# EUROPEAN *insight*

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

# SFAP: France is witnessing major developments in palliative care

In France, following a ground-breaking law on patients' rights and the end of life in 2005, developments in hospice and palliative care have been particularly rich. A major four-year palliative care development programme was announced in June 2008. Godefroy Hirsch, Head of the French Society for Accompaniment and Palliative Care (Société Française d'Accompagnement et de Soins Palliatifs, SFAP),[1] explains

**Godefroy Hirsch, Head of the SFAP**

## The 2005 law on patients' rights and the end of life

On 22 April 2005, the law on patients' rights and the end of life[2] came into force. The French Parliament voted unanimously in favour of it. It is a particularly innovative one, and it illustrates the choices that have been made in this country concerning end-of-life issues. Some of its main points are listed below.

The law says that unnecessary or disproportionate medical interventions, or interventions that would only lead to the artificial prolongation of live, can be withheld or not be undertaken. In such cases, the doctor needs to provide the dying patient with appropriate care, to ensure their dignity and quality of life. This leads to a total reconsideration of palliative care treatments and therapeutic choices. However, the expression used in the law is *obstination déraisonnable* ('Such medical interventions should not be undertaken out of *unreasonable stubbornness*'), rather than the French notion of *acharnement thérapeutique* (that is, relentless life-prolongating therapy), which means that there is still an ambiguity.

The law makes clear that patients' wishes should take priority. A patient has the right to refuse all treatment, even if this has consequences for their life expectancy. The law contains several clauses that highlight the importance of patients' wishes and choices, especially when they are no longer able to express themselves. Everyone aged 18 and over may designate a 'trustworthy person' who will represent them if they become unable to articulate their wishes. They may also write out their 'anticipated instructions', valid for three years.

If a patient is unable to voice their choices, and it is necessary to decide whether to continue or withdraw a specific treatment, a collective decision should be made by a group of people consisting of at least two doctors, other members of the medical staff and close relatives or friends. The 'trustworthy person' or the 'anticipated instructions' must be consulted. However, for those patients who are unconscious, the law provides that the final decision regarding the treatment remains a medical prerogative.

In March 2008, following several high-profile media cases of assisted suicide or requests for euthanasia, and in response to increasing pressure from the French pro-euthanasia lobbies, the French Prime Minister, François Fillon, requested a parliamentary group to look into possible changes to the law. Its proposals, made public in December 2008, include spreading the knowledge about the 2005 law, developing palliative care, reinforcing patients' rights and improving healthcare professionals' knowledge of palliative care.

## Organising French palliative care

The French palliative care system consists of long-term palliative care units in hospitals (*unités de soins palliatifs*, USP), home care services (*équipes mobiles de soins palliatifs*, EMSP), identified palliative care beds (*lits identifiés de soins palliatifs*, LISP), palliative care networks and hospice care volunteers' associations.

A recent survey shows a noticeable increase in the provision of palliative care during the past ten years, especially in hospitals.[3] It also reveals discrepancies in the provision of palliative care according to location, which raises the question of equity of access – under the 9 June 1999 Act, every person has a legal right to appropriate palliative care if their medical state requires it.[4]

On 25 March 2008, the French Ministry of Health published official instructions on the organisation of palliative care.[5] These instructions detail the missions, goals, organisation and functioning of every French palliative care structure, as well as the estimated cost of running them.

## A five-year palliative care development programme

A palliative care development programme for 2008–2012 was announced in June 2008 by the French President, Nicolas Sarkozy.[6] This estimated €230 million programme consists of 18 measures centred around three main areas, listed below.

### Ongoing development of hospital palliative care structures and home-care services

There are plans to reinforce existing hospital-related structures (USPs, EMSPs and LISPs) and to create new ones. There are also plans to help the palliative care networks in their development and to help implement palliative care in long-stay, state-funded units – especially those for the elderly or disabled. Pilot schemes will be implemented and later assessed, including the creation of *maisons d' accompagnement* ('accompaniment homes') and night nurse attendance in old age homes.

### Education and research policy

The goal is to support research in the fields of palliative and hospice care, including through the funding of studies by hospitals via clinical research programmes. It is also necessary to make palliative care an integral part of the curriculum for future doctors and to encourage the provision of palliative care training for social and healthcare workers – for example, those employed in homes for the elderly or the disabled.

### Support and education of volunteers and the general public

Target areas include facilitating the temporary accomodation of elderly people to provide respite for their carers; offering proper education and training to hospice care volunteers; and, most importantly, disseminating information about hospice and palliative care among healthcare professionals and the general public.

This ambitious programme aims to develop a new culture around palliative and end-of-life care in France. The follow-up has been entrusted to a survey committee set in the autumn of 2008. The next step is the pursuit of a true policy of palliative care development, despite budgetary limits, through the effective implementation of the measures included in the 2008–2012 plan and the proposals of the parliamentary group. In spite of undeniable progress in the past ten years, end-of-life care in France needs to be further improved and palliative care further developed. The SFAP, which represents professionals and volunteers, will continue to be a driving force, always aiming at promoting respect for the dignity of the patient.

**References**
1. www.sfap.org (last accessed 03/02/2009)
2. Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie. www.legifrance.gouv.fr/affichTexte.do;jsessionid=D08BDB6962AD0A6117491C1BEB93C261.tpdjo10v_2?cidTexte=JORFTEXT000000446240&categorieLien=id (last accessed 03/02/2009)
3. État des lieux du dispositif de soins palliatifs au niveau national. ATEMIS, October 2008. www.sante.gouv.fr/drees/colloques/demarche-palliative/synth-soins.pdf (last accessed 03/02/2009)
4. Loi n° 99-477 du 9 juin 1999 visant à garantir le droit à l'accès aux soins palliatifs. www.legifrance.gouv.fr/affichTexte.do;jsessionid=5F9A258C18E3E1E022500B20C7C6F87E.tpdjo10v_2?cidTexte=JORFTEXT000000212121&categorieLien=id (last accessed 03/02/2009)
5. Circulaire n° DHOS/O2/2008/99 du 25 mars 2008 relative à l'organisation des soins palliatifs. www.sfap.org/pdf/III-B6b-pdf.pdf (last accessed 03/02/2009)
6. www.sfap.org/pdf/0-K2-pdf.pdf (last accessed 03/02/2009)
www.sfap.org/pdf/0-K2b-pdf.pdf (last accessed 03/02/2009)

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