

## ★ " *Des maux sources de mots* " From suffering springs words

France

CCAS Saint André Les Lille  
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### Context

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The Communal Centre of Social action brings, through its Seniors Department, a very particular dimension to setting up projects for free transport, - Activities, - catering, - retired public: Assemblée des Sages (regular meetings in the districts between pensioners and elected officials); Network of volunteers, projects set up for pensioners in the commune,. We noticed that certain people - alone or in couples who were very assiduous at the beginning , attended less often and withdrew little by little from collective life. If the reasons for this withdrawal are medical involving transitory or chronic difficulties, the C.C.A.S. can try to bring a solution by facilitating home support, ensuring contact with the outside world (volunteers visiting regularly, mobilization of transport). On the other hand, the C.C.A.S. has few solutions for disorientated people who shy away from meetings and activities which they used to enjoy before and whose "sudden mood swings" have tried the patience and goodwill of close relatives, gradually worsening relations. The C.C.A.S. therefore wished to make an effort with this public by starting up new and adapted projects for people suffering from these cognitive disorders. We could not, on the one hand, remain insensitive to the distress of sick people and the anguish of their families, and on the other hand, not take part, in our capacity, in the mobilization of public authorities vis-a-vis the evolution of this disease.

Specific and adapted activities to this disorientated public were developed by the C.C.A.S.: pastel painting workshops, memory workshops, interior decoration workshops ... These activities are organized by an agent trained to welcome and listen to disorientated people (C.N.F.P.T. training). In the various workshops which saw an increase in attendance, the organizers very quickly went past the stage of practical activities and realized that their interventions should also touch on the rehabilitation of identity and experience of the participants. Indeed, even if all of the participants, to a greater or lesser extent, had lost control of the tools essential for their autonomy (word loss for some, disorientation in time and space for others), all had preserved emotions which we manage to read on their faces. We found some elements of autonomy during our meetings with certain old people. Still attached to things that made up the important moments in their lives, some people at the beginning of disorientation expressed their need to communicate , in particular by evoking their place within the family. The idea therefore came about to let these people reactivate their memories, to reconstitute bits and pieces of their life, to leave a print of their past with their close relations. The C.C.A.S. therefore seized the opportunity provided by the Foundation Médéric Alzheimer to bid for a project tender entitled "Let sick people speak", whose philosophy seemed to completely correspond to our expectations with respect to the public targeted. This project obtained the financial backing of the Foundation.

## Description

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Initially, we needed :

- to enter in contact with people affected by Alzheimer's disease and their families who were likely to take part in the project. We were able to sensitize a dozen people and their families by getting to know pensioners using town services, contacts made within the housing structures and communicating the project through the local newspaper.
- to include volunteers working alongside the elderly throughout the year in the Insolation Prevention plan by making them aware of the project. With this in mind, the C.C.A.S. has put conditions essential to the approach of this public into place. The sensitization training about Alzheimer's disease was undertaken by a clinician psychologist recruited especially for this action, a psychologist whose role throughout the project was to accompany the volunteers, answer all their questions by reassuring them on the validity of their interventions, while allowing them to progress and to personally evolve. These two objectives obtained, the C.C.A.S. could plan to approach the second stage of the project, namely recording what patients have to say. With this in mind, the C.C.A.S. has put a patient and volunteer into contact to create a special relationship between them, to set up a climate of trust favourable to exchanges. For certain participants in the initial stages of the disease, as the meetings with their volunteer went on, they initially evoked their daily lives, what they felt about the disease which was gradually taking root and their fears about the future before being able to approach their past in more concrete terms. For others, which make up the majority, where the disease had already taken hold, the confidences started to be made only after several weeks of meetings. A granny in an old people's home who no longer left her room, completely disorientated, locked up in her own world, refusing any outside contact, could little by little find her way to the restaurant. A granny, very disorientated, accompanied by the volunteer. Slight and hunched up on herself, invariably perched on the edge of her bed, she has progressively seemed to renew contact with her environment and be interested in the photographs around her. A grandpa, living at home, has been able to converse again, thanks to practising pastel painting, an activity that he had learned as a child with his uncle. He was still practising this a few years ago but gave it up following the death of his wife, as he was no longer artistically encouraged. In order to guarantee availability of the team of the Seniors department and to propose effective coordination with the project, the C.C.A.S. has recruited a person on an accompanying contract who could, in this way, give definition to its professional project with retired people.

In order to gather the memories, live testimonies, personal emotions, situations and concerns of these people, the C.C.A.S. has proposed setting up individual meetings and discussion groups to compare the experiences of each one. These talks and discussion groups aimed at:

- gathering the emotions of the patients in relation to the onset of the disease and the various stages of its evolution,
- talking to others about their true feelings in relation to the disease,
- giving a version of their story,
- letting the patients speak,
- giving shape to their life events which have emerged throughout the discussions,
- making their vulnerability a strength by recognizing their capacity of exchange.

Although the above mentioned objectives did not follow a chronological order, they were all touched on or even reached at a given moment of the contact. Indeed, certain people were able to talk about their feelings in relation to their disease while others never mentioned them at all. However, all of them were able to reveal elements of their past. Leaving some kind of trace seemed to be a driving force for these pensioners. Allowing them to reconstitute their life story by using their words as a tool was the outcome reached by our team.

## Means

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### Human, financial means (budgets):

The director of the C.C.A.S. 0.20 ETP. The manager of the Senior Department 0.40 ETP An activity agent 1 ETP 3 people in charge of homes Total Budget: restaurants 0.60 ETP 1 driver 0.40 5 volunteers 0.50 ETP 71,520?

a-. Operating expenditures: 70,820? Personnel costs: 62,020,00. Training expenses: 3.000,00 Publication expenses: 3.000,00. Running collective meetings: 800,00 Various materials and equipment: 2,000,000 Cameras: Provision of buildings (renting, loan): Logistics:travel, transport

b – Operation receipts: 70.820? Personnel - D.D.T.E.: 12.187,00 - town: 49,833,00 Foundation Médéric Alzheimer subsidy: 8,800,00

c – Investment expenditure: 700? Purchase of numerical video camera: 700,00?

d – Investment Receipts: 700? Foundation Médéric Alzheimer: 700,00?

### Exact name and address of associated community/structures/institutions:

The town hall of Saint-André, the "Le Clos Fleuri" old people's home, the MAPAD George Delfosse (SIVOM) SSIAD (SIVOM)

### Operational partners:

The town hall of Saint André (information aid). Medical staff from local housing structures. Training centres solicited. Liberal doctors and the paramedical body of the area.

### Financial partners:

The Médéric Alzheimer foundation has subsidized this project following a tender for projects suggested in 2005 (see budget).

## Assessment

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The setting up of various workshops, the reception of a disorientated population, its integration within the group is very positively perceived today. The volunteer network has been recognized as a stabilizing element for the people benefitting from this project. Children and partners of disorientated people have already showed their enthusiasm about the possibility given to have their close relatives heard. The team thought at length about how to set up this project by studying the way to approach the disorientated public, by looking for any information and documentations useful for knowing more about Alzheimer's disease, sensitizing partners and by giving all the possible means to volunteers to start up mutual trust with the disorientated person.

Today, the action will pass on to the final phase of drafting testimonies and recollections by bringing the volunteers together and by submitting the accounts to the disorientated people and close relatives. The collection will take the shape of a portrait for each participant and will be illustrated with relevant photographs. Our priority is to remain true to the retranscription of testimonies, to respect the spoken word and integrity of the individual, making it necessary to be as vigilant as possible.

## CCAS Estimation

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Alzheimer's disease has become a public health priority which challenges both institutions and each citizen. The C.C.A.S. of Saint-André, where the number of pensioners is higher than 23% of its total population, was naturally concerned. It does not manage the structures specifically adapted to people affected by cognitive disorders as these are dealt with by the old people's home (associative statute) of the commune and the MAPAD which is managed by the SIVOM. However, we do work in close partnership with them. This is why the project that we wanted to set up and which is addressed to retired people still living at home, does not have any medical responsibility but answers more to the social vocation of our structure and the sensitivity of our team. It is stimulating for the participants and enables patients to find a role in collective life and to be active in their daily lives. It also allows the volunteers involved in the project to be committed to a supportive and emotionally rich experience, and

**the C.C.A.S. to contribute to taking on responsibility for the patients by setting up an innovative action. Finally, it invites a larger audience to become more aware of Alzheimer's disease while recognizing the exchange capacity of people suffering from these disorders.**

## Target group

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This project addresses old people who are disorientated, suffering from Alzheimer's disease or cognitive disorders living at home or in an establishment

### CONTACT

Pour de plus amples informations, contactez ELISAN by mail [Europe@elisan.eu](mailto:Europe@elisan.eu)