

## WE DIDN'T EXPECT YOU SO SOON

**Claude Danan** – Neonatal intensive care is a young discipline that has made huge strides when one recalls that in the past, the approach was to mimic the intensive care of adults who are much older with the ensuing tendency to see babies as people in miniature, which they aren't at all. And so the therapeutic way forward has been observation, our real way to provide care is to bring up a stool beside a baby and look at it. The organisation of the ward was strongly impacted by this new way of looking at our tiny patients and it seemed that there was one thing that got in our way: hierarchy. It's to do with a shared history... And there are many personalities who came to the fore, often nurses who were in direct contact with the children and who transformed not only the relations between each one of us but also relations with parents. Because we are often dealing with premature babies who are sometimes minuscule, weighing 500 grams or less, and we created an environment, a way of living together rather in the manner of life in a village.

It's complicated to make a ward accessible. Many people, including carers at one time, spoke of babies with reference to their weight! "Oh, my little shrimp..." So we heard things like that. These linguistic intrusions in our working methods were really harmful and it has been a real struggle to oblige people no longer to use abbreviations. To speak in a manner that is simple and understandable by all, including by those from outside. To not refer to a child other than by its first name. And to give him his individuality, a personality, even before birth. After birth, all get involved in the interpretation of all the signs that can appear. And when a baby is in his incubator, he will have movements, ways to stretch out his hand, to clutch the finger of a nurse, to hold it to his mouth to suck it, to taste it, all these gestures but others too which comprise the language of premature babies, we need to learn them.

One day, we had our first baby that was so tiny as to alarm all of us. The mother came in and said 'Ah! Hullo everybody! How are things? I am so happy!' As a child, she had undergone radiotherapy and her uterus hadn't developed properly. She had already had three pregnancies with tiny babies that were each time a little bigger but never big enough to be capable of survival. We were almost trying to justify having such a small baby and she said 'But I have never done so well!' It was our first shot, for us the carers, of optimism and realism at the same time. Because this child has got on with his life, with all the difficulties faced by such a small baby, but he became bigger and one day, at six or seven years old, the ward telephone rang and he called us and asked 'I was a premature baby here, might I come to play my violin?'. So we replied yes of course, that he should come and play his little piece, we would be delighted to see him in any case and he came and he played wonderfully!... And with an emotion that completely

permeated the intensive care ward and all the alarms that we usually hear went silent, the babies were calm. Since then he has become a great violinist.

All these moments in which everyone has shared, where we have given the central place to the baby and of course their parents, have made us question anew the village itself, in particular its architecture, and to make space for the parents in places where they might feel more at home, with all the comforts. So this place is going to happen; right now everything has been pulled down and we have an expanse without walls... But even so when I recall the experiences of children each time I stroll around this worksite and how they will be replaced by other experiences with the continual presence of parents, this will probably completely change the way that we live.

There is an image that will stay with me all my life, that of watching a mother cocoon her premature baby, an African mother, and she is massaging him. And behind her up comes a psychomotrician who draws near and finds what she sees pretty and takes the mother by her shoulders and begins to massage her in turn. So this idea of Russian dolls where someone looks after someone else who looks after someone else in turn and then another, that is in some ways the emblem of our ward.

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