

# A new formal status for informal carers in Portugal

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*In September 2019, a new formal status for informal carers was approved by law, with considerable political consensus. It establishes a set of rights and supporting measures which are undoubtedly important for promoting informal carers' work-life balance and improving social protection for this group. However, further steps must be taken in order to effectively implement the status.*



## Description

In recent years, there has been growing concern about the need to develop supporting measures for informal carers and/or to create a new status for them. Various initiatives have been carried out, especially since 2016, culminating in the approval of a formal status for informal carers through Law 100/2019, of 6 September.

The law differentiates between two types of informal carer: principal and non-principal. A principal informal carer is a family member living in the same household as the person being cared for, providing care on a permanent basis without remuneration. A non-principal carer is a family member caring on a regular but non-permanent basis, with or without remuneration.

The status establishes a set of rights for the informal carer including the right: a) to have his/her fundamental role acknowledged; b) to receive training and follow-up; c) to receive information from health and social security professionals; d) to be provided with information regarding good practice in the capacity-building, follow-up and counselling of informal carers; e) to receive psychological support from the health services; f) to benefit from respite periods; g) to receive an allowance (means-tested; only for principal informal carers); h) to reconcile care with professional life (only for non-principal informal carers); i) to be eligible for the status of working student; and j) to be consulted about public policies aimed at informal carers.

The law also describes the supporting measures the informal carer is entitled to, including: a) an identified health professional as a contact reference; b) counselling, follow-up, capacity-building and training in the development of caring skills; c) active participation in the elaboration of a specific intervention plan for the person s/he cares for; d) participation in self-help groups of informal carers, to be created by the health services; e) training and specific information from health professionals; f) psychosocial support, in conjunction with the contact reference health professional; g) counselling, information and guidance, as well as information regarding the most suitable services and referral when justified; and h) information and referral to support networks, with an incentive to maintain home-based care, particularly domestic support services.

Additionally, in order to ensure that the informal carer can enjoy respite periods, the following measures may be activated: a) referral of the cared-for person as an inpatient to a long-term care unit; b) referral of the cared-for person to a social support unit or service, particularly to residential care services, on a temporary basis; and c) homecare services.

The law states that the informal carer is entitled to the statutory fiscal benefits (although it does not provide any further clarification) and to voluntary social insurance.

Furthermore, it states that an equivalent pay statement shall be granted to an

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informal carer who reduces his/her professional activity to part-time or ceases it completely. In this latter case, the equivalent pay will have a maximum duration equal to the person's entitlement period to unemployment benefit, and will be granted after expiry of the latter.

## Outlook and commentary

The approval of a formal status for informal carers and related supporting measures is undoubtedly important for promoting their work-life balance and social protection. It is a decisive step away from the previous almost non-existent recognition of and support to carers, and enables an approximation to standards that were already in place in other European countries.

It is even more important as statistics identify Portugal as one of the EU countries with the highest rate of care provided by informal caregivers (30.6% provide care for more than 20 hours weekly, compared with 24.5% in the EU-28 [Eurostat]), and the greatest gender imbalance (women make up 70% of informal carers aged 50+ while in all but two other EU countries covered by an OECD study the percentage varies between 45.6% and 63.3% [OECD, 2017]).

Overall, 13% of the Portuguese population aged 18 years or above report themselves to be carers, compared with 17% in the EU-28. Only 52% of carers aged 18 to 64 are in employment, which is much lower than the EU-28 average (61.5%) (Zigante, 2018).

Teixeira et al. (2017) have pointed out that without informal carers, around 80% of elderly and dependent people would be

institutionalised. They estimate the work carers perform to represent almost 4 billion euros per year, i.e. approximately 2% of the Portuguese GDP.

Additionally, they have identified several vulnerabilities affecting informal carers, such as anxiety and depression, exhaustion, isolation, increased risk of poverty and difficulties to remain in the labour market.

The approval of the status gathered wide political consensus, which was boosted by the fact that almost all parties represented in the Portuguese parliament presented parliamentary initiatives that fed into the drafting of the new law. However, various voices have stressed that the new law is only a first step towards the effective implementation of the status.

The Left-Wing Bloc (BE), for instance, declared that the next steps should, most notably, include regulation of the status (to be finalised by the government by early 2020), together with its integration into the State budget and the necessary changes to the labour code and social security provisions.

Likewise, the national association of informal workers has pointed out that although the law foresees an allowance, and tax benefits, for informal carers, there is still no indication regarding its amount and/or characteristics. Additionally, it highlights that the benefit will only be available for principal carers: a carer who decides to work part-time in order to fulfil caring responsibilities will not be entitled to it. It also notes that the status brings neither additional vacation days to the informal carer nor entitlement to days of absence from work (e.g. to accompany the cared-for person to a medical appointment).

Furthermore, it notes that the status is only available to family members, thus excluding, for example, care provided by friends or neighbours.

### Further reading

OECD (2017), Health at a Glance 2017: OECD Indicators. OECD Publishing, Paris.

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