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

Switzerland: palliative ch is taking a giant step forward

This year, for the first time, Switzerland has a national strategy for palliative care, and the Swiss society for palliative medicine and palliative care, palliative ch, is playing a major role in it. Claude Fuchs, Managing Director of palliative ch, explains

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In Switzerland, the most prominent pioneer of the palliative care movement is the late Dr Elisabeth Kübler-Ross. She grew up near Zurich and, although in the 1950s she moved to the USA to work, whenever she came home to Switzerland, which she did often, she strongly advocated for what she believed. Thanks to her, a large number of associations for the care of terminally ill and dying patients were already being set up around 1980, mostly in the German-speaking part of the country.

The beginnings

The actual beginnings of palliative care can be traced back to 1986, when Switzerland's first French-speaking palliative care meeting took place in Geneva on the initiative of Dr Charles-Henri Rapin (one of the co-founders of the European Association for Palliative Care, who died in 2008). With more than 600 participants, it was a big success.

Two years later, in 1988, Paul and Danielle Beck opened the country's first hospice, Rive-Neuve, on the shores of Lake Geneva. This was also the year in which palliative ch, the Swiss society for palliative medicine and palliative care, was set up. From the start, palliative ch held an annual conference: it became a major event and a meeting point around which palliative care could be developed. Today, the society has 2,000 members, 70% of whom are professional nurses and carers and 15% of whom are doctors. The remaining 15% are professionals from other sectors, including social care, spiritual care and administration.

A visit by Dame Cicely Saunders to Zurich in 1997 sparked a local action group that, in 2000, became a regional branch of palliative ch. The society now has 11 regional branches and three more are in the process of being set up; palliative ch will then cover the whole of Switzerland. In a country where the healthcare system is not centralised, but falls under the responsibility of the 26 cantons, it is important that palliative care is well established at a regional level.

Developing palliative care: a work in progress

At a national level, palliative ch has, for several years, been attempting to raise awareness among the public and professionals, but above all among politicians, of what palliative care can offer, as well as highlighting the gaps in its provision. Swiss palliative care services were first described in a report by palliative ch in 1999/2000. In 2008,

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The Swiss national palliative care strategy 2010–2012 was announced on 23 October 2009 by Pierre-Yves Maillard (President of the Swiss conference of cantonal health ministers, left) and Pascal Couchepin (then Swiss interior and health minister, right)

a second report showed the notable progress that had been made, but also made clear that large regional differences still existed in palliative care provision. For example, the canton of Vaud has developed a comprehensive, canton-wide palliative care strategy that has already been largely implemented. Other cantons, such as Ticino, St Gallen, Geneva and Zurich, are doing quite well. However, in some parts of the country, palliative care has received little attention.

There are no national figures on palliative care service provision (for example, on the number of palliative care beds). Our estimate is that around 70% of palliative care can be delivered by the general healthcare providers: GPs, home-care services, care homes and general hospitals (however, these providers need better palliative care education and training, as well as the support of specialist palliative care mobile teams). Only in 30% of cases does palliative care need to be delivered in specialised settings; that is, palliative care hospital departments, hospices, specialist departments in care homes and specialist home-care services.

In 2009, in an effort to join forces and circulate information about palliative care more widely, palliative ch launched an umbrella organisation called ‘pro palliative care’. It is designed to bring together organisations such as the Swiss cancer league, the Swiss Alzheimer’s disease society and the association of hospitals and care homes, as well as patients’ organisations and the churches, so that state officials have a common point of contact.

To keep members (as well as a few hundred other subscribers) up to date, we publish a quarterly magazine, *palliative-ch*. It runs to 80 or so pages and includes articles on specific subjects (in 2009, we tackled breakthrough pain, advance directives, constipation/ileus and dementia), as well as news and views about palliative ch and its regional branches.

The fact that different languages are spoken across Switzerland can make things complicated: most of our literature, including internal documents, has to be published in German and French, and in Italian, too, if possible. At our annual conferences and board meetings, the multilingual aspect may be a source of mutual enrichment, but it can also be a burden – sometimes it is necessary to retain a sense of humour to cope. Several people have already suggested that we could all just speak English ...

Independent working groups

Within palliative ch, there are various working groups that are each fairly independent.

One group is working on quality and has developed a set of criteria to enable palliative care services to be audited and awarded a 'good quality' label where appropriate. These criteria are now to be adapted to assess the quality of long-term care, and later of home-care services. This working group also aims to develop a 'minimum data set', that is, basic data about patients that all palliative care institutions would be asked to keep track of. This would make it easier to compare the quality of service provision between institutions – lack of statistical data is a problem in Switzerland; state authorities no longer even record the place of death, for example.

Another group, 'SwissEduc', is working on staff training and education. In the past few years, it has set itself a huge task: to list the skills and competences required by different professionals working in palliative care at five levels of training. In time, this will make it possible to assess whether specific curricula or training courses are delivering the required skills. For a long time, nurses have received reasonably adequate palliative care education as part of their training. However, because palliative care has not yet become part of the medical curriculum and further education, this has not been the case for medical students and doctors.

A third group aims to promote research in palliative care, bringing together the few researchers so far working in the field and co-ordinating their work so that we can encourage the research findings that are useful for developing palliative care. It is hoped that, this year, the government body supporting scientific research at national level will approve a new research area centred on the end of life, which would mean that palliative care research would receive more financial support.

There is also a group working on tariffs; their task is to pave the way for negotiations with the relevant authorities regarding the reimbursement of the cost of palliative care services to healthcare providers. At the moment, though, the main concern is to stop diagnosis-related fixed tariffs, which are being introduced in the country, being applied to palliative care. This is because it is difficult, if not impossible, to know how long a patient is going to live, or to calculate the cost of many palliative care services. For example, how do you assess how much it costs to discuss each case with patients and their families as often as required? Or the time needed to co-ordinate the transfer of patients between their home and a care home or hospital?

Miracles still happen

For years, we had tried, with little success, to draw the attention of the authorities to the patchy provision of palliative care services in Switzerland. However, in the summer of 2008, we were pleasantly surprised to hear Pascal Couchepin, then President of the Swiss Confederation as well as Swiss interior and health minister, state, during an oncology congress, that palliative care was one of his priorities. Sure enough, a few months later, a panel of experts had been commissioned to look into ways of promoting palliative care.

The panel, organised in different subgroups, started work at the beginning of 2009. By June, it had produced its final report. This document, combined with an additional report by an independent institute, provided the basis for the Swiss national palliative care strategy for 2010 to 2012, which was announced on 23 October 2009. This strategy contains measures regarding service provision, research, education and training, and information, to be implemented during the next three years by the state authorities, the cantons and palliative ch (however, it does not state how much money will be put into palliative care).

This means that we, at palliative ch, are now faced with a huge task. Until now, we have worked on a voluntary basis, but this will no longer be possible. We have to take a giant step forward, and we are not sure yet how we will manage. In any case, we know we can count on the support of the authorities and on the commitment of many of our members. In 2001, the subhead of our 'Freiburger Manifest' was 'Palliative Care – heute für wenige, morgen für alle' ('Palliative care – today for a few, tomorrow for everyone'). At the time, we thought utopia was needed to change reality. Today, utopia itself does not seem so far away ■

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