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Informal long-term care for erderly and frail persons

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Population aging is the main driver of growing demand for long-term care which results in increasing pressures on public finances. The informal care for elderly and frail persons produces many benefits and creates savings in the national budget. Nevertheless, little is known in Croatia about the problems faced by informal care providers. This Newsletter presents data on informal care coverage, indicates the available rights of informal care providers and recipients in Croatia, and proposes measures to improve the national system of informal care for elderly and frail persons based on examples from other EU Member States.

1 INTRODUCTION

Long-term care is a variety of services provided to persons with functional limitations (physical or cognitive), who are dependent on other people's assistance over a prolonged period of time. The assistance can include the performance of basic activities of daily living (eating, bathing, dressing, getting up from bed, toileting, etc.), or instrumental activities of daily living (shopping, doing the laundry, housekeeping, cooking, keeping track of finances, phoning, etc.). Long-term care can be formal (provided in institutions, such as homes for the elderly and frail, or outside institutions (e.g. in the form of an in-home assistance service, and informal (usually unpaid and provided within the family). Demand for long-term care heavily depends on age; in most OECD countries, every fifth long-term care user is under 65, while about half of the users are over 80 (OECD, 2011).

Although the obligation to care for their elderly and frail family members should not be imposed on citizens, such informal care has triple benefit. First, persons who need assistance prefer to be cared for by family members or friends. Secondly, care providers are supposed to feel good, because they provide assistance to the people they love. Thirdly, the availability of informal care considerably reduces government expenditures. The economic value of non-paid family work (house work, childcare and care for elderly and frail household members) in Europe is assessed at between 20% and 37% of Europe's GDP, depending on the assessment method used (Gianelli et al., 2010).

In Croatia, government has only a minor role in elderly care, with the family being the backbone of the long-term care system. According to Podgorelec and Klempić (2007), spouses are carers in most cases (more frequently females than males), followed by adult children (mostly daughters) and other family members and, finally, friends and neighbours. As little as about 2% of Croatian population over 65 find

accommodation in homes for the elderly and frail (MSPY, 2013), compared with the EU average of around 5%. The responsibility of the family for its elderly members is anchored in the Constitution of the Republic of Croatia (Article 64): „Children shall be obliged to take care of their elderly and infirm parents."

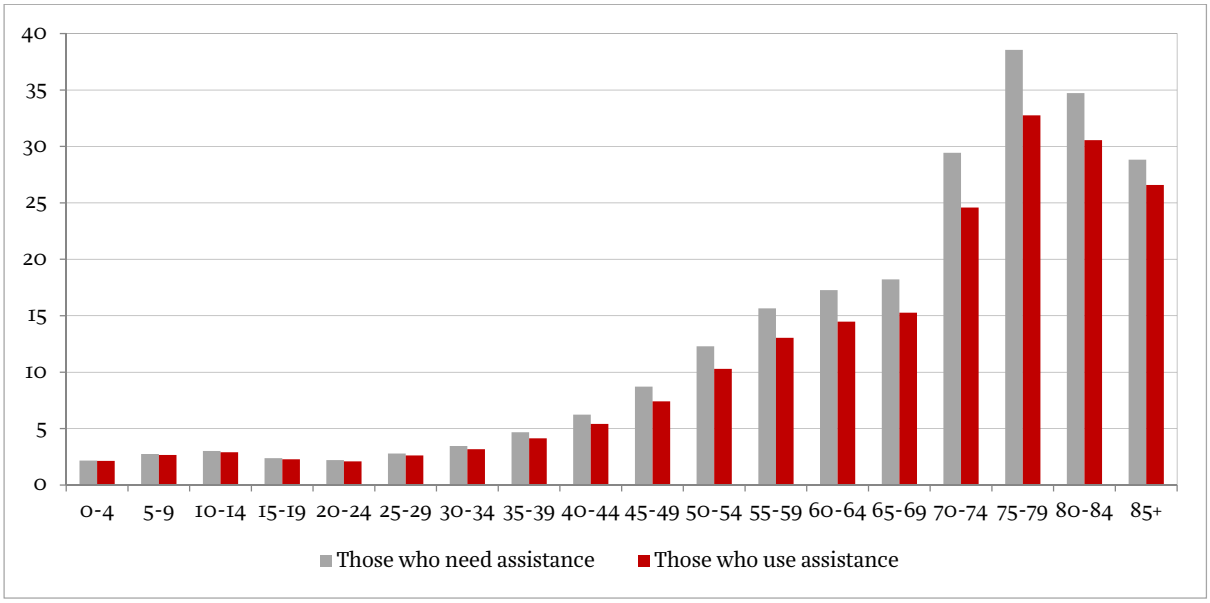
2 INFORMAL CARE COVERAGE

In OECD member countries, one in ten adults provides informal (usually unpaid) care to persons with physical limitations (OECD, 2011). The share of informal carers in total population ranges between 8% and 16% (two thirds of them are women). Over half of the cases relate to low-intensity care (provided for less than 10 hours per week), which prevails in Northern European countries, while in Southern Europe, over 30% of informal care is of high intensity (over 20 hours per week). In Spain, for example, intensive carers account for 50%. It is worth noting here that the share of elderly persons living with their children is slightly larger in the Mediterranean countries, compared with the northern EU Member States which report the lowest shares (Žganec et al., 2008). In OECD member countries, one in five persons aged over 50, suffering from one limitation of daily activities receives informal care, and this proportion doubles in the case of persons with two or more limitations.

According to the European Commission Report (EC, 2015), the scale of family care for the elderly is above the EU average: around 17 % of persons aged 35–49 reported having to care for their elderly family members at least several times a week. Despite a dearth of aggregate data on informal carers, more information should be available after the completion of the *Survey of Health, Ageing and Retirement in Europe* (SHARE) for Croatia which is currently under way. As shown by the European Commission's data (EC, 2015a), the number of functionally dependent persons in Croatia stood at 274 thousand in 2013, of which 16 thousand received institutional care, 17 thousand formal home care and 108 thousand were paid cash benefits. It can be assumed that the remaining 133 thousand persons received informal care, as did those with cash benefits. Consequently, the total number was 241 thousand. As suggested by the EC projections (baseline scenario), this number will increase by 20 thousand by 2060.

Graph 1

Persons with limitations on activities of daily living who need and use other person's assistance, by age groups (in thousands)



Source: CBS (2013).

According to the 2011 Census, which also included collecting data on the population with limitations on activities of daily living, there were around 760 thousand of such persons in total. Impairments were reported by 35% of population in the age group 45-65 and 59% in the age group 80-84 years (CBS, 2013). The need for assistance in the performance of activities of daily living was reported by 233 thousand inhabitants, 150 thousand of them were older than 65 years. Other person's assistance was used by 202 thousand persons, of which 130 thousand (about two thirds) were over 65. Graph 1 clearly shows that the need for assistance grows with age, and that most of the persons needing and using assistance belong to the age group 75-79. After that age, their number declines due to higher mortality. Among persons aged 65+, 70% are women, due to their greater longevity. By contrast, men using assistance predominate over women in all age groups up to 65 years.

3 SUPPORT TO INFORMAL CARERS

Research shows that there is scope for increasing the intensity of informal caregiving. But high-intensity caregiving (for over 20 hours a week) is associated with a reduction in labour supply: carers are less likely to find a job than non-caregivers. Moreover, employed carers work on average two hours less per week than non-carers and they more often work part-time. (OECD, 2011). Lower employment and shorter working hours are associated with a higher risk of poverty and increased prevalence of mental health problems among intensive carers, compared with non-caregivers, because caring for family members is stressful and demanding. This is particularly pronounced among carers living with care users. Moreover, caring for a family member can increase household expenses for heating, medicines, transport, medical care, etc. The difficulties faced by informal care providers suggest that government should find a way to support them. Now, what is the situation in Croatia?

3.1 CASH BENEFITS

In OECD countries, informal carers and/or care recipients normally receive cash benefits. In Croatia, benefits are paid to care recipients, as is the case in, e.g. Czech Republic, France, Italy, Poland and Spain. Article 57 of the Social Welfare Act (SWA) provides that a person who is unable to meet his/her basic needs and who therefore needs assistance in performing activities of daily living, has a right to an *assistance and care allowance*. However, this right cannot be exercised if the person:

- has concluded a lifelong support contract or a contract of support until death;
- owns another apartment or a house, in addition to that used for dwelling, which can be sold or rented for the purpose of providing the means to pay for assistance and care;
- owns business premises which he/she does not use for the performance of a registered business activity;
- received an average monthly income of over HRK 1,250 (for single persons), or HRK 1,000 (for household members) during the three months preceding the month in which the application had been filed;[1]
- can be recognized the assistance and care allowance pursuant to a special regulation;
- has a recognized right to a personal disability allowance; and
- has institutional accommodation.

[1] The amounts of HRK 1,250 and HRK 1,000 equal 250% and 200% respectively, of the base used for the calculation of other social welfare rights (HRK 500).

The right to an assistance and care allowance can be recognized in the full or a reduced amount, depending on the care intensity needed. The allowance amounts to HRK 500 or HRK 350[2]. In the case of a person with a serious disability, serious permanent changes in the health condition, or a blind, deaf or blind-deaf person, who is unable to live and work independently, the recognition of the right does not depend on the person's income and property status, but the allowance is paid in the full amount (HRK 500). The same applies to persons deprived of legal capacity, as well as to blind, deaf and blind-deaf persons, who are able to live and work independently, with the exception that they are entitled to a reduced amount of allowance.

The assistance and care allowance, recognized pursuant to the SWA, was received by 72,408 persons in 2014, with roughly half of them being older than 65 years (MSPY, 2014). Two thirds of the recipients received the full amount of allowance and one third a reduced amount. In 2014, budget resources allocated for assistance and care allowance pursuant to the SWA totalled HRK 407.7m (about HRK 470 per month, per person). Until 31 December 1998, the assistance and care allowance was regulated by the Pension Insurance Act. As at December 2014, there were 8,669 recipients of the allowance which amounted to HRK 783 on average per month (CPIA 2015). Government expenditures for the allowance recognized pursuant to the Pensions Insurance Act stood at HRK 86.1m in 2014.

If an allowance recipient stays in a healthcare or another institution for more than 15 days, the right to allowance is suspended. Exceptionally, a recipient of the assistance and care allowance pursuant to the SWA can also be entitled to in-home assistance for the satisfaction of certain needs relating to daily living, which cannot be satisfied by the family members. Generally, the right to this social service is not recognized to persons who can get assistance from their parents, spouses or children (Article 80 of the SWA); the service falls within the scope of formal home care.

Personal disability allowance (Article 54 of the SWA) is recognized to a person with a severe disability or serious permanent changes in the health condition, for the purpose of his/her participation in everyday community activities. The right to a personal disability allowance cannot be recognized to a person already entitled to the assistance and care allowance; other limitations on that right are very similar to those in the case of the assistance and care allowance. The personal disability allowance for a person without own income is paid in a monthly amount of HRK 1,250[3]. Where a person receives income from any source, the allowance is determined as the difference between the aforementioned amount and the average income received during the three months preceding the month in which the application had been filed[4]. In 2014, there were 23,740 recipients of personal disability allowance (MSPY, 2015), less than 1% of them being older than 65 years (MSPY, 2014). Budget resources allocated for this purpose in 2014 totalled HRK 354.8m (about HRK 1,245 per month, per person).

Croatian legislation does not provide for obtaining the status as a carer for elderly and frail persons, but only as a carer for children with developmental difficulties or disabled persons (Article 63 of the SWA), and disabled Croatian homeland war veterans (DCHWV) of category 1, i.e. disabled persons with 100% body impairments, who need assistance and care from other persons in their daily lives (Article 85 of the LRCHWV).* Carers have the right to compensation, healthcare and pension insurance rights, as well as rights in the case of unemployment as persons employed under special regulations. These rights are funded from the state budget. When it comes to children with developmental difficulties and disabled persons, the carer can be a parent or, exceptionally, other family members. The carers of DCHWVs can

[2] The amounts of HRK 500 and HRK 350 equal 100% and 70% respectively, of the base used for the calculation of other social welfare rights.

[3] The amount of HRK 1,250 equals 250% of the base used for the calculation of other social welfare rights (HRK 500).

[4] Income does not include the guaranteed minimum benefit, compensation of housing costs, pension up to the minimum pension earned for 40 years of service, orthopaedic allowance, means of support received by a child pursuant to the family relations regulations, scholarships received by pupils or students during the regular secondary or university education, and children's allowance.

* *Law on the Rights of Croatian Homeland War Veterans, translator's note.*

be family members (except children while attending school), unemployed persons, pensioners and foreigners. The selection criteria for a person eligible to provide assistance and care, as well as the manner of and procedure for exercising the rights are laid down by special regulations.[5]

In 2014, there were 3,279 persons with the parent-carer status and 69 persons with the status as carers. (MSPY, 2015). The net monthly compensation paid to a parent-carer or carer stood at HRK 2,500[6]. The budget allocation for this purpose amounted to HRK 137m (around HRK 3,410 gross (including mandatory contributions), per month, per person,). The number of carers of category 1 DCHWVs, stood at 437 on average, per month in 2013. The amount of allocated funding for this category was HRK 28.9m (about HRK 5,510 gross, per month, per person). The net wage of the carers equalled the personal disability allowance of a category 1 DCHWV. More information on the personal disability allowance and assistance and care allowance for DCHWVs (which are not mutually exclusive), pursuant to the LRCHWV, is given in Box 1.

Box 1 The rights of DCHWVs to assistance and care allowance and personal disability allowance

The right to assistance and care allowance is granted to DCWVs of category 1 and DCWVs of categories 2-4, who are impaired, regardless of their military disability, and whose impairments, together with the military disability, equals the impairment of a disabled person of category 1. The allowance amounts to around HRK 3,800 (100% of the personal disability allowance paid to a disabled person of category 1) for the first degree (DCWVs of categories 1-4 who are totally incapable of performing all activities of daily living and who need permanent assistance and care from other persons), or HRK 2,500 (66% of the personal disability allowance paid to a disabled person of category 1) for the second degree (other DCWVs). The entitlement conditions are laid down in Article 67 of the LRCHWV, and they basically relate only to the disability degree. Personal disability allowance is a fundamental right of a DCWV, arising from his/her body impairment, and it forms a basis for all other rights relating to body impairment. The allowance is determined according to a DCWV's disability category; the lowest category includes persons with a disability of 20%. The monthly amount of allowance paid to a disabled person of category 1 is equal to 115% of the fixed budget base for 2015 (HRK 3,326), i.e. HRK 3,825. The monthly amounts of allowance paid to disabled persons of groups 2-10 are determined as percentages of the first category disabled persons' allowance, as laid down in Article 66 of the LRCHWV.

Latest available data on DCWVs who exercise their rights pursuant to the LRCHWV relate to 2013 (Government of the RC, 2014). There were 822 DCWVs receiving other persons' assistance and care allowance, for which HRK 32.3m (about HRK 3,300 per month, per person) was allocated from the budget. On top of this, there were 27 Croatian peacetime military disabled persons who were allocated a total of HRK 928.4 thousand (about HRK 2.870 per month, per person). Personal disability allowance was paid to 57,238 DCWVs, for which HRK 220.1m was allocated from the central budget in 2013. The bulk of the recipients belonged to DCWVs of category 10 (21,289); they received HRK 115 on average per month, per person. HRK 3.8m was spent on personal disability allowances of 856 Croatian peacetime military disabled persons. According to Article 84 of the LRCHWV, where a DCWV is unemployed, or receives no pension or wage compensation, he/she is entitled to a special supplement, as of the date of acquiring the right to vocational rehabilitation and during that rehabilitation, that is equal to 50% of his/her personal disability allowance. In 2013, there were 622 recipients of this supplement, for which around HRK 830 thousand was allocated from the budget. For other rights of DCWVs, see the LRCHWV.

Targeting compensation on persons providing care to elderly and frail persons is a difficult task, because it requires the definition of: 1) eligibility criteria to be met by the primary carer; 2) the level of care (hours per week; 3) the relationship between the carer and care recipient (family relationships, shared housing, etc.); and 4) the intensity of care needed by the recipient (OECD, 2011). However, it may be administratively

[5] Rules on the selection, manner of and procedure for exercising the rights of persons providing assistance and care to 100% DCHWVs of category 1 (OG, 43/05).

[6] Five times the base (HRK 500) used for the calculation of the amounts of other rights.

difficult to verify all this in practice, there is a possibility of abuse, and the requirements are often viewed as unfair and arbitrary. Moreover, making the entitlement to compensation subject to means testing may result in disincentives to work. Finally, the question remains, when it comes to high-intensity care: wouldn't formal carers with more experience and better skills be more efficient in providing such care? In the United Kingdom, for example, due to strict entitlement requirements, only one tenth of all carers receive compensation for their work.

In 2014, government (county and state budget) expenditures for covering the shortfalls of revenues over expenses of decentralised homes for the elderly and frail stood at about HRK 175m, i.e. around HRK 1,350 per month, per person (OG 7/14; MSPY, 2015). This was almost three times the amount of the in-home assistance and care allowance, which means that, if the homes operated without losses, there would be some scope for allowance increases or some other forms of support to informal care. Also worth noting is that government participates in covering the accommodation costs for those care recipients who are unable to pay them (in full nor in part), even if they get help from their families or sell their own assets. The right to accommodation is denied to a person who can receive assistance and care from his/her family members, or from other sources (Article 93 of the SWA).

3.2 Support in addressing the balance between informal care and employment

In Croatia, parents have a right to leave or half-time work, to care for children with serious developmental difficulties. About two thirds of OECD countries, however, additionally provide for the right to leave for elderly and frail care, while half-time work arrangements for this purpose are less frequently used (OECD, 2011).

Care leave is usually unpaid and, if paid, it is mostly limited to a maximum of one month or to cases of terminal illness. In Belgium, for example, paid care leave is granted for as long as a year, and the employer can deny it only if it poses a serious risk to his/her business operations. In Norway, the amount paid for care leave is equal to the entire wage amount. Unpaid leave in some countries (e.g. France, Spain or Ireland) can be longer than a year. However, in Spain and Ireland, employers can deny paid leave for business reasons, while in France, the entitlement conditions are stringent: a family member who needs care and who lives with the carer must be at least 80% disabled. Unpaid leave can last three months in the Netherlands and six months in Austria and Germany. However, unpaid care leave in Austria is limited to terminally ill family members.

Although they can take advantage of the right to care leave, employees are reluctant to do so because this might affect their careers and income. Therefore, in the cases of low-intensity care, they prefer using sick leave or annual leave. On the other hand, persons providing high-intensity care to their spouses are more prone to take care leave. Research shows that care leave is more often used by public sector and large company employees (OECD, 2011). Moreover, in companies where employees use care leave women are in a majority, employees are better skilled and these companies more often belong to the services sector.

In addition to care leave, flexible work arrangements also help carers to stay in employment. However, flexible work arrangements are mainly used in the cases of care for children, as the laws generally allow part-time work only to parents. In the Netherlands, roughly 90% of companies allow part-time work, but as little as 5% of it is used to provide care to the elderly and frail. In some countries there is a possibility to automatically switch between part-time and full-time work arrangements.

3.3 OTHER FORMS OF SUPPORT

Research for Australia and United Kingdom has shown that financial support to carers does not significantly change the negative impact of care on the carers' mental health (OECD, 2011). Therefore, it is important to find ways to reduce mental pressure on carers. The most common way of help is the so-called respite care, a temporary care service which allows the usual carer to rest. Carers are usually reluctant to "leave" a family member to somebody else, because they either have no confidence in the quality of that other person's care or they cannot afford it financially. Sometimes, the problem lies in the availability of such care. It seems, however, that not even respite care has any major influence on the mental health of carers, except in the cases of: high-intensity care, employed carers and care recipients with cognitive difficulties (Davies et al., 2000).

Ireland and Austria have special compensation for respite care, while in most other countries, this is only an available service funded by the recipient's family. In Sweden, municipalities provide for free respite care at home. Carers are also offered a free hotel stay for a day or two, while somebody else provides care to their family member. The most similar to the respite care service in Croatia is the *temporary stay service* (Article 86 of the SWA). A stay can be full- day or half-day; a person can be granted a stay for one or more days in a week or for all working days in a week. This service is usually provided by homes for elderly and frail persons and family homes. A full-day stay can last from six to ten hours and a half-day stay from four to six hours a day. During this time, recipients are provided with food, personal hygiene services, healthcare, nursing, etc., depending on a recipient's identified needs and choices.

In 2014, there were 38 users of the temporary stay service, incapable of meeting their basic needs (MSPY, 2015). The Act also provides for the *temporary stay* of a child and an adult (Article 92), thus giving carers an opportunity to rest. However, this service is only reserved for persons with the legal status as carers, notably parents. In 2014, the service was used by 77 children and 3 adults.

Counselling with health professionals can also be effective in relieving carers' stress (OECD, 2011). It is usually locally organised in the non-governmental sector and on a voluntary basis. Ireland went a step further with its "Care for the Carers" programme, which includes courses on the necessary informal care skills. In the Netherlands, social workers visit or contact carers by phone, in order to prevent mental health problems among carers, especially during the initial months of care. Websites and leaflets with pooled information on all available services could be an additional asset to carers. In Scotland, family physicians are encouraged to identify informal care providers, record them in a register and provide them with all care-related information materials. Information on elderly care services in Croatia can be found on the Central Government Portal and the website of the Ministry of Social Policy and Youth, as well as at the social welfare centres. The Zadar County, for example, has published a useful "Old Age Guide", and the Karlovac County has issued a "Seniors Info Directory" for elderly citizens of the Karlovac County. However, none of these materials contain any direct information on informal care.

Persons covered by health insurance in Croatia can use an *in-house healthcare service*.[7] The right to that service is granted to bedridden persons and persons with moving difficulties, chronic patients at advanced stages of disease with complications, persons with transient or permanent health problems who cannot take care of themselves, persons who have undergone complicated operations and terminal patients. The healthcare provision also includes educating the recipient and his/her family members about the implementation of the healthcare procedures.

In-house healthcare was provided to 100,481persons in 2014; most of them (about 25%) belonged to the age group of 75 to 84 years (Croatian Public Health Institute, CPHI, 2015). Persons aged 65 and above

[7] Rules on conditions for and the manner of exercising an insured person's right to in-house healthcare under the mandatory health insurance (OG 88/10, 1/11, 16/11, 87/11, 38/13, 49/13, 93/13, 62/15 and 77/15).

accounted for 56% of the total. Almost half of recipients were bedridden persons. Most home visits (444 thousand) were for the complete health care of bedridden patients or patients with moving difficulties, while about 120 thousand of visits were for family education. Bedridden patients or patients with moving difficulties can also receive *in-home physical therapy*. The entitlement conditions are laid down by special regulations.[8] There is also a *health visiting service*, provided by senior nurses specialised in health visiting. The bulk of visits in 2014 (761,308) were paid to chronic patients with a view to giving instructions and demonstrating certain self-control and complication prevention procedures related to the basic chronic disease, and carrying out therapy procedures for bedridden patients and patients with moving difficulties.

4 CONCLUDING REMARKS AND RECOMMENDATIONS

According to the European Commission's projections, in 2060, almost one third of Croatian population will be older than 65 and about one tenth older than 80 years (EC, 2015a). Population aging is accompanied by a steady decline in the number of childbirths and growing numbers of divorces and single-person households. As shown by the latest Census data, about one fourth of households in Croatia are single-person households, half of these persons being older than 65 years. Migrations had another adverse effect on the demographic structure of rural and extra-urban settlements. Eventually, by 2060, the participation rate (the ratio of the labour force to the working age population) of women aged 55-64 years will go up by 17 percentage points, i.e. to 50% (EC, 2015a). All these factors contribute to a future decrease in the number of potential informal carers. Should only 1% of functionally dependent persons in Croatia move from informal to formal care, the number of formal institutional care recipients would double by 2030, as would the number of formal in-house care recipients (EC, 2015a). As a result of this, the share of long-term care expenditures in GDP would rise from 0.4% in 2013 to 0.8% in 2030.

One of the goals set out in the MSPY's Strategic Plan for the period 2015-2017 (MSPY, 2014a) is to develop non-institutional forms of elderly care, particularly in elderly persons' homes and in local communities, allowing the elderly to live in their own environment as long as possible and improving their quality of life. In collaboration with local and regional self-government units and NGOs, the Ministry intends to continue to offer and further expand the range of social services enabling the elderly to remain independent in their homes, as well as to provide expert assistance to elderly persons living with their families. In this context, the focus is on the social service of in-home assistance.

Despite its potential contribution to reducing long-term government expenditures, potential adverse effects of informal care the carers must not be ignored. As argued by Bonsang (2009), in the case of persons with grave disabilities who need high-intensity care, informal care provided by children to their parents is a poor substitute for formal care. Nevertheless, where families are able to care for their elderly and frail members, they should be supported by:

- promoting flexible labour contracts, especially to prevent early retirement of carers;
- considering the introduction of elderly and frail care leave, taking good account of its duration and whether it will be (at least partly) paid;
- stepping up the temporary stay service and, possibly, supporting it financially, while targeting support on employed high-intensity carers;
- identifying carers and providing them with guidance; family physicists and social welfare centres may initially be of help here;
- providing one-stop shops for all information needed by informal carers, and
- ensuring effective coordination between formal and informal care.

[8] Rules on conditions for and the manner of exercising the right to hospital treatment under the mandatory health insurance through in-house medical rehabilitation and physical therapy (OG 46/07, 64/08, 91/09 and 118/09).

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