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Pain

Infomotrice

PAIN CAN BE REDUCED WITH YOUR HELP



Dear friends,

The prospective study¹ that we conducted in 2008 shows that pain is the first concern of CP patients and their statements as well as those of nursing staff or researchers that you will find in this issue confirms it.

La Fondation's mission is to bring answers to our children who grow up with this pathology, to their families, to adults who live everyday the difficulties and pains of their handicap. For this, we need to direct the research effort to solve the most urgent of problems. Alleviate the pain is amongst those.

The subject of pain reminds us of La Fondation's three missions: give information, assess and encourage research.

The patients and their families must know that pain is not inevitable; that nurses and physios learn how to recognize it, in particular in people (suffering from multihandicaps for instance) who have limited communication capacities. Creating pain assessment grids will permit to adjust the cures to patient's needs. By raising the professional's awareness and developing expertise, treating the pain must be the aim for everyone concerned.

La Fondation must also encourage research projects on pain related to CP, by helping these projects to become a reality like it did for Dr. Hodgkinson's study mentioned in page 3.

All this is possible only because your, donators, sponsors, friends of La Fondation, helped us with your donations. Your donations are what transform a project into a reality and contribute to giving answers to the questions that handicapped persons pose to research.

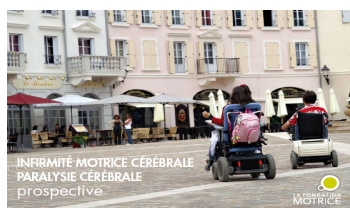
The pain is something which is often neglected as too closely associated with daily life and it will be one of our main priorities for 2010. For this new year, we must mobilize all our efforts to be up to par with the hopes and needs expressed by those we asked to speak in this letter.

We thank you with all our heart for your continuing commitment to La Fondation and wish you all, donators, patients, families, carers, nursing staff and researchers, a Merry Christmas and Happy New Year.

Dr. Alain Chatelin
Chairman

¹ The book describing the approach and main results of the 2008 prospective study is available with the Fondation.

INFIRME MOTRICE CÉRÉBRALE /
PARALYSIE CÉRÉBRALE : Prospective – 144
pages, 15 euros



“Pain is so much part of my daily life that I don't even speak about it anymore ...”

REDUCE THE PAIN LEVEL IS THE MAIN EXPECTATION OF CP PATIENTS

When asked, patients mention pain as their main concern. This issue was examined at the Conference on October 29th.



Conference of October 29th held for Association des Amis de la Fondation Motrice in the Council Hall of Paris XVème : **“Pain in children and adults with CP”**, with Dr. **Chantal Wood**, in charge of Assessment and Treatment of Pain Unit at Hopital Robert Debré in Paris and **Marc Zabalia**, professor of child and teenager psychology at Caen University.

This result came as a surprise to those who thought that mobility improvement would come as the main priority. However, it confirms what many professionals have observed for several years, i.e. the importance of pain in the daily life of CP patients.

➔ **Pain in children is still often underestimated**

Until 1988, only two studies were available on this issue said Dr. Chantal Wood. But in the last fifteen years huge progress have been accomplished in the recognition and assessment of pain in children and in particular handicapped children.

Chantal Wood and Marc Zabalia also underline the importance of assessing the pain through assessment grids that facilitate an exchange of information between parents and doctors and the effective treatment of the child's pain. For instance, *Profil Douleur Pédiatrique* is one of the tools made available to parents to help them recognize the signs and “measure” the pain in their children who are unable to communicate orally, on the basis of pain indicators (changes in posture, in facial expressions) which they can then use to give indications to medical teams.

➔ **Pain is the cause of more than half of the medical consultation of adults** supervised by medical teams from Breizh IMC network.

Nevertheless, this figure, high as it is, does not reflect the importance of pain in the daily life. Many patients are so used to being in pain that they “forget” to mention what they feel or are resigned to suffering. On their part, because they are not fully aware of this issue, many doctors see it more as a “symptom” than a phenomenon that requires a specific treatment. Yet, solutions exist or begin to appear, like the use of botulic toxin to relax muscles as spasms are the first source of pain in CP.

For pains that make daily life even more difficult and can increase the handicap, causes are also to be found in bad postures during physiotherapy sessions or repeated spasm of certain limbs, such as, for instance, chronic shoulder tendinitis when the arm tends to bend backwards.

In the seventies, it was thought that mentally deficient people probably did not feel pain.

Preventing pains that will appear in adulthood is one of the reasons why children are operated when growing up and these operations are *per se* a cause of pain. Patients and parents must therefore compromise and make choices between treating the pain even if the cure has a negative effect on vitality, between treating with medicines or surgical operation, between “living to the full” today without knowing what tomorrow will be and treating with the future in mind.

To all these questions we do not have enough answers: not enough pain assessment in children and in adults; no enough assessment on the effects of treatments with medicines, of surgical and orthopaedic treatment; not enough clinical tests to adapt treatments to specific features of CP...

But most of all, the fact that pain is not treated as a separate issue reflects the lack of information on this problem : patients and carers are not sufficiently informed about existing therapeutic solutions, even though recent public programmes have improved awareness.

- 82 % of the participants declared being in pain, with an evolution on several years for 73 % of them.
 - 25 % of the population never saw a doctor for that reason.
 - 61 % of patients who saw a doctor felt an improvement in their situation.
- (Sample: adult CP patients in Brittany).

Extracts from “Pain in adult CP patients”

P.Gallien, B. Nicolas, F. Dauvergne, S. Pétrilli, A. Duruflé, J. Houedakor, S. Robineau
Revue Motricité Cérébrale n° 30 (2009)

Pain evolves during life, depending on orthopedic issues, surgical interventions, rehabilitation or age.



Dr. Isabelle Hodgkinson, expert in functional rehabilitation for children at l'Escale hospital in Lyon, conducts a study to better understand pain mechanisms in children. La Fondation is cofinancing this study.

Why is your study so specific?

The study is based both on a great number of children (about 385, between 4 and 10 years of age, all over France) and on a long period as it will be conducted over 10 years. The participating children are all suffering of a serious form of CP and cannot walk. During 10 years, we will observe the evolution of pains, posture, hip dislocation in those patients, rehabilitation programmes and everything that is likely to influence their hip problems

What is the reason for this study?

Several years ago, I conducted a descriptive study on teenagers aged over 15 suffering from CP, none of whom was able to walk: the idea was to observe the condition of their hips and to determine whether they felt pain. The starting point was that, at that time, children underwent hip operation at a fairly young age but I felt that these operations were not a solution to cure the pain. In fact, the study showed that those who had had an operation were no less in pain than people who had not had. Therefore, it was important to define another research protocol to find proof and enough comparative data to possibly question some practices. Hence this study.

What concrete results will this study bring to CP patients?

With a better understanding of pain mechanisms, we will be able to improve treatments with medicines, surgical interventions or rehabilitation, according to what is more adapted to the patient's needs.

Which part has La Fondation played in your study?

La Fondation is part financing the study, for "only" 30 000 € out of a total amount of 200 000 €, but its support allowed us to convince Hôpitaux de Lyon of the study high value and they provided the balance.

La Fondation's contribution was therefore essential.



Réseau Breizh IMC

Pain is always associated to CP but evolves according to the age of the patient. The situation with Dr. Philippe Gallien, expert in physical medicine and rehabilitation, and Fabienne Dauvergne, ergotherapist, members of Breizh IMC network.

In a 2008 study, you underline the issue of pain in CP and the link between age and pain level.

In our CP consultation for adults, we had noted that pain was the main reason to visit us and according to our estimations 80 % of our patients present pain pathologies caused by prosthesis or in the joints but also related to their age. The 2008 study confirmed this last point: in 75 % of cases, the pain level increased with age.

But isn't ageing is always associated with pains for every human being ?

Yes, the fact that pains usually increase when we grow older is not directly associated to CP. But we should rather consider that people with CP are more vulnerable to pain as because of their pathology the pains come at an earlier age and higher frequency. Indeed, the handicap increases with ageing.

Is this phenomenon sufficiently taken into account ?

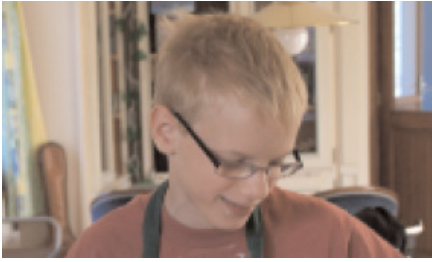
That question is precisely at the root of our approach : we aim to insure that the handicap does not prevent the screening of "ordinary" pathologies, and in particular pain, to which CP patients are exposed, like everyone else. For many doctors, the handicap "deletes" many other physical problems and it is more difficult to access health care.

What are the solutions?

Training, information, improved access to care for handicapped persons. They must know that pain is not unavoidable and have a right to be taken care of and relieved. Health professionals must be trained to pain screening. Today, it is not so much that there are no solutions, but rather that there has been no research on this specific problem. La Fondation has a part to play in this area, by helping to create multidisciplinary expert centres and support wide ranging and long term studies, or even retrospective research, to assess therapeutic practices and their benefits over time, so that strategies established for young children reduce the pain problem when they grow up.

PAIN IN EVERYDAY LIFE

Alexandre and Clemence's story



“Stop talking and hold my hand, I must concentrate”...

Alexandre is 15, not a child anymore. He has CP and cannot walk but for a few steps he is able to take with some help. This autumn, he had to have, like many others like him, a heavy surgical treatment with 5 operations on his legs: thigh bone, knees and feet. It is his fourth time he has to undergo surgery. Nothing unusual for a child with his condition, but every new operation reminds him of the previous ones, of the pain and it makes it worse.

As he cannot walk, these operations to his legs are important to correct bad postures that could be sources of pain in the future, to help him bend his knees without pain et make sitting more comfortable. Also not to have pains in his feet, something he has been suffering from for one year.

But at 15, he is a teenager like any other, living in the present and the pains linked to the operation and rehabilitation are not reduced by knowing they will reduce his suffering in the future. After the operation, Alexandre was in a cast from the waist down to his toes for 6 weeks and was in a lot of pain. “I imagine things that do not exist, like knives that slice my skin”. Sometimes, he just cannot take more and yells at his parents or carers when a change of position is too painful : “Stop manipulating this body, I cannot take it any more ! “ as if his own body was no more his...

In the last few days, Alexandre has progressively started to be put in sitting position but he still has not set a foot on the floor nor bent his knees (they are still painful). It is difficult to know whether the operation will have the expected results before rehabilitation terminates. So, his courage fails him sometimes : “You see that this operation was useless, I am in as much pain as before.”

In his class newsletter, Alexandre wrote : “Operations are very unpleasant. And after that, a lot of courage is necessary to stand up and go through two rehab sessions every day. Most of all, what I need is COURAGE, COURAGE, COURAGE, courage !!”

For Clémence, 28, pain is a constant companion. She can only wait for new therapeutic solutions

What causes the pains ?

It comes from spasms that are typical of CP. My doctor explained that my spasticity has become worse in the last 4 or 5 years and indeed every spasm has become more painful. I have constant pain in my back and legs. The pain is permanent and gets worse with every movement or spasm. My only relief is when I have a session with the physiotherapist when we do exercises to relax my legs or I get a massage or when I sleep. But sometimes pain wakes me up at night.

Apart from the physiotherapy, there is nothing to relieve your pain ?

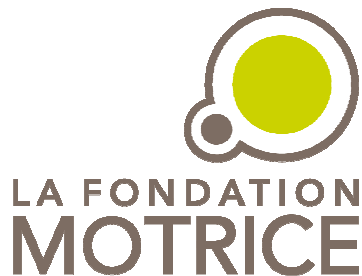
I tried many things but it did not work. My only hope at the moment is the Lioresal pump. It will be inserted under my skin and will release along the bone marrow this medicine to relax my muscles either at all times or at specific moments. I know that existing pain will not disappear quickly but being more relaxed I should be more comfortable.

“I wish something would be found to relieve me, but research must not be limited to this area : pain is part of a much wider problem”.

In the meantime, how do live this situation ?

It is very hard to live like that day after day and my handicap is more difficult to live with today. Pain, added to spasm, is extremely tiring. At certain periods, I have to lie down regularly to rest. Even during holidays, I sometimes must give up on some activities so rest after a day out.

At the moment, even if I know that people are aware of my situation, they do not have many solutions...



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