# Jan Foubert: champion of cancer nursing

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Jan Foubert knows the value of a good cancer nurse – someone who understands the patient's needs, knows how to help them cope with the disease, symptoms and side-effects and has skills to apply that knowledge. He believes it's up to Europe's nurses to redefine their role in cancer care – but he'd also welcome a bit more support from the other oncology disciplines.

If there is one factor that can help a core oncology specialty to develop around Europe it is consistent and long-term leadership, which European cancer nurses have enjoyed in recent years in the form of Jan Foubert. His credentials include a background in paediatric oncology nursing, academic nursing positions at the Erasmus institute of higher education and the Free University in Brussels, and he is the immediate past president and longstanding board member of EONS, the European Oncology Nursing Society. Most recently, the US Oncology Nursing Society selected him for their International Award for Contributions to Cancer Care, which he will receive at the ONS Annual Congress next April.

It is, however, a new role at EONS that will cement his relationship with the nursing cause in Europe. "I have accepted an executive director's post, that will allow the society to build on all the projects and development work I've been involved with as a board member," he says. While the details of the new post are to be decided – he will also continue with his teaching duties in part – his direction is unequivocal. "I've just turned down two other jobs so I can work with EONS – a director's post at FECS (the Federation of European Cancer Societies) and a principal's position at the university."

Those who have encountered Foubert on the conference circuit and as a board member of EONS and FECS will not be surprised by his decision. While always open to discussion, he has long been of the view that Europe's oncology nurses – and there are around 30,000 in EONS – need a strong, independent voice, and they have enjoyed precious little support from the medical oncology community, despite the supposed rise of multidisciplinary working. Further, although oncology nursing has developed as a specialty in a few countries, the overall picture is very fragmented in terms of recognition, educational opportunities and requirements, and clinical knowledge and research.

In fact, Foubert feels there is an urgent need to address what he calls a 'loss of identity' among the nursing community generally. "A shocking definition I've heard of a nurse is that they do things that can also be done by others," he says. "What a lot of nurses still do goes back to the days of Florence

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"Nurses complain about respect and image – but we have to create our own image and earn respect"

## Too often, trainee nurses bursting with ideas end up in units where there is little scope to change things

Nightingale – basic care and being dependent on doctors to tell them what to do." While there are, of course, many specialised and advanced posts in oncology – such as pain management and tumour-specific roles, and some senior nurses acting as 'mini-doctors', as Foubert puts it – there is a danger of the bulk of bedside nursing remaining stuck in an assistant nursing role, suffering from a lack of knowledge and empowerment. "Governments will say, 'Why should we pay so many registered nurses when one or two can coordinate the care?'"

The present-day situation is exacerbated, he adds, by societal changes that have seen nurses less valued than they were. "The uniform and presence once meant you were respected – now society sees nursing as any other job. Nurses often complain about respect and image – but we have to create our own image and earn respect."

It is the majority – the bedside oncology nurse – who Foubert has most in mind in his work to help raise the profile and professional attainment of nursing. Apart from his involvement in the politics and strategic agenda setting for EONS, his teaching experience has no doubt informed the development of the society's most important programmes so far. These include educational initiatives such as TITAN, which deals with thrombocytopoenia, anaemia and neutropoenia – conditions where nurses can play key treatment roles – taught in a way that shows how such potentially forbidding topics can be shaped to be of practical value and not discarded as being too theoretical.

Foubert's own pathway into a nursing career was quite remarkable. Brought up in Germany, he had initial ideas about being a psychologist, until a friend of his mother, a night sister at a hospital, invited him to spend a shift with her – where someone died. "He was put in bed in a bathroom, with no one with him. I thought, 'This can't be right.'" Then in a school holiday he found himself visiting a nursing home for older people with dementia, again through a family contact. "The director was looking for holiday help – I went on a tour with my mother and in one room there were four women, one of whom was spreading faeces on a hot radiator. I stayed and did the evening shift. My mother couldn't understand it."

This highly unlikely holiday job for a teenage boy – which was probably illegal – was nevertheless highly stimulating, although Foubert says he had to grow up rather rapidly. He was determined then to qualify as a nurse, which he duly did at a nursing school in Brussels, and then went to a new hospital, Queen Fabiola Children's University Hospital, also in Belgium, as a paediatric intensive care nurse. University training, as he often says to his students today, hardly prepares you for the realities of such a job, but in this unit he was able to learn quickly about all manner of high-, medium- and low-intensive care situations.

Foubert was also able to fit in a master's degree, specialising in hospital science, which also had an educational option, meaning he was then equipped to teach other nurses. "The hospital director asked me to build up hygiene practices in the hospital, and then one day called me in and offered me the head nurse position in the paediatric oncology ward – I had to take it there and then." He notes: "As a new nurse you have to be visible to the decision makers so that they can see that you have competencies that can be of use for the organisation. Don't follow the crowd."

Foubert realised he knew next to nothing about oncology. "The doctors might as well have been talking Chinese," he says, adding that today's nurses receive little oncology teaching on undergraduate courses, which hardly stimulates them to look at specialised postgraduate cancer options. In a month or so he had read up on cancer to the extent that he felt he knew more than most on the unit, and brought his intensive care skills to bear – showing other nurses how to perform a resuscitation in one case and how to monitor and assess children in a critical situation on an oncology ward.

He also led the reorganisation of the unit. Nurses

were working on only one of several areas, such as ambulant care or closed bone marrow treatment rooms, and they were asked to vary their work. This proved unpopular with some (who then left). Some evidence-based practice was brought in – such as the use of specially prepared sterile food for bone marrow patients. "It was from my master's study that I showed the food we could get from commercial sources was much safer than food we prepared ourselves – all we needed was a decent kitchen with a store of safe food in a fridge, and a microwave."

These two themes – challenging ingrained habits and introducing evidence-based nursing – have become central to Foubert's views about developing nursing practice. "If there is one profession that is difficult to change, it is nursing," he says. "Nurse training is about a lot of theories and models – but when you go into practice you don't often see them." Too often, he reckons, trainee nurses bursting with ideas end up in units where there is little scope to change things, although there are some places where being assertive and dynamic is welcome. "But the most frustrating thing a new nurse hears is, 'We have always done it this way.'"

Meanwhile, at the children's hospital, Foubert and a doctor colleague who had been working in the US brought in outside finance to equip the oncology department with TVs and toys, and decent bedside clinical equipment. "I realised that to build a unit you need charitable donations, which we obtained from business people. It became an exemplar unit, visited once by Princess Diana. Everyone wanted to see it."

It was on a Europe Against Cancer course that Foubert was noticed by the director of the Jules Bordet Institute in Brussels, Belgium's only dedicated cancer centre, and he moved there as a nurse manager, taking a step away from the bedside. "At the time this was an ideal place – one of the few hospitals doing rehabilitation, pain management, stoma therapy, breast cancer nursing and so on. It was a pioneer, particularly in rehabilitation under psycho-oncologist Darius Razavi."

However, Foubert says that it is all too easy to lose leadership status, which he feels happened at Jules Bordet from his nursing perspective. "You need to keep on top of protocols, standard care plans, clinical pathways and quality – things you can measure – and not just take care of the basic needs of patients, which makes oncology nursing no different from general nursing. I was busy with nursing shortages, and generally the hospital, like many others, was firefighting and found it hard to go forward with nursing development."

With other cancer centres springing up in Belgium, all starting to do similar things, adds Foubert, it becomes difficult to maintain a unique reference presence. His main focus there was as a nurse champion, visiting every unit each day, and paying particular attention to the needs of head nurses, who he says can often be in very isolated positions.

Foubert went on to become a continuing education coordinator at Jules Bordet, while starting a teaching career as a lecturer in nursing and midwifery at Erasmus. He still has a strong link with Jules Bordet, however, as he runs a fatigue clinic there half a day each week – fatigue is a special

## FATIGUE – GOOD ADVICE IS KEY

Fatigue has become one of the more difficult side-effects for healthcare professionals to tackle, despite it being one of the most common complaints of cancer patients. "Doctors and nurses tend not to be interested in it because its origin is not known – they prefer to treat symptoms such as pain, where they know they can do something," says Foubert. At the recent World Congress of Psycho-Oncology, he presented a case study of someone with fatigue and borderline anaemia. "The only questions from doctors were about the anaemia – it was a psychologist who asked me how you measure stress levels and was interested in the problem of fatigue in cancer survivors.

"Also, what I've learnt in my fatigue clinic is that most studies on fatigue have been done on patients undergoing treatment, but it can continue in people who are cured or no longer treated – there is little available on this population in the literature."

Fatigue management should be integrated as a standard care plan, as with pain management – but it is not happening in most places, according to Foubert. He says nurses are well placed to develop management strategies by approaching the problem as a lifestyle issue, in a similar way to a dietician advising on weight loss. "If you want to lose weight I can coach and motivate you – but you are the only one who can lose weight. Fatigue is the same – you have to change your lifestyle and habits and think about how you deal with reduced energy."
This can touch on painful personal issues. "When I ask women with families, 'When was the last time you did something for yourself?,' they often start crying. When someone is diagnosed with cancer, the emphasis is on the war against it – the treatment – and not how you come to terms with it. We have to change our minds about lifestyle issues being too difficult to tackle."

"A bedside nurse wants practical, interactive training that they can actually implement"

interest and one especially relevant to oncology nursing (see box).

At the same time, an involvement with EONS started to take off. Initially, he had little knowledge of European oncology societies, or conferences such as ECCO (the European Cancer Conference). That was all to change as he quickly made his presence felt, soon being invited to become an EONS board member.

"When I first became involved, EONS was looking at the status of oncology nurses, especially in eastern European countries. It's still the case that there are major differences in status in Europe between east and west and north and south – and what I saw was that EONS could only be important if we could reach the bedside nurse, those who do not normally have the opportunity to go to conferences. That was my goal from day one, and I'm happy to report that, by the time my presidency of EONS came to an end, we had increased membership to 32 national oncology bodies from 28 countries."

EONS has a core strategy under the acronym CARE – meaning Communications, influencing the Agenda, Research and Education – and education has been the most important main activity, and should remain so, according to Foubert. "It is the biggest need of European oncology nurses," he says, noting a number of challenges, from increasingly specialised cancer treatments, to shorter hospital stays (which may mean community nurses needing some cancer expertise), to changing role boundaries in hospitals, with some countries allowing what were previously medical procedures to be carried out by nurses – those 'mini-doctors'. He would also like EONS to be the platform to launch specialist nursing groups, such as for breast cancer, palliative care and geriatric oncology.

According to Foubert, what has been lacking are educational packages that address real needs – rather than supposed requirements – and also materials that are usable across the many different cultural healthcare environments in Europe. "What used to happen was that the industry would bring out a pack, say on nausea and vomiting, for nurses, but there was no research on whether there was a need for it, and what the current state of knowledge was. Also, much educational material has come from the UK. While some of this is very valuable – such as materials on biological therapies – it is much too complicated for the bedside nurse, and of course it is written or presented in English, not a common language for many nurses. Bedside nurses don't want an all-day lecture – they want practical, interactive training that they can actually implement."

What has also been missing, he adds, is evaluation of the impact of education and the dissemination or use of the new knowledge. "We assume that people who have been educated will perform better. When I was an education manager, if a problem came up, managers said nurses need to be trained and the problem will be solved. That's nonsense."

Educational programmes at EONS, says Foubert, now emphasise needs assessment, piloting, evaluation and dissemination, and don't just assume that the training alone is enough. The first initiative was NOEP (Nutrition in Oncology Educational Program), launched in 2003, and a raft of other programmes with impressive sounding acronyms have since got underway, such as TITAN, BONE (Bisphosphonates Oncology Nurses Education), Speak Up! (dialogue with patients on nausea and vomiting) and Target (training in targeted therapies).

TITAN is being rolled out across Europe by national oncology nursing bodies. So far, more than 2,000 nurses have taken the course in 21 European countries, and it is now spreading worldwide, with Australia running its debut course last November.

Foubert – who travels to teach it himself – says cultural adaptability is a key marker of success. "I was in Slovenia at the Institute of


Team TITAN. At ECCO 13 with colleagues from the training course on thrombocytopoenia, anaemia and neutropoenia which was developed by EONS and is now taught all over the world

## "The context of care in a complex situation is never the same – that's where evidence-based nursing fails"

Oncology in Ljubljana recently – they have translated the materials, and even attended the training in English on a Saturday." But there can be obstacles to overcome. "In this case, a medic called the nurse director and said they could not give this course as there is no medical doctor speaking – how can nurses possibly explain anaemia management? It was cleared, though, by asking the medical director, who supported the nurse director. This sort of situation still arises in some countries."

The educational approach that EONS is developing is also designed to fit in with the Bologna Agreement, the European Union programme that aims to standardise higher education across Europe – examples are a core curriculum for cancer in older people and the EONS post-basic core curriculum in oncology nursing.

Foubert is concerned by a global lack of attention to 'evidence-based nursing' – he feels there is a pressing need to evaluate how research can translate into effective practice in often complex care situations. Existing models, he says, "are not appropriate for the complex interventions in which the experience of the patient plays an important role in effectiveness. The context of care in a complex nursing situation is almost never the same, and that is where evidence-based nursing fails, as its principle is that the situation is always identical." The solution, he adds, lies in nurses receiving training in scientific research – and researchers in clinical research.

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An example close to his heart – especially with his experience with children – is the assumed need in many units to wear protective clothing when with patients, say with neutropoenia, who are at high risk of infection. As even newborns in incubators – one of the best protected places in a hospital – are colonised by many bacteria within 72 hours, evidence now points to abandoning protective isolation, with subsequent benefits for patient contact (such as being able to hold a child). But for such initiatives to become the norm, says Foubert, training, measuring and monitoring, reflection on current practices and above all nursing leadership are required.

He cites thoughts from various academics about how advanced practice nurses can 'unite the worlds of scholarship and practice,' and that nursing, like all healthcare, needs 'knowledge workers' with skills such as leadership and delegation, clinical judgement, teamwork and use of new technologies.

It all adds up to a substantial agenda – and for allies in the effort, Foubert says partnerships with patient advocacy organisations offer one of the best ways forward. "Nurses are often closer to patients than doctors, and can be of great help when patients have to make decisions," he says, adding that EONS is forming close links with leading advocacy organisations, such as Europa Donna and ECPC (European Cancer Patient Coalition). "Patients and nurses together are much stronger than on their own and have much more power than the medics at the political level," he says.

He is direct about problems he sees with doctor–patient communication. "Although most doctors say patients are important, they are often afraid to involve them in decision making. When I was on the board of FECS and other advisory boards I kept saying, 'Shouldn't we ask patients?' How else are we to know what they think and need?" A particular bugbear for him is educational material given out by nurses that has had no input from patient groups.

## "Patients and nurses together have much more power than the medics at the political level"

This is not to say that nurses can assume they are close to patients – factors such as the shorter time patients spend having treatment make communications more difficult, while communications itself is a skill that needs training. Further, doctors have an advantage in that communication about, for example, a certain treatment is easier, as there is a specific goal in mind. "Years ago I did research for a patient league in Belgium that found patients were more satisfied with explanations they got from doctors, who may have carried out hundreds of the same procedure. I think that nurses often talk to patients without a clear objective in mind."

As part of solving the nurse 'identity crisis', Foubert feels that making more of being an advocate who makes time to know patients better will help, and he is an advocate himself of having nurse case managers to provide continuity and a single point of contact for a patient – currently an 'unusual role'.

On the wider stage, Foubert is organising the patient programme at the next ECCO meeting in Barcelona, previously managed by doctors. He sees this as an interim step to handing over the job to a patient organisation such as ECPC. As he says, he knows how to 'work the system', through working with FECS and EONS, and is hopeful that the patient advocacy organisations will avoid the mistake he feels that oncology doctors have made – speaking with too many voices. "It has been very difficult for politicians to know who to listen to. I hope the patient organisations will avoid having too many lobby groups."

These concerns played a role in his recent decision to turn down the offer of a director's job at FECS. "I was honoured, and may well have accepted a post to run the conference side earlier in 2006 – but I don't want to be part of lobbying, as the mission of FECS is still not clear to me."

It was certainly a brave step to offer Foubert that FECS post given his trenchant views on multidisciplinary working and the tough time he had as a board member, where he often spoke his mind. "When doctors talk about multidisciplinary teams they usually mean medics and not nurses. But nurses have to earn their place on the team – and that has to do with image, respect and leadership."

Foubert is a member of the ethics committee at the Free University of Brussels, a post he enjoys greatly and where he feels among equals. As for his lecturing post, he admits he's known as a pretty strict teacher, not tolerating lateness or backchat, but says he applies himself more as a mentor and coach, taking a lot of time to help students achieve goals. "Teaching is just explaining things – but coaching is, say, going on practice with students and working together towards objectives." Any new job for Foubert will have to accommodate at least part-time teaching – it's a love he won't relinquish.

Foubert and his partner live in Antwerp, where he's forced himself to get out to cultural activities such as opera and ballet by buying season tickets. Long cycle rides are also on the agenda, and he likes entertaining – but not with prepackaged foods. A favourite book is *The Queen and I*, by Sue Townsend, which imagines Britain's Royal Family forced to live as ordinary, poor citizens – but any thought of bringing down medics a peg or two is purely coincidental.

"I have made a clear choice about my future by taking on the daily business of EONS," says Foubert. "If I'm honest, I can't say I've been the average nurse; I'm a man and I did not encounter any major opposition at work as a nurse. Now I'm travelling everywhere, staying at the best hotels. I recognise that it's easy for me to say to nurses, 'Stand up for your rights,' but I hope I'm respected enough for nurses to know I really do mean to close the gap between the worst off and the best."