Medicine of the Person
65th International Meeting
28th- 31th August 2013
NL – SCHOORL

Conference 5
Dr. Pierre Carnoy, F

August 31rst 2013

Let us learn to better hear the voice of older people

Those who came in 2012 to Sancey-le-Long in the French Jura will maybe remember how the saint of that village founded a community of sisters of charity under the protection of St Vincent-de-Paul at Besançon. She lived at the end of the 18th century, lived through the French Revolution and was an important figure providing medical care for the poorest of the poor.

That was Jeanne Antide Thouret (1765-1826)

A very thick book tells the story of her life : 'We have heard the voice of the poor.' I am still practicing as a geriatrician and I oversee a call centre at the hospital. My career has always led me to look for novel solutions to all the calls for help that we receive. Here we are in 2013 and I would like to reflect with you how the attitudes have changed in your country to the next challenge which is ageing.

I have chosen two very different subjects;

The first is so important for all older people : 'Will I be able to stay in my home when I become more dependent?' What are we proposing in France and in Europe and are there any new solutions?

The second, much more technical, concerns some new responses to that dilemma frequently faced by older people : 'I can't sleep.' My experience of overseeing the night shift at the telephone service has meant my ideas have evolved considerably with regards to this.

1/ Staying in one's own home

Jeanne Antide Thouret was a woman who got up close: she went where others didn't want to go, an area with a bad reputation, a military hospital with old wounded soldiers who were starving, covered in lice – yes, we are talking 1800-1815 – she was there with her sisters to feed them their bouillon, their herbal remedies and the cures prescribed by the doctors.

Everyone appreciated the very real benefits of her service, thieves almost became lambs, the morale of the troops improved, all because of her presence, her care and her human warmth. In parallel with this she had created schools for girls, her mission to teach being as important to her as her call to tend the sick. She was so successful in 30 years that many were jealous even within the church itself with denunciations and false witness. Each time Soeur Jeanne Antide took the part of the poorest. As you say in English 'She was tough!' Napoleon himself in 1807 wanted to reform religious congregations recognising the indispensable role of communities dedicated to service in hospitals and in teaching.

Let us leave for the moment Sancey-le-Long, and and let us examine 200 years later what care at home we propose for older people.

The specialty of geriatrics is only 40 years old and I remember that as a junior doctor in 1976 the elderly care job (nick-named 'hospice') was not very popular. For me, during my 4 years training I sought the exciting jobs (emergency, paediatrics, cardiology, gynaecology).

Around the same time, France was waking up to the emergence of so-called 'medicalised' retirement homes….all of which decreased the chance of keeping the person at home. Palliative care was in its infancy, and for a doctor, admission to hospital, so unsettling for the patient was frequent and inevitable.

A young sociologist friend, Guillaume Malochet, was asked in 2010 by the prime minister to study the ageing process of older people in France and to compare them to 7 other countries: we as a nation have taken the wrong path and fallen behind but are thankfully catching up. For humanitarian and economic reasons (the crisis has struck!) countries which opted for keeping people at home and promoting other ways of keeping people independent (serviced accommodation, community living, intergenerational living) **are doing better.** The level of patient satisfaction is much higher. Yes, in France things have been changing over the last 8-10 years, our ATTITUDE has changed influenced by a combination of choice and new ideas.

As community physician, I am now more focussed on my patients' homes. I stopped being the doctor responsible for a retirement home in 2010 and I can spend more time visiting patients at home. This coincides with most doctors being unwilling to do these domiciliary visits. Patients have to come to the clinic whatever their level of dependency.

I like to imagine Sister Jeanne Antide encountering all this misery, these 'malodorous areas', these homes transformed into a hospital room, these flats that are often not adapted to the patient's needs. I dare to make a further parallel with her, as she in her time, trained a number of nursing sisters who went out into the community.

Where are we today? Less than 10 years ago the doctor was often the only one alongside the family (if there was one) caring for these demanding patients: he had to make do, help was put in place, but without co-ordination, evaluation or real planning. Now that geriatrics is much better taught to students and better recognised in training programmes within the hospitals a useful transformation has been allowed the happen: the key word is creativity: the creation of new services, of networks, of systems, of new careers incorporating a goodly quantity of humanity and professional conscience.

How has this happened? By motivating the carers, better training, the beginnings of recognition of their roles by their seniors and above all through the patient and his family. There are two inevitable pitfalls to avoid: too much help and the financial side (will we be able to honour our commitments to the elderly in these times of austerity?)

Madame Paulette, 67 years old, lives with her companion who is much older than her; they become more and more isolated and Madame sinks into serious alcoholism. In spite of the care offered, social care, meals on wheels, district nurses, the situation becomes worrying. I call on a community psychiatric nurse who first of all, seeks to create a relationship with her. It is only gradually and after a certain time spent just observing that trust grows. I can set up a plan and thus, at a critical moment, can talk to Paulette about going into hospital in a specialist psychiatric unit. She accepts, but unluckily, there are no beds; I have to direct her towards a non-specialist service (psychiatry of the elderly with dementia). It is 2pm, it is an emergency, I call the psychiatric nurse. It's a new

situation for me. What ATTITUDE will she have? 'I will accompany her myself' says this nurse who thus at 4pm resolves the crisis in a humane and professional manner; she succeeds in admitting the patient, reassures her, convinces her this is the right thing to do. During this stay in hospital to withdraw from alcohol, the same nurse will stay in touch and look after her discharge in the same way. WE see her each week: there is no relapse, and in return, Paulette expresses to us her gratitude for being there before the worst could happen. This first example shows how novel solutions are possible when the various players providing healthcare get on and use their initiative.

Soeur Jeanne Antide also knew how to provide palliative care in 1810. The sisters didn't abandon the sick person, the religious aspect of care was tolerated in those days, one can imagine the conversions, the absolutions as death approached. Things are different in 2013 but not that different. Let us consider hospital at home, a service provided by the nearest hospital which aims to care for the patient at home. What is excellent about it, I think, are the facilities (everything one could wish for to provide palliative care is available – morphine pump, suction….), but above all else the human element: trained nurses and nursing assistants. What ATTITUDE do they have? 10 years ago, many incurable or elderly sick people had no choice; they had to go into hospital to die. Once it's been decided to provide hospital at home, the doctor remains the pivot of care, prescribing, accompanying and working with the team : Sister Jeanne Antide cared 24 hours a day and hospital at home guarantees that constant presence, the nurses can even be reached at night, they provide reassurance for that last stage in life by their ATTITUDE: competence, empathy (understanding what the sick person is feeling). Barely 15 years ago the word empathy didn't exist, it must have emerged due to the prayers of many saints!

In the area of Alzheimer's disease which is so topical, I have seen important changes which have occurred in only a few years. Those in Canada, and above all the Quebec have always taken the lead by their ATTITUDE;

Two examples;

"MORE CARE than CURE": more personal care rather than technical procedures.

The Alzheimer's care bundle: this permits family helpers to have a rest, to GO AWAY for a few days or weeks: staff come to look after the old person with dementia living with them at home 24 hours a day (Jeanne Antide thought of this with her devoted nuns there permanently!). This system is being set up in France, supported by the French Foundation.

"CARE MANAGER"

Just in the last six months in my service at Moulins, a new post has been created: that of CARE MANAGER (in French 'Gestionnaire de cas'): a huge improvement for us doctors; this coordination of care and technical provision. Sister Jeanne Antide would have approved of it….it is this formation of a community, this communication between all providers of health care. The General Practioner knows the patient the best and will always remain the pivot of health care. He or she can't do everything, particularly when it comes to social care and to the family. Equally, after trials of summaries, liaison booklets, coordination centres, encounters and sharing of care, there was one piece missing in this medico-social puzzle, and that was a 'care manager'.

Jacques, 87 years old, lives with his cat who kept him company all one night after an unfortunate fall, and he is hugely grateful to this animal. His precarious situation and his refusal to be admitted to an institution mean that everything becomes complicated: his family live a long way away, neighbours are not there as much. Problems with memory and a strong personality complicated his package of

care: the nurse visiting, failure of delivery of meals when he wanted to go to a restaurant by taxi without letting anyone know, difficulties with domestic help.

Stephanie, our new 'care manager' came to help me, to take the conductor's baton to organise the music as Jacques wanted it: to give him the choice to continue living at home. Not at all easy day to day, it was necessary to react quickly to a variety of problems. Stephanie was to look after him as well as 40 other patients in her care.

One example: I use the internet a lot in my work, his children are far away and yet near (Colombia, Paris, Spain). With Stephanie we all communicate by e-mail, the 5 of us, and when there are rapid decisions to be taken, I can ask Stephanie to carry out the necessary actions (vet, restaurant, changing glasses, co-ordinating the help). We will return later to what became of Jacques.

The transition is not easy, we will leave Jeanne Antide (end 18th – beginning 19th century) to find one of her contemporaries Charles Darwin. We are going to talk about SLEEP.

2. How to Sleep Well?

I would like to talk to you about sleep, about your sleep. Did you sleep well? We often say this in the morning to those we meet at breakfast. Behind the banality of this remark, please allow me to draw some conclusions.

Our day will be determined by the quality of our sleep. Some people will get up on the 'wrong foot' (a very French expression); they are already tired, not to say grumpy before the day has even started. Others will tell you about the dream they had or which nightmare has disturbed them. Thankfully, some of you will be able to say to me: I had a great night! It's the third day of the conference, Pierre, I'm on good form this morning. You can see that it's important to get a good night's sleep.

I would like to remind you that by the time you are 80 you will have spent 25 out of those 80 years asleep! It is in all our interests to look after our sleep, particularly after the age of 60: the ultimate aim is to rest our brain and the rest of our body. I would like to compare our attitudes as a function of our age and of our medical experience. Have they changed where sleep is concerned? Are we, doctors, sufficiently comfortable with this subject to offer medical advice? It took me some time to have a view of it that was clear, liberal and ecological.

Recently, I was at SAMU (the French emergency medicine coordination centre), as doctor controller of emergency telephone calls. It was 2 in the morning and I took a phone call: 'Doctor, I can't sleep.' I have to admit that didn't put me in a good mood! I felt like telling him that he should first of all talk to his own doctor, but he told me dryly that he wished to speak to me. Was this just an excuse and was he really ringing about night-time anguish? You can see that insomnia can become a reason to call.

I am not going to deal here with severe insomnia, but that which we deal with day to day.

In 1980, when I was appointed, a medical visitor came to my consulting rooms: 'Doctor, I would like to recommend a new anxiolytic, LEXOMIL (Bromazepam), which is much better tolerated than TEMESTA (Lorazepam) and which induces less dependence. Look at this capsule, it can be cut into 4, so you can give very small doses ¼ - ½ - ¾ '. It is true that since 1972 TEMESTA has been considered a 'drug' which few patients manage to wean themselves off. With the passage of time my attitude has changed profoundly and for several years, having experienced periods of insomnia myself, I have been researching the why and the how.

We are going to review together the physiology, and we will rely on the work of a French professor, sleep specialist, Professor PEROL who taught me to understand and have a great affection for Charles DARWIN.

DARWIN (1809-1882) went on to become a naturalist and a great scientist after studying medicine. On board the Beagle in 1831, he went on a 5 year journey round the world and returned convinced that man had evolved according to his theory of the origin of the species ('the Beagle Channel' in Patagonia is named for him); Our ancestors slept very little, there was always a 'black eagle' in the group, a watchman to alert the rest if a bear approached their cave.

Gradually, I have become a doctor specialising in sleep, as often, at the end of their consultation patients want to talk quickly of their insomnia. I get them back for a 'sleep consultation': I take the time to explain to them the normal functioning of sleep and then I move on to the problems linked to insomnia, in particular, anxiety.

This approach is based on the scientific study of sleep based on recordings of sleep. Let us be precise and accurate! We all know that as we get older we sleep less: after the age of 60 we sleep about 7-8 hours; after the age of 80 it can be only 6 hours. The quality of sleep changes as well: the sleep is more shallow, we wake up much more often, we have more trouble falling back asleep and we think, incorrectly, that we haven't slept at all.

The night can be split inot 4 cycles of sleep lasting about 90 minutes each

I'm going to call them the **trains of sleep**. After the age of 60, there is the one from 22-22.30, one from midnight to 12.30, from 2-2.30, from 4-4.30. If you miss one of these trains (because you go to bed very late, you have woken in the middle of the night because of illness or worry), the train will not wait for you, you will have to wait for the following one, but what to do in the mean-time?

Everyone has their own idea of what to do: for some a good book, a moment of meditation, relaxation exercises, for others a manual job: the washing up, the ironing, avoiding the television or the computer. You see that I recommend that the person gets up if they cannot get straight back to sleep. This period of being awake could last 30 minutes or more: but don't worry, the next train will arrive, you just need to calmly await the sign that you are about to fall asleep: yawning, eyes closing or even better the book falling on your nose!

After a certain age, it is no longer possible to sleep like a baby: out of 4 successive nights, it has been shown that you have to accept one or two poor nights, then the 3rd or the fourth will be good and the 4 night cycle will start again. So, I often say, it's like the weather forecast, the weather is not always fine, and inevitably, the weather forecast of your sleep will be unsettled.

This is the moment to talk to all those who take a sleeping pill or a tranquiliser (occasionally or all the time). I hope that at the end of my talk some will want to try and wean themselves off them. It will take a long time; it will have to be done very gradually with good medical advice.

Let us return to the **great sleep train;**

(I have illustrated it as an appendix and in colour thanks to Philippe Lernould)

According to this model, you see that the wagons are attached. I haven't yet mentioned that there are 10-15 minutes between each 'train': those are the mini-awakenings. As children or young adults, we don't remember them: we think we have slept all night. In contrast, once older than 60, we wake up to some extent; this should not the time to think, to keep mulling over our problems, to go over

what we are going to do the following day, but to relax, focus on our abdominal breathing, be kind to ourselves, to WAIT.

Let us deal with the quality of sleep in each cycle:

There is a part where it is non-REM sleep (RESTORATIVE) and there is part which is REM sleep (NON-RESTORATIVE=the brain is active, whence dreams and nightmares).

Examine well the difference in colour between each wagon with this model;

At the beginning of the night there is a lot of BLUE (restorative), little RED (non-restorative).

The length of each type of sleep is reversed at the end of the night, during the last cycle; LITTLE BLUE, LOTS OF RED.

I can deduce how you will be the following day as regards tiredness;

Lots of BLUE; the person who goes to bed pretty EARLY and gets up EARLY (6.30 is VERY, VERY GOOD): you will be on good form.

Lots of RED; the person who goes to bed very late, misses some of the cycles, and above all gets up late; they will be tired. I must emphasise; if you want to ARTIFICIALLY PROLONG your night at 7 or 8am and want at any price to take another train, that period of sleep between 8 and 10 in the morning will be very poor; too much RED, and don't forget, **the brain is working,** so it requires energy; you brain will be churning when you wake up; it is a paradox, you sleep but you don't rest! Understand, I am not in favour of lying in. Even for young people, getting up at mid-day is a big mistake as far as their physiology is concerned.

In my eyes, this is a very serious topic, tackled very badly by doctors. We are dealing here with LOSS, and in French as in other languages we talk of 'losing sleep' of 'not managing to find sleep'.

Even our pope Francis, on the evening of his election on the 13th March this year, thought of this: his first words to the crowd in Italian were 'Good evening!; and at the end he took the microphone and very simply wished us 'Good night! Sleep well!'

To finish with, I return to Darwin's theory; some people are more 'black eagle' than others. Their sleep quality is less good. But we have just been explaining that we can keep a natural sleep cycle. To resort to medication should be a rarity and only for a limited time and on the advice of a doctor.

I would like to finish my talk by returning to Jacques, that 87 year old man and his cat! In spite of several months of effort by my team, yet another hospitalisation resulted in his admission to a retirement home. This went well, he had been well prepared, my new mission was to try and preserve his new measure of freedom. Professor Huguenot, a great specialist in abuse, used to say; 'Admission to an institution is the most violent of traumas, experienced during a period of one's life when one is least adaptable.'

In France, last March, an annual report made waves: the national director of prisons wanted to extend his area of expertise to old age homes, frequently places of deprivation of liberty. The minister of health was not in favour but acknowledged that the question of 'old people's consent to admission' needed to be addressed. Much rests on a future law dealing with society's adaptation to ageing scheduled for the end of 2013.

Faced with an ever-growing level of violence against older persons (ill-treatment, lack of means, insufferable waits for the emergency services), we can still find other tools to combat the violence

such as kindness and gentleness. Jean Paul II wrote; 'Mankind has need of affection. It has need of intimacy.'

Finally, I turn to Paul Tournier, who I never knew. At the age of 76, he was asked to write about ageing and he was delighted, as this was 'his second career' as writer and lecturer. At the end, he would say, that in spite of adversity; 'A new adventure lies ahead of you, it's up to you to create it.'

Soeur Monique from Sancey-le-Long is thinking of us this evening, and I would like to thank her for helping me to tread in the foot-steps of Jeanne Antide.

Bibliography :

- Théodule Rey-Mermet : Nous avons entendu la voix des pauvres (we have heard the voice of the poor) (Ste Jeanne Antide Thouret)

- Jean Yves Pérol : Vaincre les insomnies et l'anxiété (overcoming insomnia and anxiety)