

## Parental care: the woman's pivotal role as home carer

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This is an entirely female model; the home carer for family members in our country. The percentage of men dedicating a part of their day to looking after an elderly parent, sick partner or child is minimal.

The workers are a silent and poorly-assisted army of 5 million Italians, constituted by more than 80% women, performing care in the home, with a severe impact on work and income, to the point that the legislator has moved on the issue of non-professional caregivers, represented mainly by in-home caregivers, who in recent years have become so numerous.

This and much more besides is the scenario depicted in the White Paper 2018 titled *Women's Health. Caregiving, health and quality of life*, now in its sixth edition, as usual edited by the Osservatorio Nazionale sulla Salute della Donna e di Genere - ONDA (National Observatory on Women's and Gender Health), recently presented and compiled in collaboration with Farmindustria.

*Italian Journal Gender-Specific Medicine* talked about this with the Chair of ONDA, Francesca Merzagora.

### Why is this White Paper dedicated to the provider of caregiving?

As we do each year, we dedicate the White Paper to exploration of a theme relating to women's health. This year we wanted to focus our attention on caregiving in the light of the phenomenon of the increase of elderly people in the population and the "Pink and Silver Star Points" initiative we launched three years ago in recognition of the Health and Care Residences decorated for their attention to humanisation in caregiving. The population is aging and the theme of caregiving to the sick, but also to the elderly, is very important especially if we consider the impact

on the physical and psychological wellbeing of the caregiver, and not only this.

### Could you paint us a picture of the scenario in Italy?

A first analysis regarding length of lifetime confirms something we already knew, that women live longer (84.9 years) with respect to 80.6 years for men, but have a lower expectation of years of good health (57.8 years) with respect to their male counterparts (60 years). Women live longer but get sicker. We also compiled statistics on fertility and births, where we found confirmation that there is indeed a sharp drop in births and a progressive increase in maternal age on first pregnancy. We examined the determinant factors influencing health, concentrating on the lifestyles that differentiate between women and men. Since last year tobacco smoking has increased immensely in the female gender: 12 million (2017 data) Italians smoke but the numbers concerning women have increased from 4.6 million to 5.7 million, a very negative statistic. Levels of physical activity also reveal an important gender-based difference: in all age-groups women emerge as lazier and more sedentary than men, and this actually increases with age. Another important point that emerged from the investigation relates to vaccines and re-

vealed, thanks to the Lorenzin law decree, an improvement in both female and male vaccination take-up. In the area of secondary prevention, we examined the overall numbers on breast, colorectal and cervical screening, which revealed insufficient (though improved) levels of cover, but still patchy.

### Can you fill in a few details in this matter?

On the theme of care assistance, we focussed attention on caregiving, which is taken in its most specific definition as care work as it relates to individuals who are no longer autonomous, being ill or disabled and no longer self-sufficient. It is also a very important job as it involves adherence to treatment programmes and for the types of interventions required. We have defined two categories: formal caregiving, i.e. the paid sort which covers 17% of families, and is typically personified in the figure of the in-home caregiver; and informal caregiving, i.e. the aid the family itself contributes and which can involve one or more components of the family who assist a family member. The numbers clearly show that women are the prime caregivers and that 86% of them are employed more or less in assistance to elderly and/or sick family members. One woman in three takes care of her loved ones with no external help. Only half of these women receive occasional help from other family members, and in only 14% of cases is there help from outside the family. One of every four women is facilitated in her needs by her employer.

While there are examples of virtuous companies that facilitate, by means of secondary welfare practices, this type of work, mostly carried out by women working alone who are forced to invent a myriad of stratagems for the care of the family member, while still going out to work and performing their normal daily activities. In a previous research we made in 2016, it emerged that 73% of Italian women caring for family members in the home; another research conducted by



Ipsos and commissioned by Farmindustria put the figure at 85%.

### **What is the psychological impact of all this?**

There is without doubt a weight linked to caregiving, determined by various factors among which the age of the caregiver, the illness or disability of the cared-for person and the training of the caregiver, in the sense that often, when an ill person is released from hospital, the reference family member receives no training on what will be necessary in terms of care assistance. Consequently the impact can become very serious. It varies in relation to whether the person is elderly, is suffering from cancer or affected by neuro-degenerative or psychiatric pathologies. In some cases the caregiver can be subject to such strong and prolonged stress as to fall victim to emotional, mental and physical exhaustion caused by the overwhelming pressure deriving from the duty of care to a family member. This situation can trigger veritable psychological unease caused by anxiety and a situation of distress that can be manifested in a state of depression.

### **And when the woman providing the care gets sick?**

When this happens, it is the very same woman who takes care of herself. In 46% of cases of slight health problems and in 29% of more serious situations, the woman is alone in providing her own care. A good 68% of women, with a high number involved in caregiving, are totally autonomous in the management of her own health problems, even where those illnesses are very debilitating.

Very often the woman performing caregiving, so involved in her duty of assistance to her ill or not self-sufficient spouse, not only tends to become isolated and to reduce her social life, but also begins to neglect herself and her own health. She does not attend medical checks or postpones them; she does not eat properly or very little, does no physical activity, has no free time, changes her habits, sleeps fitfully; all this over time has an

impact on her physical and mental wellbeing as well as changing the nature of her own affective relations.

### **What is missing in terms of social security for women who dedicate many hours per day to looking after parents?**

This whole very complex picture is not properly taken into account by any national framework for caregivers. A simple answer is to state that for women workers the situation is further deteriorating in the sense that only 1 of 4 can get access to part-time, smart-working practices or public-funded childcare.

A precise framework is indisputably required. The Legislator has acted in response to this significant social phenomenon. In 2017 the budget set up, at the Ministry of Labour, a 20 million euro fund for supporting and protecting the role of the caregiver. But then the government was ousted and in 2018 no further funds were forthcoming. As often happens in our country, there are examples of virtuous Regions, such as Emilia-Romagna, Campania, Lazio, Lombardy and others, which have passed regional laws; but a nationwide approach is missing. The good news is that on October 10th 2018 a White Paper was tabled in Parliament and began to be discussed by the competent commissions. This White Paper contained very interesting proposals in its 13 articles, where it is requested not only that the caregiver role be recognised by a certificate of qualification issued by INPS (National social security and welfare institution) but that there should also be regulations set down specifically to enable formulation of essential performance levels as well as crucial levels of assistance in favour of the caregiver. The key concept of the forthcoming Law Decree is that it supports the principle of conciliation between the work and care aspects of the role; this means that the employer must give the caregiver an agile and flexible work contract. In this regard, we note that some employer companies are more virtuous than others, for example pharmaceutical companies.

However, there is truly very much to be done in this regard. The Decree also requires that the caregiver's work be recognised as highly wearing. Lastly, article 11 looks to a refinancing of the caregiver's fund in order for all the needs this very important figure in our society and our welfare system requires to be met. In other countries, such as France, Great Britain, Switzerland, Denmark, very much more advanced than ourselves, there are various examples of employment protection for caregivers, which we would do well to adopt. For the moment Italy lags badly behind in this aspect.

### **And what are the levels of male presence in the caregiving scenario?**

We know that gradually men too are getting and feeling more involved. There is a fairly significant shift in the traditional scenario. This is clearest in the case of young couples, where men participate in childcare. In the light of the progressive aging of the population, the dearth in births, the miniaturised family nuclei, we will be forced to reach male-female parity in respect of parental care too.