

Together, step by step

INTRODUCTION

When a child is affected by cancer, it is a particularly shocking and painful experience that can push an entire family to the edge of what is humanly conceivable and endurable. Despite the undeniable progress made with treatment, cancer remains the source of numerous problems with grim consequences.

It is a traumatic experience for the sick child, who is forced to confront an enemy that weakens both body and mind and causes the child to experience not only physical pain and discomfort, but also a sense of loneliness, a disruption of both social and school life and the destruction of everything that the child knew before this point. It is therefore essential to protect the child's survival instinct alongside everything that forms part of the child's life because although they are going through a unique experience, they nevertheless remain a child.

In light of this, the role that parents play is certainly essential. Yet the structure of a family becomes very fragile as a result of the exhaustion and fears directly related to the illness of a child. Other factors can also play a part; additional burdens to bear, which completely overhaul the family set-up such as feelings of sadness, loneliness or incomprehension, financial worries, or even work difficulties.

The ill child's siblings are spared no less, and experience feelings such as neglect, guilt and jealousy aggravated by the situation, as well as aggression and difficulties in expressing their worries and in coping with their parents' own fears. These children suffer too, and are left with permanent scars of this difficult period in their family life.

However, due to the intensity and the depth of emotion felt throughout this experience, the disease can add value to the life of all and be a unique lesson in life.

OUR ORGANISATION

Each of the founding members of the organisation '*Ensemble, pas à pas*' is the parent of a child who has either suffered from, or is currently suffering from, cancer, and has been treated by the Cancer and Haematology Unit of Brussels' Children's Hospital (Hôpital des Enfants). Following our own contact with other parents and our own personal experiences, we established an initial discussion group called '*L'étoile de Margot*' to meet the needs of these parents to be listened to, to talk with others, and to share their own experiences. Our desire to open up to other families and to organise other activities resulted in the creation of '*Ensemble, pas à pas*'.

Our aim is to offer to other families going through this experience a place where they are welcome to meet, to listen to others and to speak freely, removing the sense of isolation felt at different stages of the disease and allowing everyone to achieve a quality of life that is as balanced as possible under the circumstances. With the help of the medical and paramedical teams, various activities are organised for:

- the sick children themselves,
- their parents,
- and their siblings.

We do not want to in any way interfere with the work of the medical and paramedical teams. Neither do we wish to disrupt the work of others who play important roles, such as teachers, clinic clowns, musicians, and other existing charities.

We simply want to offer families the opportunity to 'go part of the way together', by lightening everyone's worries, reducing the social gap caused by cancer, and creating an atmosphere of trust between the various intervening parties.

This moral support will always be given with the highest respect for the opinions of all, whether these are of a philosophical, a religious, or even a political nature.

OUR ACTIONS

Taking families in their entirety.

We offer moral support to all the members of a family, be they the sick children, parents, or siblings. This support is offered at every stage of the illness :

- upon diagnosis of the disease and in the initial phase of treatment as these moments are crucial. When a new case arises, we aim to visit the child and their family, to discuss the situation and to offer our support ;
- throughout the treatment - at hospital or at home ;
- once the treatment is over, during the child's recovery from cancer ;
- and in the event of mourning.

Since the organisation was founded, we have made the following a reality :

• **The availability of a sympathetic ear on a daily basis** : At any moment, children like their parents, can ask us for individual contact depending on their needs and personal expectations. We offer meetings in the Cancer Unit when a child has been hospitalised, as well as meetings outside of the hospital context, and even contact via the telephone.

• **The opportunity to share experiences** : The discussion group '*L'étoile de Margot*' continues to run sessions every Wednesday morning. Parents, or indeed any adult close to a sick child, are invited to attend these meetings with the opportunity to express themselves freely or if they so wish, to simply listen. The meetings provide the opportunity to address various aspects of the disease together so that no-one is left alone to deal with issues and emotions that the disease causes.

The groups are open and free for all to express themselves. They do not have pre-determined themes so parents can discuss any issue that is worrying them and offer different points of view. These meetings allow attendees to inform and support each other whatever the situation, encouraging parents who may temporarily be disheartened and reducing possible

misunderstandings. The meetings also help to lessen worries and to make situations seem less alarming. Above all they create a sense of solidarity between parents. During the meetings, attendees are asked to refrain from expressing any judgment whatsoever on the values of others. The volunteers who conduct these meetings undergo regular training sessions, attend seminars and conferences and read specialist documentation.

• **A workshop, 'Ensemble, à petits pas', aimed at the siblings of sick children.** Twice a month, siblings over the age of five are invited to expression workshops. At these workshops, we encourage the children to keep personalised journals, to draw, and to model. We offer them the opportunity to express themselves, to listen to others, and to be listened to in a place of trust, security, and respect for every child and every family. It is a place where they can share their experiences, questions, anxieties and joys as well as their worries, difficulties, anger, wishes and expectations. It is a place for them to discover themselves by discovering the others.

Quotations from brothers and sisters...

Sharing experiences with other children made it possible for V. to make his ideas of the disease seem less alarming: "At first, I thought that cancer was a contagious disease".

A. enjoys coming to the workshop every Wednesday afternoon. He feels close to his brother in hospital by taking part in a workshop that has truly been designed for siblings.

X. was able to communicate his jealousy towards his sick sister: 'It's normal to be jealous ; she's always receiving loads of gifts'.

T. feels alone: "It's difficult to organise to go out with my friends because our plans are always messed up at the last minute because of my brother's illness".

The workshop is supervised by Cancer & Psychology.

• **Sailing activities : 'Le pied Marin' :**

Summer courses reserved for siblings : If siblings of a primary school age voluntarily attend the sibling workshop, it can be another story for their teenage counter-parts, meaning that sometimes it is difficult to keep a happy homelike atmosphere there. In collaboration with the organisation 'Force Douce' (You can visit their website at www.forcedouce.org) we offer teenagers the opportunity to experience the feeling of being a 'sailor'. This activity allows them to understand that being more than just a dream come true, sailing can provide a sense of solidarity, of team spirit, and can help to improve self-confidence. In July (since 2006), it was anchors away for 6 teenagers who set sail from Newport, Belgium into the North Sea.

Beginners' sailing courses offered to the ill children : From the beginning of the 2008 season we wanted a new challenge and so it is that we now offer the ill children the opportunity, through sailing, to turn the tables on their illness, to forget their worries and stress, and to reunite themselves with a body which has for a long time been mistreated. We hope this will help them to find some sort of fulfilment. Principally, these beginners' courses take place on indoor artificial lakes though we anticipate a series of trips to the sea during the summer for the more daring. Training in effort, perseverance and self-confidence, sailing offers these young children special moments in which they experience new sensations, improve their fighting spirit and learn to view life in a new way. This project can only be run by ensuring a close working relationship with the medical team and the non-profit organisation 'Force Douce'.

Young People's Experiences...

Sometimes the illness can result in difficult consequences. V., 13 years old and affected by a bone tumour, experienced great difficulty in settling back in at school. There was no intellectual gap to blame but he sensed a distance from his classmates at break times or during sports activities. Sailing distinctly allows him to turn the tables on his illness.

F., 13 years old and affected by a brain tumour, has had a particularly long and difficult personal experience. He has suffered from the illness ...for 13 years !... with a visual handicap, hormonal deficiencies, and epilepsy. More than giving him new sensations, sailing reenergises him, greatly improves his self-confidence as well as his independence.

M., 13 years old and affected by a brain tumour, has undergone a long course of neurological rehabilitation (psychomotor problems and speech problems). Sailing allows her to work on her problems with balance, and her independence.

K., 15 years old has suffered from the illness and then from the loss of his younger brother. For a few months he has also been facing his father's illness and his mother's depression. The summer course gives him some much needed breathing space.

M., 15 years old, has a younger brother who has been battling leukaemia for some years. It is the first time that she has been invited to participate in an activity for siblings, which allows her to put on one side her feelings of jealousy. A fan of the television and of video games, she often becomes withdrawn. Sailing provides her with a sports activity and a social opportunity.

- **Information** about the disease, treatment, treatment locations. We offer the possibility of adapted written support such as a colouring-book used to explain to particularly young children what chemo-therapy is, a brochure for parents called '*Pour vous, parents*' ('For you, parents') published by the French organisation '*Choisir l'Espoir*', a booklet for siblings called '*Pour nous, frère et soeur, Pas facile à vivre... Arthur a un cancer*' ('For us, brother and sister, It's not easy to live ... Arthur has cancer'), also published by '*Choisir l'Espoir*'.

- This information is supported by the release of a quarterly '**Newsletter**' ('La Lettre d'Info'). This is not meant to be either philosophical or scientific, but instead simply provides information about different aspects of the disease and its treatment as well as consequences of this on daily life and solutions for difficult encounters. The letter also includes information about how we can help you and about what we have done recently within the organisation.

- **Meetings between families outside** the hospital environment. For example, in December, we organise a Saint-Nicholas Day afternoon party where we offered party games to suit both the individual ages and capabilities of the sick children and the structures of each family such as the number and age of brothers and sisters. Through the party, families had the opportunity to meet 'under different circumstances', away, in the strictest sense of the word, from the disease and from the hospital environment.

- For the sick children who are of school-age, we encourage them to create a '**drawing/writing book**', a sort of private diary, in which the child, by drawing or writing, can express their emotions, fears, anger, and joy, and can write down their questions or observations. We remind the children that the book is personal (it is up to the individual child to decide whether or not to show it) but also that they should always remember that they are surrounded by people in whom they can confide and to whom they can turn such as their parents, doctors, nurses, psychologists and our organisation's team.

- For children hospitalised in the hospital's sterile unit, we have installed **computers with Internet connexions** and webcams. The sterile unit has six rooms, two of which are 'flux' meaning that they are destined for children who need to have a marrow transplant. In May 2005,

we installed a computer in each of the six rooms, choosing to use laptops as these require less space. In addition to the activities function, which includes games, paint, and DVDs, the purpose of these computers is to lessen the children's sense of isolation by means of **communication**, while in hospital for what can sometimes be a long period of time in a part of the unit where social and family contact is by definition limited. The children thus have the opportunity to access forums for sick children, exchange messages with their family, friends and even their school friends or teachers.

Notably, it was in this way that P. was once again able to contact his family living abroad, whilst E. remains in contact almost daily with her classmates. A more unusual use of the computers is that of the mother of A., who keeps herself up to date while her son is resting, and is able to make important payments via internet banking.

It would not have been possible to set up this project without the invaluable help of the 'Petit Coup de Pouce' team of Belgacom. The team financed the purchase of the equipment in two stages, first with three fully equipped laptops in May 2004 and then with three others in May 2005. We wish to extend our sincere thanks to this team.

- Help is offered to the sick children to pursue school activities, through links with their former school, the work of the R. Dubois school (the school at the Children's Hospital), and teachers at home.

At a child and/or parents' request, we may provide teachers or classmates with information about the disease.

- The launch of a **website**: www.epap.be (in French only). For the moment, this 'development at home' is limited to general information about our work such as our charter, actions, and partners. We are hoping to extend it soon.

- In April 2006, thanks to sponsorship and the help of parents and friends we were able to completely renovate the '**Parents' Room**', installing a kitchen and a rest corner so that all families now have a comfortable and relaxing surrounding at their disposal.

- Throughout the year, we have on several occasions distributed books, magazines published by children's press such as Wakoo and Astrapi, symbolic presents such as South American 'good luck' dolls, Easter eggs, and even sweets for Saint-Nicolas Day or Christmas to the children in hospital.

All of the projects are achieved through the work of charity. In order to purchase required material, to fund the cost of supervision, and to cover management expenses, etc. we appeal for sponsorship, or even organise 'home made' products sales such as through Christmas or flea markets.

AWARDS

2 important awards for us :

- ✓ in March 2006 : "Coup de Chapeau" from the "Fondation Roi Baudouin", RTBF and VivaCité, for the whole work of the association ;
- ✓ in 2008 : International Grant from Mattel's Children Foundation, for our sailing activities.

OUR PROJECTS

We envisage other projects, which we will only be able to realise over the medium or long term, dependant on financial and human resources. The projects include, amongst others :

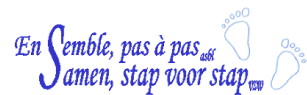
- more comprehensive psychological support for families, with the help of psycho-therapists, and also additional care provided to siblings,
- the facilitation of home care, be it treatment of the disease or palliative care,
- proper support in situations of mourning,
- further development of our website and the publication of our 'information letter'.

FINALLY

We have a dream : to pull these children and their families away from the turmoil into which cancer has pushed them. It is indeed 'together, step by step' that we wish to accompany them on this long and difficult journey, which at the same time is an intense and enriching experience. We know the task is hard but you too can actively contribute to achieving this dream. The support of everyone is vital for the success of our current and future projects.

Thank you all for your attention to our work.

Thank you all for providing the indispensable means to provide these children and their families with much needed welfare and support.



Rue des Augustines 74 - 1090 Jette - tél. : 02.425.60.54

Web-site : www.epap.be e-mail : info@ensemble-pasapas.be

Bank : BNP Paribas Fortis 001-4184509-05 IBAN : BE96 0014 1845 0905 SWIFT : GEBABEBB