs were initially created in order to support municipalities in implementing ACTION (see 3.3) (Hanson et al., 2011).

## 4 Austria

### 4.1 Short introduction to the care system

Already in the early 1990s – and thus very early in comparison with other European states - Austria started looking for political solutions for its ageing population. For instance, there has been a care allowance designed to promote family and outpatient care since 1993. This allowance is to empower people in need of care to decide on their own about how to use this money and for which kind of care service (Reich et al., 2017).

One Austrian specificity is the 24-hour care system. In this system, the care of a person in need in their own home by a qualified care worker is supported by the state. The support allowance ranges between 275 and 1,100 euro and is independent of the person in need's income – just as the care allowance (ibid.).

This instrument already indicates that outpatient care plays an important role in Austria: The majority of people in need of care are being cared for at their homes. Informal care plays a particularly important role here. In 2013, 59 percent of all recipients of care allowance were cared for by family members or friends alone; a further 22 percent received a combination of both informal and professional care support (Fink, 2016: 5).

In Austria, federal government and federal states are jointly responsible for measures to support people in need of care. Generally speaking, the federal government is responsible for the care allowance, whereas the federal states are obliged to provide care services. There are striking regional differences with regard to counselling. The development and expansion of these counselling services vary from region to region. On the one hand, providers of support and care services are active in this field. On the other hand, there is also care counselling provided on state, district and social level (the so-called "Sprengel")<sup>9</sup>.

### 4.2 Information and counselling services

Counselling services are offered on federal, state and municipal level and can differ vastly between the single states and municipalities.

A special feature of the Austrian age and care counselling are *Hausbesuche* (home visits) by care staff to recipients of care allowance. These visits were implemented within the framework of the work programme (2013-2018) of the Austrian Federal Government with the goal of "being cared for independently at home". This included an "expansion of home visits to recipients of care allowance in order to counsel family carers". The home visit is intended to provide information, counselling and support to recipients of care allowance and/or family carers. As a follow-up to the home visits, *Angehörigengespräche* (family carer interviews) with

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<sup>9</sup> The Social- and Health-"Sprengel" is a territorial and organisational unit comprising a catchment area precisely defined by the state, in which a uniformly defined spectrum of basic social and health care services is offered. In terms of organisation, these depend on different providers. The basic services that are provided by all social "Sprengels" are: financial social assistance, home care and basic social and educational support. From: Gerhard Mair: Die Sozialdienste.

family carers who have indicated psychological stress due to the care situation take place, if necessary. The aim of both these services is to ensure the quality of home care and to gain an insight into the care situation (see details under 4.4).

Telephone counselling on federal level is provided by the [BürgerInnenservice](#) (citizen service) of the Federal Ministry Labour, Social Affairs, Health and Consumer Protection (BMASK). Focus is put on general social issues as well as care and support. The service was formerly known as “Helpline”.

The respective online platform of the BMASK ([pflagedaheim.at](http://pflagedaheim.at)) serves as an information hub for persons in need of care and family carers. It offers information on care and nursing homes, provides support for family carers, presents and explains 24-hour care, contains information on dementia and presents information on financial benefits, relief offers, self-help groups and training courses. Information is also given by the [information service of the Ministry for Social Affairs](#). Here, people in need of care and their relatives can get information on both mobile social services as well as care and nursing homes.

Care counselling with regards to psychosocial support in Austria is for the most part performed by the association free welfare. The Red Cross, for instance, offers [psychosocial counselling](#) on the issues of care practices and social law, addressing family carers, persons in need of care and professional carers alike. A fee of 15 euros has to be paid for the consultation.

Other non-governmental organisations provide counselling and information points as well, among them for instance the [Pensionistenverband Österreichs](#) (Pensioneer Association Austria) which operates as information point for issues regarding care and support. Local and district groups exist nationwide. Besides counselling, the association also offers educational, cultural, leisure and sports activities. An example of offers at state level is the *Kuratorium Wiener Pensionisten-Wohnhäuser* (board of trustees of Viennese pensioners' residences). The board is a provider of inpatient care and pensioners' clubs. Far-reaching [information and counselling services for family carers](#) are provided at their „Häuser zum Leben“ (Houses for Living).

The [Hilfswerk Österreich](#) (Relief Organisation Austria) is one of the largest private providers of social and health services, providing information and counselling in addition to concrete services. Besides the federal office, there are seven state branches with respective additional district offices.

The [Fonds Soziales Wien](#) (Vienna Social Fund, FSW) is an enterprise in the health and social sector which also leads the Social Assistance Fund of the Mayor of Vienna. The offer includes services in care and support, assistance for persons with disabilities, support for homeless persons as well as basic care for refugees. FSW also offers direct information for family carers via a customer hotline, as well as advice in a total of six counselling centres in Vienna.

The website of the [Interessengemeinschaft pflegender Angehöriger](#) (interest group of family carers) offers, among other things, information on legal and financial questions, aids, self-help groups, social services and nursing homes. This information is partially backed with further

links. The interest group focuses in particular on improving the living circumstances for family carers in all of Austria.

The description above underlines that the field of counselling is very fragmented on regional level. With regard to the formats, one can conclude that personal counselling is predominant. Digital services are limited to websites. Counselling via mobile applications appear to be non-existent. Tablet-based solutions for care are currently being prepared, but the development is still in its infancy.

### 4.3 Training

The free welfare provides trainings for everyday care to family carers on local and regional level. Among the service providers are the [Red Cross](#) and [Caritas](#), for instance.

The *Bundesarbeitsgemeinschaft Freie Wohlfahrt* (Federal Work Group for Free Welfare) provides [culturally sensitive care information for migrants](#). In this way, it responds to the growing need for support of people with a migrant background by providing professional care services. The courses are geared particularly towards women as they continue to provide the major part of care work and therefore have a specific need for counselling. However, one obstacle in combining care services and home caring by family members is the language barrier. The project aims at offering information and strengthen the care competences of family carers. There is close cooperation with migrants' associations in terms of organisation and contents of the courses. The courses provide information on the term need for care, the difference between diseases and need for care, benefits in kind and financial support as well as local services. The courses are offered in Turkish, Albanian and Serbo-Croatian languages. The project is supported by the BMASK.

The [national dementia strategy](#) (2015) recommends measures with the aim of “strengthening the competences of family carers”, which entails the establishment and expansion of a nationwide range of low-threshold, cost-effective information and training services for family carers of people with dementia.

### 4.4 Example: Good practices

#### **Good Practices: Home visits and family carer interviews**

- **Home visits** to people in need of care are performed by certified care professionals.
- The service is offered to recipients of care allowance.
- Home visits are done upon request and are free of charge.
- Aim: Information and counselling regarding the organisation of care as well as support; determining the actual, concrete care situation.
- Organised by the Austrian Farmers' Social Security Authority and the competence centre “Quality assurance in home care”, commissioned by the BMASK.
- Introduced as an instrument of quality control.



- In 2015, 94 percent of home visits included counselling on social services, aids, living conditions, care allowance, mobility or 24-hour care.
- By now, home visits have been made to about 50 percent of all recipients of care allowance.
- Family carers who have indicated at least one form of psychological stress during the home visit, are offered a **family carer interview**.
- Family carer interviews are conducted by trained psychologists and social workers.
- Aim: Reducing psychosocial burden, identification of resources in the family carers' environment in stressful situations, facilitation of access to support services.
- The home visits have been a nationwide programme since 2015. The family carer interviews were started in 2014 as a joint project by the BMAS, the *BAG Freie Wohlfahrt* (free welfare) and the Austrian Farmers' Social Security Authority. In 2016, the project was expanded and implemented nationwide.
- The federal programmes are offered nationwide and free of charge.
- More information: BMASK, 2016: 23-27.

#### 4.5 Networking and coordination of services

In Austria, there is no coordination and networking (or central contact and information points, for that matter) of counselling services at federal level. This is due to the federalist state structure which also shows its effects in care counselling.

The [\*Pflegedrehscheibe\*](#) (Care Hub) is a central contact and information point for issues related to care and support by the social welfare office in Graz. This hub cooperates with all local health and care providers as well as hospitals, social workers and self-help groups and brings these into contact with each other. The Care Hub describes itself as the first contact point of its kind in the state of Styria.

## 5 France

### 5.1 Short introduction to the care system

Since the beginning of the 2000s, public spending for long-term care has increased significantly in France. The development of social services for the elderly as well as for people with disabilities has taken on an important role in French policy-making, too. It can be assumed that this development has also contributed to a broader understanding and the establishment of support measures for family carers (Triantafillou et al., 2010: 40).

The share of informal carers in France is above OECD-average (OECD, 2015: 203).

The law on adapting to an ageing society ([\*Loi n°2015-1776 du 28 décembre 2015 relative à l'Adaptation de la Société au Vieillessement, ASV\*](#)) includes - in particular in chapter 3 (articles 51-54) - support for, relief of and strengthening of carers as well as expanding training services for carers. The definition of family carers laid down in this law also includes friends who regularly support the person in need of care in everyday activities and on an unprofessional basis.

There are currently three national plans and strategies by the French government which include components geared at family carers. These are: The Action Plan for the Development of Palliative Care and End-of-Life Care 2015-2018, the Neurodegenerative Diseases Action Plan 2014-2019, and the Cancer Action Plan 2014-2019.<sup>10</sup>

For the most part, measures such as the provision of information, training and discussion groups for family carers caring for people with dementia are provided. Dementia has in the past 20 years been established as an important topic in public and political discussions nationwide. Among other initiatives, France was the first European state (in 2001) to develop a national dementia strategy. Currently, however, measures are tending to go into the direction of strategies and measures aiming at all family carers.

To honour the work of family carers, there is a [national family carers' day](#) held in October every year.

### 5.2 Information and counselling services

There are numerous organisational arrangements in France offering information on help and support as well as counselling.

On national level, there is an [information portal](#) for greater autonomy for elderly people and their relatives (*Portail national d'information pour l'autonomie des personnes âgées et l'accompagnement de leurs proches*). This portal provides targeted

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<sup>10</sup> *Plan pour le développement des soins palliatifs et l'accompagnement en fin de vie 2015-2018*  
<http://www.spfv.fr/actualites/plan-national-2015-2018-pour>; *Plan maladies neurodégénératives 2014-2019*;  
[http://solidarites-sante.gouv.fr/IMG/pdf/Plan\\_maladies\\_neuro\\_degeneratives\\_def.pdf](http://solidarites-sante.gouv.fr/IMG/pdf/Plan_maladies_neuro_degeneratives_def.pdf); *Plan cancer 2014-2019*  
<http://www.e-cancer.fr/Expertises-et-publications/Catalogue-des-publications/Plan-Cancer-2014-2019>.

advice and links for family carers, showing them where to find counselling, information and support services. These services are offered on national level, but also on the regional level (*Départements*). Among other things, there are also direct prevention recommendations, frequently asked questions and answers, information on support services, search engines for care and nursing homes for relief or short-term care, and information on the reconciliation of care and work. The portal is maintained jointly by the Ministry for Solidarity and Health (*Ministère des Solidarités et de la Santé*) and the national care insurance fund (*Caisse nationale de solidarité pour l'autonomie; CNSA*)<sup>11</sup>.

The municipalities provide information and local addresses dealing with care and offer support in applying for care allowance via their communal social centres (*Centre Communal d'Action Sociale; CCAS*)<sup>12</sup>. The pension fund (*Caisse d'Assurance Retraite et de la Santé au Travail; CARSAT*), the social security insurance (*Mutualité Sociale Agricole; MSA*) and the retirement fund (*La caisse de retraite*) also provide information and counselling.

Local contact points are the Centres for Gerontological Information and Coordination (*Centre Local d'Information et de Coordination gérontologique*) in short CLIC (see chapter 5.4).

Another remarkable counselling structure are the platforms for support and relief (*Plateformes d'accompagnement et de répit*). These platforms were initially established as part of the National Dementia Strategy 2008-2012 (*Plan Alzheimer 2008-2012*) to support family carers who care for family members with loss of autonomy. Today, these platforms have been expanded and now provide support for all family carers, independent of the diseases of the person in need of care. There are currently around 170 platforms providing specific measures for family carers. Measure 28 of the strategy for neurodegenerative diseases (see footnote 10) sets the goal of establishing at least two platforms per Department by 2019. Further expansion and better configuration of these platforms is also enshrined in the 2015 Law on Adapting to an Ageing Society. The tasks of the platforms include information and counselling, in particular. Information that is to support family members in dealing with the diseases of their relatives leading to loss of autonomy is passed on via the platforms. Support for family carers – such as individual psychological support and counselling or group discussions for mutual support and exchange between families in the same situation – are provided. Services and solutions for relief and short-term care are sought together and also passed on to others. Moreover, leisure and cultural activities are offered as well. The platforms are mainly affiliated with an existing structure (nursing home, hospital, day care facility) and usually operate as non-profit organisations. In 2015, about 35 percent of these platforms were publicly sponsored. The

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<sup>11</sup> The CNSA was founded in 2005 and has been responsible for financing aid for elderly people with loss of autonomy and people with disabilities since January 2006. The *Allocation personnalisée d'Autonomie (ApA)* is an allowance that patients over 60 years of age can apply for through CNSA in order to finance professional or informal care services in their own homes (or a portion of their stay in a nursing home). Regarding care services, the ApA is the most commonly used service. It aims at ensuring equal treatment for the above-mentioned target group in France. The allowance fund has a budget of more than 25 billion euro.

<sup>12</sup> In towns with less than 1,500 inhabitants, the municipality's administration performs the tasks of the CCAS.

platforms aim to prevent health risks of family carers and reduce potential stress for them (Castel-Tallet et al., 2016).

The [Points Info Famille](#) (PIF) are contact points for families, offering up-to-date information and orientation on all situations in life (in the context of social counselling). The PIF have been financed publicly since 2004 and fall under the competence and responsibility of the Family Compensation Fund (*Caisse d'allocation familiales*; CAF).

The associations, self-help groups and carer organisations also provide a vast range of counselling and support services. The largest organisations are the [Association Française des Aidants](#); [France Alzheimer](#); [la maison des aidants](#) and [Génération Mouvement](#). The *Association Française des Aidants* (the French Association of Carers) has established the [Cafés des Aidants](#) (Cafés for carers). These are meeting places where affected people can share their experiences and receive further information. The meetings are assisted by a social worker and a psychologist. These professional counsellors support the relatives with information on financial support, contact points as well as national and local measures, for instance. Each meeting focuses on a specific main topic. There are about 130 *Cafés des Aidants* in France by now.

In addition to the contact points, there are various guidelines for family carers (*Guides pour les Aidants*). One example for this is the [Guide de l'aidant familial \(2016\)](#) which has been published by the Ministry for Solidarity and Health. This guideline explains the legal rights of family carers, but also lists services and contacts. Also worth mentioning is the [Guide de l'aidant familial \(2017\)](#) by *France Alzheimer* which provides specific information on the needs of relatives caring for people with dementia (and related diseases).

### 5.3 Training

In France, the national care insurance fund (CNSA) has since 2008 funded trainings for family carers on national level (Eurocarers, 2016: 19). There is a framework agreement between the *Association Française des Aidants* (French Association of Carers) and the CNSA, aiming to implement a training programme for family carers on national level between 2015 and 2018. Within the scope of the national plan, this framework agreement has also been established as a reaction to the challenges in dealing with Alzheimer's disease. It envisions a total of 143 partnerships with local care structures that are to adapt to and implement the [training programme](#). The courses comprise six modules of three hours each, four of which are optional. An evaluation of the first trial phase has confirmed positive effects on the lives of relatives who have completed this training (Eurocarers, 2016: 53).

A free [online training](#) is available since September 2017 as well. This online training is designed as an addition to the trainings under the national programme by the *Association Française des Aidants*. The family carers can thus choose whether they want to participate in the trainings only online, or attend on site.

There are further organisations offering free trainings for family carers, among them [France Alzheimer](#), [France Parkinson](#) and [Génération mouvement](#). The trainings provided by these organisations are in part also financed with means from the national care insurance fund

CNSA. Another online training for family carers that is free of charge is offered by [Savoir Être Aidant](#). It provides more than three hours of video material on six different topics. The programme is financed, amongst others, by the European Union's European Regional Development Fund.

#### 5.4 Example: Good practices

##### **Good Practices: Centre Local d'Information et de Coordination gérontologique (CLIC) – Centre for gerontological information and coordination**

- Also known as *point d'information local* (local information point).
- A central local information point providing information for elderly persons in need of care and their families.
- The CLIC provide services of all kinds on local level.
- Aim: providing information locally, listening, counselling and supporting, but also coordinating services and raising awareness about these services.
- Since 2000, there have been about 600 CLIC centres and 120 networks.
- There is at least one (usually more) centre per Department.
- The contact points in the single regions can be found via a [search engine](#).
- The services provided by the contact points differ (different levels, building on each other consecutively): 1) information on locally available services and solutions; 2) the situation and needs of the person in need and their relatives are assessed, and an individual assistance plan is drawn up; 3) the implementation of the personal assistance plan is coordinated with the help of external actors.

#### 5.5 Networking and coordination of services

The *Association Nationale des Coordinateurs et Coordinations Locales* ([ANCCLIC](#)) is a national association of coordinators and local coordination points of the CLIC-centres (see chapter 5.4). The ANCCLIC-association is comprised of 120 networks. In 2008, the association was initially founded for the CLIC-centres in order to meet the demand for exchange and improved quality. Since 2014, it is open for all stakeholders in the field of information and coordination, aiming for an organised, institutionalised and independent professional cooperation. The aims are, among others: Promoting cooperation between the various actors and service providers in their coordination and networking, but also facilitating the exchange and the development of joint actions aiming to maintain the autonomy of the single affected persons and improving their quality of life.

On structural level, the aim is to improve the quality and the general provisions by CLIC, MAIA<sup>13</sup> and other services.

The platforms for support and relief (*Plateformes d'accompagnement et de répit*), which have already been described in chapter 5.2, each offer local networking activities with providers of various care services with the aim of being able to provide good care and advice to relatives.

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<sup>13</sup> Initially, the MAIA (*maisons pour l'autonomie et l'intégration des malades Alzheimer*) were a measure taken under the National Alzheimer's Strategy (2008-2012). It was a model aiming for improved integration and a self-determined life for people suffering from Alzheimer's disease. In the current strategy 2014-2019, the MAIA have been renamed to *méthode d'action pour l'intégration des services d'aides et de soins dans le champ de l'Autonomie* (MAIA) - an action plan to integrate the provision and care services for a self-determined life. The change in name is to underline that the MAIA are no longer specialised on dementia patients only. It is thus not the institution that has been changed, but rather its approach. MAIA is not an organisation or agency in that sense, but an organisational model with a holistic approach adapted to the local level. It is a method for holistic cooperation between all involved stakeholders and for the integration of all services.

## 6 Comparison and Conclusion

This working paper gives an overview on the care environment in the field of old age and care in four European countries. Providing support for family carers is part of policy-making in all four countries and consists of a wide range of information, counselling and training services. Even though this working paper reflects merely a part of the existing service environment in each of the four analysed countries, it already shows how broadly diversified the existing services are.

In all surveyed countries, there is fragmentation in the services provided – be it on different political levels or also between the different stakeholders and actors. Together with authorities and self-help organisations, civil society groups play an important role in providing such services.

In Scotland and Sweden, municipalities are required by law to provide counselling and support for family carers. However, this obligation does not include concrete requirements for the specific services offered. The implementation is left to the municipalities and thus varies broadly. In Scotland, family carers have the right to an assessment interview. The municipalities are obliged to offer such interviews. In Sweden, in contrast, the municipalities are free to choose which measures they want to take in order to support family carers. However, many municipalities also work with a model of family carer advisors.

In Austria, the nationwide services of home visits and family carer interviews stand out. The fact that outpatient care plays a major role in Austria is also underlined by the 24-hour care service system.

In France, the platforms for support and relief as well as the CLIC contact points and the ANCCLIC association constitute important counselling structures.

With regard to digital service offers, the research has shown that there are barely any innovative services. In Sweden, there are some ICT-offers in the field of training for family carers, for instance the internet-based programmes provided by ACTION.

The field of training is extremely fragmented as well. Dominating in this aspect are the usually free service offers by the self-help organisations and welfare associations. Some political strategies – such as the Austrian dementia strategy and the Scottish strategy for carers – hint at the strengthening of skills and the expansion of training offers as potential measures, and these are partially financially supported as well. As part of a French national strategy plan, there is currently a cooperation between the national care insurance fund (CNSA) and the association of carers aiming to further develop a training programme for informal carers at national level.

In Scotland, Austria and France, some official national internet platforms support carers by offering search engines to find contact points, nursing homes etc. Beyond that, there are only few noteworthy activities concerning networking or coordination at national level. In most cases, the coordination of services is performed on municipal level.

In many instances, services or measures are geared towards specific target groups, mostly family carers caring for people with dementia. This focus probably stems from the fact that the care of people with dementia is associated with particularly high burdens. It can thus be seen as an indicator of an urgent need for action. One assumption is that this specific focus on family carers caring for people with dementia in turn benefits all family carers, as this could bring more recognition, advice and support offers and generally lead to an increase in more diverse service offers.

Due to the fragmentation and multitude of service offers, it is on the one hand difficult for family carers to find their way through the vast range of services. On the other hand, there is potential to save costs arising from parallel offers and structures.

One central challenge is therefore the networking and interlinking of existing offers. Far-reaching networking and coordination points were rarely found, though. This is also important with regard to the visibility of service offers in the public sphere. Existing offers have to be made more widely known by “marketing” them better. Moreover, the specific target group should be reached more effectively. Family carers often do not consider themselves as this target group and thus sometimes fail to recognise the added value that such counselling offers can bring them.

The aim of good counselling is to focus on individual needs and to enable those seeking advice to shape their own lives as actively and independently as possible (empowerment). In addition to that, counselling should help in the organisation of daily care and contribute to the prevention of health problems of the person in need of care as well as of the family carers. Those seeking advice should – by means of counselling – be enabled to make informed decisions on how to deal with the need for care. Good counselling is a basis for good and stable home care.

In Germany, the counselling landscape is very diverse, too: counselling is provided by associations, care support points (*Pflegestützpunkte*), health and care insurance funds, care services and municipal contact points, among others. There is a legal right to free professional care counselling in Germany. This right is enshrined in the Social Security Code (SGB) XI<sup>14</sup>. However, according to the Centre for Quality in Care (*Zentrum für Qualität in der Pflege*), 60 percent of the population do not know about this legal entitlement. The diversity and multitude of offers in the counselling landscape is considered to be one reason for the lack of knowledge among the population (ZQP, 2017). This is an opportunity for action.

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<sup>14</sup> The SGB XI provides for: Right to information and counselling according to § 7, care counselling according to § 7a as well as care courses and individual home training according to § 45.



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