

Development and current state of Volunteering in hospice and palliative care in Italy

The Federation of Palliative Care



Geographical distribution of the 93 NPOs part of FCP

The Federation of Palliative Care (FCP) is a second-level organization of the Italian third sector that represents the network of Non-Profit Organizations (NPO) operating in the field of palliative care of the country. 93 Non-Profit Organizations are currently members of the FCP gathering more than 6.000 Volunteers.

The FCP, active in helping and assisting people with an evolutionary and incurable disease with poor prognosis, was established in 1999 with the aim of promoting and developing palliative care, spreading its culture and preserving dignity of the person, also guaranteeing the right not to suffer.

The Federation of Palliative Care (FCP) is in constant relationship with the NPOs associated and maintains ongoing close working relationships both with the Italian Society of Palliative Care (SICP) and with a significant number of external NPOs.



Law February 26th 1999, No. 39

"Provisions to ensure urgent action to implement the 1998-2000 National Health Plan"

The Minister of Health [...] adopts a program on a national basis for the realization, in each autonomous region and province, in consistency with the objectives of the National Health Plan, of one or more structures, located in the territory in order to allow easy accessibility for patients and their families, dedicated to palliative care and support primarily for patients affected from terminal neoplastic disease requiring care aimed at ensuring a better quality of their life and that of their families.

Law March 15th 2010, No. 38

"Provisions to guarantee access to palliative care and pain therapy"

[...] Having heard the main scientific societies and non-profit organizations operating in the palliative care and pain therapy sector, homogeneous training courses are defined throughout the national territory for the volunteers who work in the two networks (Federation of Palliative Care – FCP and Italian Society of Palliative Care – SICP).

Law December 22nd 2017, No. 219

"Rules on informed consent and Advance Health Care Directive"

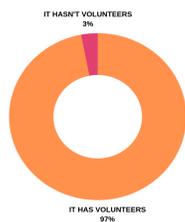
The time of communication between doctor and patient constitutes cure time.

Number of NPOs belonging to FCP per year



FCP increase its confederates year by year

Presence of Volunteers in the NPOs belonging to FCP



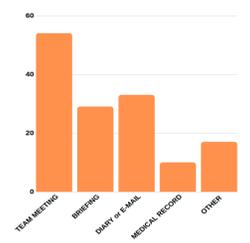
97% of FCP members has Volunteers



Our concrete response, realized in collaboration with the Italian Society of Palliative Care, is a tool.

All the organizations that manage Volunteers "of Staying" provide for interaction tools between the volunteers and the professional team. There are many ways to interact, but the most common is participation in the team meeting, followed by information sharing via diary or email and by briefing. Only in a few cases the medical record is shared.

Method of interaction with the Professional Team



The role of the Volunteer in Palliative Care

VOLUNTEERS BRING THEIR PRESENCE

This happens in a context in which "being there" is revolutionary; the volunteers are present where suffering, loss of autonomy, death prospectus lead to risk of loneliness and isolation.

VOLUNTEERS ARE FACILITATORS OF THE RELATIONAL WORLD OF THE SICK

Volunteers offer an important opportunity for relationship and closeness especially in situations of profound loneliness. Due to the global suffering that the disease brings to emotional relationships, sick people can happen to be in great difficulty, even when they have a family, friends and acquaintances. They struggle to maintain a relationship capable of giving satisfaction and response to the needs for

relationship, closeness, care. Prepared volunteering does not replace itself but helps the family to play a fundamental role.

VOLUNTEERS ALLOW MOMENTS OF NORMALITY

The presence of volunteers alongside the sick person promotes the sharing of daily life activities, allows the proposal of recreational initiatives, promotes the maintenance of personal interests, offers a relationship not necessarily linked to disease problems and concerns.

VOLUNTEERS OFFER SUPPORT AND EMOTIONAL SHARING IN RELATION TO UNCHARGABLE DISEASE

A prepared volunteer knows how to "stay" in a conversation even when it concerns sickness, death, suffering, concern for the future of the sick or of family members.

Although aware of not having solutions or answers, the volunteer can make a very important contribution through listening, welcoming and through emotional participation in the history of people to whom he has freely chosen to dedicate time.

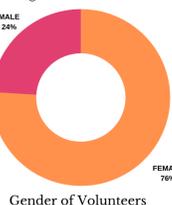
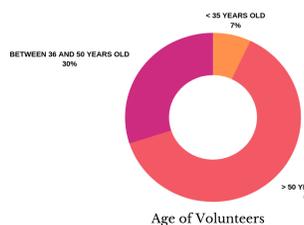
VOLUNTEERS PERFORM A SOCIAL ROLE

The volunteer, together with his Association, represents a member of the community capable of bringing the outside world to places of care, overcoming physical barriers linked to lodging or, in any case, reduced mobility. In the same way, the Association, through the volunteers, can transfer information, sensitivity, values such as gratuitousness matured with experience, helping to grow local communities that can give support, capable of expressing closeness and inclusion also to sick people.

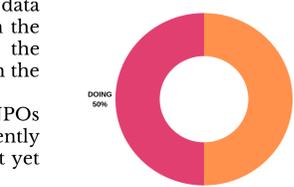


The Federation has always been committed to collecting data related to the associated NPOs and to all those active on the national territory, this with the purpose of providing the citizen who needs care or information direct contacts with the organizations operating in their geographical area.

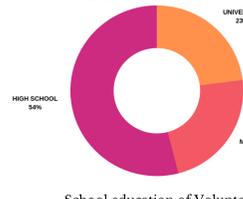
The Federation has collected the data of the associated NPOs in 2012 (69 NPOs), in 2015 (71 NPOs) and it is currently processing the recently acquired data about 93 NPOs, not yet available.



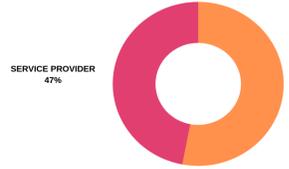
Gender of Volunteers



Volunteers "of Staying" and "of Doing" on the total of 4891 Volunteers active in 2015



School education of Volunteers



NPOs of FCP network: percentage of direct provision of services in Palliative Care

Needs of Palliative Care in Italy. An FCP-SICP document

Italian population - 60 million 494 thousand residents
In 2017, approximately 647,000 people died in Italy
Needs of Palliative Care
Prevalence: 1-1.4% of the adult population Estimate: between 524.000 and 733.000 people
Incidence: 72%-80% compared to the number of deaths / year
Estimate: 465.000 – 517.000 people every year

Parliament Report on implementation status of law No. 38/2010, three-year period 2015-2017

Hospice
No. of admissions = 42.572
7.15% of the total cancer patients
Home
No. of assisted patients = 40.849



The publications of the Palliative Care Federation: best practices made through heterogeneous working groups

Since 2008, the FCP has published the "Punto e Virgola" - which meaning is semicolon - series, the result of the experience of the members of the confederate organizations and of the most authoritative Italian voices in the field of palliative care. The volumes intend to welcome and guide the ONPs and the aspiring Volunteers, accompanying them in their path: they offer food for thought and relevant information to the citizens, support the work of the professional Hospice team.

FCP works in accordance with the Ethical and Behavioral Code subscribed by all members.



CHALLENGES Board of Directors FCP 2018 – 2022

MAPPING

It is necessary to collect, through an accurate survey, data and information both on the organizations that provide Palliative Care services and pure voluntary organizations, in quantitative and qualitative terms, with the aim of having an overview of the current scenario and conducting an analysis on possible improvement paths;

NON - ONCOLOGICAL PATIENTS

We want to promote access to palliative care for non-cancer patients by implementing care pathways, consistent with the needs, timing and peculiar characteristics that characterize the assistance of the different categories of patients;

SHARED CARE

We know that end-of-life care is not enough. Timely and early management procedures have to be promoted. These are characterized by interventions by the palliativist together with the branch specialist, aimed at the management and shared planning of care with the patient;

TRAINING/INFORMATION

Specific training projects, aimed at implementing integrated palliative care pathways, for specialist teams, GPs / PLSs and hospital health workers, nursing homes / Residences for Disabled and Integrated Home Care, have to be developed. The Federation intends to develop, in synergy with voluntary organizations, information and awareness projects aimed at citizens;

INSTITUTIONAL ACCREDITATION

The relationship of ONP with the National Health System and Regional Health System must be regulated exclusively through "Institutional Accreditation". All conventional forms must therefore be overcome, in particular the allocation of services based on tenders and tenders. The management of the Accredited Structures (Hospice and Domestic UCP) cannot be outsourced, by the Accredited Body, through "calls for tenders".

