



In this new section, European palliative care organisations are invited to explain their goals, express their hopes and voice their concerns

## FCP: why Italy is a special case when it comes to palliative care

Italy was a late starter in developing palliative care, but things are now changing rapidly. Nevertheless, the country seems to be unique among its European counterparts in still suffering from 'opiumphobia'. Francesca Crippa Floriani, President of the Federazione Cure Palliative (FCP), explains what is being done for terminally ill patients and their families



Francesca Crippa Floriani, President, FCP

### The start of the hospice movement

The development of palliative care in Italy got off to a slow start in comparison with other European countries. However, in recent years, things have begun to change more rapidly, particularly with regard to the establishment of hospices. Ten years ago, we had just one. In 2008, there were more than 150.

The rise in the number of home care services has been slower. In 2005, there were 121 palliative care units; in 2008, the figure had grown to 161. This slowness is probably partly due to the lack of laws, at national and local level, favouring the development of palliative home care.

Since 1999, post-doctorate courses in palliative care (less than a dozen) have been set up in universities to train doctors, nurses, psychologists, social workers and other health- and social care professionals, giving them a systematic, in-depth knowledge of palliative care. As yet, however, there are insufficient educational opportunities to train enough staff for the new hospices.

The fact that palliative care is not a recognised medical specialty in Italy creates further problems for doctors seeking a career in this field. In fact, to practise in a hospital, doctors must have a degree

in another medical specialty – usually anaesthesiology, oncology or geriatrics.

Palliative care needs to be formally recognised as a medical specialty. This would enable hospices to gain more experience and improve the competence level of their staff. It is also essential that more hospices are created, so that they spread throughout the northern and central regions of the country and reach southern Italy in suitable numbers.

### What needs to be done

Over the next few years, healthcare professionals, decision-makers and not-for-profit organisations will have to tackle a fundamental task: the creation of a co-ordinated and efficient care network that can guarantee timely and competent assistance, in the most suitable setting, for chronically or terminally ill patients and their families.

Not only will this network need to provide patients and families with adequate care, but it will also need to give them assistance in managing the difficult aspects of everyday life. At the same time, it will have to ensure a smooth passage between the different care

settings, taking care of the bureaucratic aspects so that these are not a burden for patients and their families.

## Italy's opiumphobia

A specific problem that sets Italy apart from most other European countries is the so-called opiumphobia that still prevails. Many doctors – and not just general practitioners – are still fiercely resistant to prescribing opioids for alleviating pain, especially cancer pain. This is matched by a high level of mistrust among patients, who are often reluctant to start an opioid therapy even when it has been prescribed to them.

There are many causes for this distrust of opioids, but the main one is cultural, conditioned by a persistent denial of the seriousness of disease and terminal illnesses. It is often difficult to deal openly with matters related to palliative care because, to date, there is a great resistance to talking about prognoses of terminal illnesses among families and patients, and consequently among doctors and patients. Palliative care is seen as a defeat and, as such, is to be postponed for as long as possible.

Another reason for the distrust of opioids is that palliative care professionals do not receive appropriate training, at university or post-doctoral level, on the efficacy and safety of opioids and, therefore, do not have the necessary knowledge to feel comfortable using them.

## The role of not-for-profit organisations

Until about ten years ago, there was very little care or support for terminally ill patients provided through the public health or welfare systems. With rare exceptions, the only co-ordinated, continuous services were organised by not-for-profit organisations at local and community level. These organisations were mainly run by volunteers. Over time, they have become service suppliers, directly financing and organising the home palliative care teams or partly financing pilot projects of Italy's national welfare system.

In the absence of publicly available information about incurable illnesses issued by the mass media and institutions, not-for-profit organisations began to inform the public on the rights of dying patients by organising studies, seminars and other events throughout the country. For many years, this was the only information at hand.



**A meeting of the FCP, the Italian Palliative Care Federation. Created in 1999, it now has more than 60 member organisations working in the field of palliative care**

From the start, not-for-profit organisations have strongly supported those scientific sectors that are striving to promote the principles of palliative medicine (and more generally of pain relief) among palliative care professionals, doctors, nurses and psychologists. By attending training courses, the volunteers indirectly became an authoritative source of information for the movement against unnecessary pain and in favour of the right to be adequately cared for when a cure is not possible.

## The creation of the Palliative Care Federation

It was against this social, cultural and organisational background that the Palliative Care Federation (Federazione di Cure Palliative, FCP) was established, in 1999, by 22 not-for-profit organisations that had been working for many years in the palliative care sector.

Today, the FCP has more than 60 member organisations (out of a total of 140 not-for-profit organisations operating in this field in Italy), characterised by their common mission to provide the best possible support for those

in advanced and terminal phases of incurable illnesses, and for their families.

The FCP member organisations offer concrete support, both in terms of information and care. They co-operate with health- and social care institutions, with the aim of avoiding needless pain for the more than 250,000 people who die every year in Italy from incurable disease.

As well as helping terminally ill patients and supporting family members who look after patients at the end of life, the FCP disseminates the most relevant information in the field of palliative care and pain relief, among its members and the wider public. It favours the exchange of experience and knowledge at all levels.

Since 2002, the FCP has had an internet site ([www.fedcp.org](http://www.fedcp.org)). The site, which is aimed at both FCP members and the general public, contains practical information – including the addresses of Italy's home care centres and hospices – as well as constantly updated information on regional, national and international laws, on pain relief, and on associations working in the field. The site also carries information on training courses, especially those aimed at volunteers.

The not-for-profit organisations of the FCP represent the most effective link between the citizens and the institutions working in the field of palliative care. To date, they are the best-placed to convey to the institutions – and to all palliative care professionals involved in providing assistance to terminally ill patients – what is really needed in terms of training, funding and recognition.

The FCP assumes a vigilant role to ensure that the ethics and principles of solidarity that underlie palliative care are not restrained by the logic of economics or profit.

## **An annual day against suffering**

The FCP has always identified the fight against pain and suffering as one of its main objectives. For this reason, it has dedicated 11 November each year to this commitment. This day is known as 'The day against useless pain in the incurable person'. In recent years, on that day, the actions listed below have been organised.

- In 2001, the day was dedicated to the rights of the terminally ill patient, and a petition to the government was organised in support of a 'Charter of rights for the dying person'.
- In 2002, the FCP wrote the 'Decalogue of the family rights in taking care of the incurable patient', which was signed by 40,000 people.

- In 2003, the chosen topic was 'Suffering in the incurable elderly patient', one of the crucial issues in fighting pain.
- In 2004, a press conference was organised with the then Italian Minister for Health, Girolamo Sirchia, who was presented symbolically with all the signatures that had been collected in previous years, which numbered about 80,000. On that occasion, the minister announced that Italian citizens would no longer have to pay for painkillers, including opioids.
- In 2005, a project called 'Living without pain: from hospital to home' was promoted. Fundamental requisites for palliative care, such as continuity of care, were highlighted.
- In 2006, the topic was 'Less bureaucracy for the use of opioids against pain'. The FCP, together with the Italian Society of Palliative Care (Società Italiana di Cure Palliative, SICP), organised a petition to the government to make the prescription of opioids less complex and to eliminate the potentially negative connotations of their therapeutic use.
- In 2007, a new petition to the government was organised to request that, after the great steps taken to build hospices, the same commitment should be shown to develop home palliative care services in the country.
- In 2008, after a thorough review of the work carried out in recent years, the FCP once again invited the not-for-profit organisations to organise a petition to present to the government. The aim was to inform citizens about, and involve them in, what still needs to be achieved to improve the Italian palliative care network – for example, developing home care and training healthcare professionals. A specific request was the abolition of the special prescription pads required for opioids for therapeutic use, which are a very complex and bureaucratic way of prescribing opioids to patients. Abolishing them would make it easier for doctors to deliver these drugs.

This year, a new petition will be presented to the government, with the aim of enforcing the 'essential assistance level'. This means that all medical services will be at the expense of the government and free of charge for citizens.

Italy still does not have a specific law for palliative care; the FCP is committed to collaborating with the current government to put one in place.

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