

The transmedia project *I Still Exist* is composed of:

- An exhibition of photographs and testimonies
- A book based on dialogues between young onset patients with doctors and volunteers questioning the differences between Alzheimer's disease, Lewy Body Disease and Frontotemporal Lobar Degeneration.
- A web-app for tablet developed with the support of DistAlz allowing patients and families from countries involved in the project to add their contributions.

To get involved, order the book or for more information, please contact:

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# I Still exist

MUNICH, 31 AUGUST – 2 SEPTEMBER 2016



An Alzheimer's patient is considered young, in France, if the first symptoms appear before they are 60. Some are affected by other related diseases like Lewy Body Disease or Frontotemporal Lobar Degeneration.

Young onset patients often don't feel they are understood when they receive the same care as older patients as the disease has a different impact on them. These young onset patients are keen to communicate their point of view. They are ready to express themselves and even be photographed. They want recognition and to be understood.

The artistic project **I Still Exist** aims to give them a voice. To achieve this goal, I have chosen to involve patients and families in the creative process. During interviews and support group meetings we have been looking together for testimonies and visual representations of their perceptions and feelings.

Their stories have often been left untold until now. They are fragile and needed courage to be expressed. The project has provided moments that have been joyful, moving, difficult, unimagined or unexpected but always a privilege.

The Munich exhibition concentrates on FTD patients and families that I met in Belo Horizonte, Lille and Gaildorf. The international approach highlights the cultural, social and universal aspects of the disease that we wish to develop with new partners.

**I Still Exist** is the result of a long term co-operation with Dr Lebert and Pr Pasquier in France who introduced me to Pr Caramelli in Brazil and Pr Janine Diehl in Germany. I would like to thank them for their support.

**Carl Cordonnier**  
*Photographer, Dailylife*

## GAILDORF - GERMANY

*'Every day of the week, we go for a walk with Carmen. She has two preferred tracks. One goes through the forest and the other one follows the train line that we used to take when we were going to school. We can only go one way as Carmen does not like to go backwards. I know exactly where she will stop, turn and cross the road. At the weekends, she goes to my parents and my brother's house. It gives me time to breath and keep a personal life.'*

Helga, Carmen's sister

## WISSANT - FRANCE

*'I was paddling in the sea just like we used to do after a run or when we'd been out mountain biking or even just out for a stroll. When I told you I'd been out and showed you the photos you just looked at me and in this look I saw no spark of memory. Today everything is wiped out. How I wish you remembered.'*

Josette, Patrice's wife

## GUINES -FRANCE

*'I have to constantly stay in the moment in order to be able to complete the normal activities of daily life.'*

Marie France, Alexis' wife



## BELO HORIZONTE – BRAZIL

*'I won't be alone'*  
Wagner

*'Every day is a new battle'*  
Camila, Wagner's daughter

*'I know that I will not be alone for this journey.'*  
Carmen, Wagner's wife

