Alzheimer Cafés: a Wealth of Experience 2012
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The Geriatrics Research Group (GRG) is a non-profit association established 27 July 1988. The inspiration of a number of professionals who had been working for some time in the field of gerontology and geriatrics, it was created to promote research, studies and activities aimed at tertiary age epidemiological, clinical and socio-assistance problems.
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In today’s society social fragility is increasing and problems linked to inclusion and participation within a given territory are no longer exclusive to developing areas but directly affect our own communities. Due to the breakup of old assistance models, new groups at risk of exclusion are emerging, including the elderly.

By combining real needs with successful theoretical models, UniCredit Foundation has promoted various intervention models in order to accompany the elderly in their everyday lives and create the bases for improved quality of life. For this reason, the Foundation focuses its commitment on the concrete needs of the Tertiary Age, such as the availability of adequate care for those suffering from so-called longevity illnesses and the creation of service networks for the elderly and their families.

The publication, “Alzheimer Cafés: A Wealth of Experience”, is the result of two years of work, dedicated to the development and diffusion of innovative therapeutic spaces - Alzheimer Cafés - based on the interaction and exchange of experience between people affected by the pathology together with family members and experts.
In addition to guaranteeing socio-economic support for some of the centres that are already operational, the project has also promoted the activity of the Brescia Geriatrics Research Group, coordinated by Professor Marco Trabucchi, in defining guide-lines for the establishment of Alzheimer Cafés. Today, this model is available for local authorities and voluntary work associations that wish to replicate best-practices on a local level.

This text, which brings together direct experience gained in Italy, sets out a host of concrete ideas on how to activate forms of effective self-help, starting with generous, voluntary commitment.

Best regards,

Maurizio Carrara

*UniCredit Foundation Chairman*
Dementia: a future full of hope?
Dementia: a future full of hope?

ALZHEIMER

“She’s very sweet” you said
Challenging our incredulity
Of the lifetime companion
Who lies on her bed
And slowly turns to the horizon
Of her impenetrable exile.
Then, on her way to eternity,
With a whispered: “It’s the end of a Calvary”
You replied: “It’s only the start”.

And now you too
Share that bitter destiny
Bent over in a chair against the wall
As if to protect your treasure
Of glories displayed and miseries rejected
You dive into the unfathomable mystery
Of an unceasing present
Of which you have no memories
Nor any plans for the future.

And yet...
A friendly face still
Draws out your innocent smile
And the caress of loving words
Kneaded with the bread of memories
Reawakens the echo of lost emotions
Moistening your eyes, prompting you to say,
Reshuffling our certainties,
“Thank you for a different kind of day”.
Bitter destiny.
We have chosen to start this publication focusing on new ways to help people affected by dementia and their families with a poem by Alceo Gianani because in the concluding part of the text the affected person unexpectedly expresses her gratitude to those who are close to her (“Thank you for a different kind of day”). We can state - without any risk of sounding rhetorical - that the above poetry is a beautiful, implicit confirmation of the role played by Alzheimer Cafés. The latter promote moments full of “loving words”, which “can bring forth a response, even from the mysterious black depths of the minds of those who have withdrawn into their private mystery, who no longer have any ability or hope of being able to establish any kind of relationship”. The latter words are taken from some comments by Franca Grisoni on Gianani’s poem, published in issue no. 1 2011 of Psychogeriatrics. Indeed, each issue of the Italian Psychogeriatrics Association Journal ends with a page of poetry, reaffirming that sometimes (often) the reality of suffering can be better understood if science, with all its certainties, is accompanied by a vision of the world that tends to unify reality and reveal all its many and profound implications. It is as part of such an approach that this book analysing the activities of Alzheimer Cafés must be interpreted: their utility cannot be demonstrated merely with numbers but also - and above all - through experience expressed as realized commitment.

“A massive amount of personalized care.” A statement made by a famous doctor in order to explain the general atmosphere in which one must carry out, over the coming years, the care of elderly persons, especially those affected by cognitive alterations. An affirmation that seeks to be, at the same time, an act of realism (the number of people needing assistance will continue to grow, as indicated by demographics and epidemiology) and a commitment towards the vulnerable elderly (notwithstanding all the objective cultural, organizational and economic difficulties, it is medicine and the assistance systems that are responsible for providing an adequate service capable of satisfying the specific needs of each individual person).

We have adopted this phrase, together with the poem by Gianani, as theme concepts for this book because the combination of realism, commitment and overall evaluation of the suffering human person is a central issue in the future assistance service for the elderly. It responds to a precise invitation made many times by various parties and recently confirmed on the front page of the medical journal, The Lancet: “It would be a serious error to continue to interpret the extension of human life that has occurred in recent years as a negative event. On the contrary, it should be viewed positively, not least because it is a significant demonstration of nature’s potentialities.” It will be the specific duty of those who exercise cultural leadership to communicate the impact of such affirmations and their effects on individual and collective behaviour. It will not be an easy task. In this field negative rhetoric is still very much alive but it is a
task that cannot be avoided. However, today’s trend to respect the autonomy of those who receive care is irreversible (in the case of dementia patients, autonomy is exercised for the most part by the caregiver). Services must therefore consider sick individuals as primary actors – which is precisely what happens in Alzheimer Cafés.

Similarly, when dealing with dementias it is essential that we abandon the kind of negative expressions that often accompany descriptions of the illness. On the contrary, it is important to reaffirm that the human identity of the ill person continues up to the moment of death, and that caregiving work is vital because it prevents the death of the patient from being the death of a mere ghost of a person. Capable and loving care offers meaning to the life of others, through a sort of transfer of humanity between those who offer their time and those who receive their care. And in this way the former too realise their lives and confer meaning on them. The act of giving is never a one-way transaction.

The Scenario
A realistic analysis of the scenario that accompanies the life of people affected by dementia also has to be based on considerations regarding the current historical period, characterised by a strong economic crisis whose effects can be noted above all in services for the vulnerable in society. In coming years there will be changes that we cannot even foresee today in their dimensions, changes that will pose continual questions with no easy solutions. Where will the welfare crisis strike next? Will there be some privileged sectors, because they are characterised by a greater level of suffering and difficulty, which will at least remain partly unaffected by cuts? How can low cost services be provided without compromising assistance quality? What alternatives will be available to cover services currently provided by the wider society? Will there be a return to institutions financed by charity, as in the nineteenth century? Will the changes that have occurred in lifestyles in recent decades, which valorise individualism at the expense of social solidarity, be compatible with the recovery of a sense of responsibility relative to less fortunate people? This is a serious and extensive subject, involving as it does dynamics that interact in increasingly more complex ways, relative to a past which it would be absurd to try to resurrect. It is therefore essential to tackle it by adopting an approach that is radically different from our accustomed one.

However, it is also necessary to consider solutions in the immediate term given that the crisis does not allow us more time. Mapping out approaches which, on the one hand, make it possible to make savings and, on the other, to organize low cost services is therefore a duty to ensure valuable proposals are not impossible to implement due to a lack of adequate financing, thereby rendering them irrelevant. The significant reduction experienced in 2011 in clinical and diagnostic services, following the introduction of new payment tickets, can be
interpreted as either a reduction in the number of unnecessary services or as an alarm bell, indicating that for economic reasons citizens may well choose not to seek medical aid. Whatever the interpretation of the phenomenon, it is in line with an increasing recourse to low cost and high added value solutions like those offered by Alzheimer Cafés. For example, it would be appropriate in the light of the above to carry out a critical analysis of the costs generated today by hospital assistance in order to identify possible savings which could be directed towards continual assistance for elderly persons who are affected by chronic illnesses like dementia. A serious spending review regarding the same could make it possible to relatively quickly make savings of at least 10% of total costs, for an amount in the order of 5-6 billion euro. To date, in this field, nothing decisive has been done. Even where the decision has been made to close small hospitals the courage needed to implement truly incisive changes has been absent. Hence low quality services continue to be offered, without any real advantage in terms of assistance available in a given territory. However, it is not just the problem posed by small hospitals that has to be considered. In the overall organization of hospital assistance it is necessary to intervene in order to reduce the number of redundant services, the proliferation of cost centres, especially as regards more modern technologies, a waste of economic resources that is often the result of less than fully transparent manoeuvrings. Some are of the opinion that the social pressure on large hospitals and technologies - often heralded as miraculous in their effects - hinders any alternative cost distribution. In this regard it is important to recall the role of politics - which should not be influenced by more or less irrational decisions but ought to manage changes in order to guide them in the right direction, generating a democratic consensus around them. A typical example of the same is provided by costs for hospital medicines, which have increased very significantly over recent years. Relative to this subject motivations of a scientific, clinical, economic, organizational and ethical nature have been cited. Only strong political leadership is able to indicate a pathway which is at the same time respectful of the needs of both the individual and the collective, without caving in to pressures that are often less than open and transparent. To cite an example, which I hope will be interpreted correctly by the reader: some anti-tumour treatments carried out in hospitals cost € 30-40,000 per year and lead to an increase in patient survival for a few months. The period of stay of an elderly non-autonomous person in a nursing home for a whole year costs a similar amount (and is frequently the only valid solution capable of guaranteeing dignified survival, indeed survival itself). We therefore repeat: it might seem inhuman to pose these two competing alternatives but the problem must be faced with clarity and intelligence, in line with a policy that is able to interpret the true needs of the collective rather than being “torn and twisted” by conflicting interests that are difficult to reconcile. Nor is it appropriate to create antagonism between expenditures for the young or adults and that for
the elderly. It is necessary to carefully observe the evolution of phenomena in order to make rational decisions. On the other hand, one increasingly notes low cost hospital organization models are being discussed in the relevant literature, models that have demonstrated they are able to produce results on a par with those of traditional hospitals. Obviously, one is dealing with a “revolution” that will need time to be more fully developed (though less time than one might think!). However, there is no doubt that it is the only true and realistic solution to the current continual and unsustainable increase in health costs. It can be achieved with a significant investment in ICT (for example, pre-admissions can be carried out remotely via Skype), using a Fordist type reorganisation of work that permits major specialization of the team, with a reduction in work times relative to both diagnostics and surgery, plus rigid control of clinical evolution, and all in architectonically appropriate environments, promoting maximum flexibility and energy savings.

What is set out above could seem too specific relative to the subject in this book. However, we place it before the reader because it indicates how, in a complex society, there are many interactions, including between subjects that seem remote from each other. At the same time it is necessary to have strategic leadership relative to social dynamics, especially to protect the conditions of those who are more vulnerable. Obviously, such leadership must not be oppressive but must respect and valorise what is rich and spontaneous in the collective (the Alzheimer Café model is a significant example of this). And while waiting for the programmer to take note of spontaneous energies in a society that has not yet been entirely submerged by a welter of weaker everyday motivations, the work presented in this book represents a contribution to valorise a specific aspect of the wealth of constructive models and work that can be found in our cities. A body of potentialities that represents an example of how research into new ways to introduce useful projects within the health system reflects the high level of commitment accompanying those who work in these areas, which could be summarised in the famous phrase delivered by President Clinton: “Don’t let the economy kill your dreams!”

As you can see from these few lines, the “massive amount of care” theme is very serious and still in continuous evolution. However, for this very reason the second part of the phrase is extremely important: the elderly in need must not fear for their future, because doctors, other elements in assistance teams and volunteers are committed to individualized care. We insist on this element of fear for the future, because such fears are increasingly found in the minds of the elderly. One begins to see the first signs, for example, in the fact that some families are withdrawing their loved ones from care homes in order to make savings in boarding costs. The enormous reductions in some care homes due to recent government cuts could make it more difficult for families - who are often al-
ready disadvantaged by members who have lost their jobs - to keep their elderly members in a care home. It is certainly true that the availability of individual operators and their commitment cannot affect these often dramatic dynamics. At the same time, they represent a positive aspect in a scenario that is very dark from various points of view. A vital glimmer of light, even if it is not sufficient in and of itself to illuminate an entire pathway for the future!

But what does individualized care mean? The word itself has a twofold meaning: on the one hand, it indicates an intense relationship between those who offer a service and those who receive it, a relationship that must be characterised by kindness, careful listening, answers appropriate to requests made, including when they might seem inopportune. But above all the term indicates that the technical-clinical approach to care is made by analysing the situation of individual people, whatever the gravity of their illness, their level of functional and cognitive impairment. This offers the greatest guarantee of providing effective care and the realisation of a positive result. Age is not an indicator of need nor is it a life context. Indeed, at 80-90 years of age there can be illnesses and health situations that are completely different from each other, which require an analysis of historical factors, a careful examination of current conditions and recourse to instrumental analyses to arrive at conclusions that offer appropriate therapies. The same can be said for care home location. Living in a nursing home (or other permanent institution) does not mean anything as regards individual health conditions and cannot a priori be assumed as an indicator of appropriate therapy decisions (indeed, for the doctor it often ought to represent an alarm bell due to the risk of inappropriate treatments in the previous history of the guest).

The collective-individual distinction which has been discussed above will lead to dynamics that are even more important for the future of assistance as regards the non self-sufficient elderly. The fact that this subject has been openly stated in a medical context can be both an advantage (relative to the commitment taken by those who enjoy direct responsibility) and a limit (because the needs of non self-sufficient people are not solely clinical). However, it is an indicator of an approach that must be accompanied by a high degree of attention on the part of those who feel a weight of responsibility regarding the most significant event of our times i.e. the ageing of the population and old age as a life experience. The individualisation of assistance is the work approach characterising innovative services like Alzheimer Cafés. Indeed, the distinction between being “containers of suffering” or “care contexts” is very fine. Containers can be closed; care, on the other hand, requires openness, respect, relationship. In this way one guarantees the user a normal perspective, in the context of which one tries to interpret needs in order to provide appropriate solutions. Sometimes the construction of closed services is defensive in character, in the absence of an ability to understand the real needs of the elderly which, though fragile and
limited in their psychophysical expressions, are always centred in a demand for meaning and sense. Those with compromised cognitive functions too pose, to those who assist them, continual demands - implicit or verbalized - as to the aim and purpose of the care that is offered. Sometimes a response is difficult in overall terms, not least because care is a de facto continual renewal and repetition of acts that assume, on a case by case basis, their individual meaning. However, a strong connection between the care location (whatever it is: house, hospital, institution) with the exterior world makes it possible to construct truly significant projects.

**Research and the future**

President Obama has recently decided to make a major economic and organizational investment in Alzheimer dementia, outlining the construction of a series of projects whose final goal is to prevent and effectively provide for this illness by the year 2025. In the scientific and research world some have accused the President of the United States of pessimism. Others, on the other hand, have been more cautious and have not advanced any risky forecasts. The author of this book has been committed to the study of neurodegenerative illnesses for at least 30 years and I do not feel that I can make any forecasts as to time scales, not least because ten years ago I expressed a more optimistic opinion as to results that could be achieved - only to be proved wrong as time passed.

With this uncertain context, two positions can be noted today that seek to create hope for those members of society who feel anxious about old age accompanied by dementia. The first is characterised by attention and commitment to ensure that research can continue with appropriate financing as well as extensive social support. Indeed, pessimism is always negative, both because it risks influencing the decisions of those who allocate public and private funding and because it makes researchers feel isolated. Fortunately, in recent months, interest in Alzheimer’s Disease has been reignited round the world because some research work is beginning to provide us with promising results and - as always happens in these cases - positive data is generating considerable enthusiasm, which is reflected throughout the entire study area. By blocking the diffusion of a certain toxic substance in the brain it may be possible to control neuronal damage and hence avoid any development of dementia. These results match the overall level of progress made to date, which has demonstrated the slow evolution of the illness, lasting for several years, whose signs can be identified in the brain using modern imaging technologies or in the fluid, including well before any clinical signs appear i.e. symptoms like memory loss or behavioural changes. The future is therefore characterised by positive data from a scientific-biological point of view.

The second position - equally important in terms of wellbeing research - seeks to guarantee the best conditions of life for people who are already affected by
various forms of dementia. Indeed, although no instruments for a definitive cure have yet been found, it is possible to implement interventions to defend quality areas, albeit during the course of a life that will be very difficult. This defence - which is based above all on recognition of the dignity of the person, regardless of physical or psychological health conditions - is implemented in various ways in terms of clinical matters and services organization. As regards clinical matters, the main care task is to guarantee that the person in question does not suffer any excess disability, in addition to that specifically due to the illness (hence conserving the maximum possible number of relationships; not relegation but activation; no inappropriate substitutions or changes in basic activities), while at the same time taking care of intrusive symptoms (for example, it is very difficult to understand physical pain in a person who has lost his memory and therefore does not know how to verbalize the location and characteristics of the said pain). As regards services too it is possible to offer considerable assistance in accompanying ill people and their families during the many years of the natural course of dementia. Indeed, in chronic illnesses, with dementia a preeminent example of the same, services carry out an essential multi-purpose function, from the time the diagnosis is made to repeated staging, to the implementation and orientation of therapies, to rehabilitation approaches. Services protagonists comprise many different persons and groups, each with their own role, as well as their own practical and cultural specificity. Hence the Alzheimer Evaluation Units carry out a role that differs from that of home help, hospitals and centres based on voluntary work. The last mentioned is an area in which the Unicredit Foundation has been strongly committed in recent years. Focusing attention on initiatives that arise in civil society, and in particular among voluntary sectors, means supporting those who are committed to making the life of the sick easier, while awaiting - as mentioned above - the identification of specific and definitive measures to prevent and cure illnesses. It also means assisting in terms of widespread public generosity on a technical level so that qualified services can be constructed at reduced costs, and often with further advantages in terms of location and relationships, which are particularly significant.

**Café research**

The research dedicated to Alzheimer Cafés presented in this book is part of an approach to encourage the growth of innovative services and propose ways to improve the kind of performances offered in Italy by voluntary or self-help groups so that the energies of such groups, contributed with generosity and intelligence, can accompany the lives of both the people affected by dementia and their families, thereby achieving the maximum result possible. The commitment of Unicredit Foundation and Brescia Geriatrics Research Group has made it possible to critically analyse some experiences and to extract from them those aspects that are most effective in defining “good practices”, avail-
able to groups which, in the coming months, wish to commit themselves to this highly important assistance work. Obviously, the number of experiences examined is limited due to the economic-organizational conditions of the analysis, which prevented an extension of the sample from including scores of active situations in this field in Italy. The selection was also dictated by the need to present, within a short period of time, a qualitative analysis that could encourage readers to enter this field, rather than a statistical analysis, with the latter difficult to develop given the non-homogeneity of the sample.

In a period of crisis like the one we are currently experiencing tackling a subject like that set out in this book is at the same time a sign of optimism, since we believe in the potential of collective generosity; at the same time it is an act of realism, since the requests for qualified support for people who are suffering are ever more frequent. On the other hand, again relative to research into innovative ways to intervene in favour of the vulnerable, it is important to note what the sociologist, Ilvo Diamanti, recently wrote relative to our ability - those of us who are involved in defining effective care - to also explore opportunities outside higher level sectors (academia and politics), in order to identify, in small practices, important indications for care work. Diamanti writes: “Common sense should force us to undertake more rigorous self-analysis relative to what is happening on a micro-social and local level, in the personal and interpersonal sphere. To explore other theories and other methodological approaches. But the common approach of specialists (...) leads us to pretend that nothing is happening. To deny reality in order to avoid changing the spectacles through which we are observing it. From on high and far away.”

This approach, which has inspired our work, leads us to valorise a more extended world, full of so many people who offer care to those suffering from dementia, who think, project and experiment. We have no real appreciation of the wealth of ideas we can find in these sectors, seemingly peripheral; wealth that could easily be evaluated and tested, provided it is understood and analysed with due rigour. This book is a sign, albeit a small one, that this approach must be pursued, with the examination of those models that arise spontaneously, inspired by original intuitions located at the local level, drawing conclusions from them of a general nature. This is a meaningful and innovative approach, one that is increasingly adopted as an instrument to critically analyse various situations and contexts, proposing them as replicable models.

In the field of original innovation outside the “high level” circuits (as referred to by Diamanti), and as such of great interest, a significant example among the many that one could cite, in addition to that of the Cafés, is represented by the project devised by a French entrepreneur, creating a town able to host people affected by dementia, constructing individual and common life environments and spaces based on 1950s styles i.e. those in the memories of most elderly people suffering from dementia.
The idea has been criticized by many, but we are waiting for the project to be realised before expressing an opinion. However, quite apart from some barbs that have been expressed regarding this “Dementiaville”, there remains uncertainty as to how to best protect the most vulnerable persons (for various reasons, cognitive or non) i.e. whether or not to adopt models like that proposed in France.

On the other hand, the term “cafés”, indicating locations where people affected by dementia can meet together with their families, has a certain level of refined originality, which some might fail to understand. Recently, Zygmunt Bauman, a most acute expert on modernity, has written: “The inhabited world is structured so as to be hospitable - convenient and comfortable - for its normal inhabitants, the people who constitute the majority. Cars must be equipped with lights and horns to warn people of their arrival; instruments of no utility to the deaf and blind. Ladders are of no use to people who are confined to wheelchairs. I myself, in my old age, having lost the greater part of my hearing, am not able to hear my telephone ringing or my doorbell if anyone comes to visit me.”

I have no wish to construct an antithesis between those who criticize Dementiaville and the affirmations of Bauman, but with regard to these antinomies (protection in dedicated spaces or maintaining natural living locations) it is important to develop a calm and rational debate, one that is above all serious. Open to all those who feel responsible for constructing an extended world of care, one that is increasingly adapted to meet real needs, as well as increasingly more accepted by the wider society living around vulnerable people. Alzheimer Cafés exist within such dialectics. Those who operate them are usually quite aware of conflicts, inadequacies, difficulties. However, the experience gained from work carried out and the interpretation of its meaning offer very good reasons for going forward, without any self-referential excesses, but with a tranquil awareness that important milestones have been achieved in creating relative wellbeing for those who are the subject of assistance care.

The totality of the observations made to date delineates a condition of care for those suffering from dementia that is rapidly evolving. From this condition the signs of possible hope are beginning to appear. It is not a question of guaranteeing a cure but a combination of factors has now radically modified the prospects for people affected by dementia. Unfortunately grave problems remain and are characterized by stigma, fear, unexpressed pain or, even more, pain that is not listened to or cared for. However, the scenario has certainly changed in recent years. The contents of this small book is a concrete and tangible testimony to the same: the aim of the writers is to encourage - especially among people who are not strictly speaking experts in this kind of work e.g. volunteers who commit their time to assisting the elderly - the growth of a much greater feeling of positivity.

Focusing one’s energies on the “dramatic situation” experienced by people af-
fected by dementia is not a “drama without a future”, because one can now find thousands of areas that make care and accompaniment interventions meaningful and important. In other words, there is a future for those who are under care, but also for the generous contribution of those who take care of people affected by dementia. All of which is part of a search for normality. Though difficult, this style of care obviates incorrect behaviour. The clinical-assistance technique must be realised in an environment that seeks to recreate the everyday living conditions of everyone, both healthy and ill.

One could conclude that in an Alzheimer Café it is possible to realise a synthesis of generous, voluntary personal commitment and the desire to improve our entire society through this work. This is an individualized vision in which those who carry out and receive care are closely connected to each other, not just in terms of their relationships, but above all in their reciprocal improvement, which progressively embraces and permeates the entire community.

Special thanks to our colleagues: Giuseppe Bellelli, Nicola Berruti, Angelo Bianchetti, Stefano Boffelli, Renzo Rozzini, Sara Tironi from the Geriatrics Research Group who have edited parts of the manuscript, offering many interesting ideas for reflection. Dr. Enrica Cerantola from Unicredit Foundation managed contacts with various organizations that have taken part in the study, firmly controlling difficult coordination matters with ease and professionalism. Finally, my warmest thanks to the primary protagonists of this study i.e. the coordinators and collaborators in the Alzheimer Cafés. They quickly understood the aims of our analysis and provided valid data and indications. If this book can help reproduce the most significant experiences and hence construct new and useful services for people affected by dementia, it is above all due to their intelligent contributions.

We started this introduction with a contemporary poet, who expressed thanks for “a different kind of day”, a lighter moment, that passes by. We wish to conclude with some eternal lines from Virgil, speaking of the loving relationship, one that outlives all time, between Aeneas and Anchises:

“Arise, my beloved father,
Put your arms around me;
I will carry you on my shoulders,
Your weight is no burden to me;
Whatever fate befalls us,
One and the same our danger,
One and the same our salvation.”

Both pieces of poetry, so different, are nevertheless perfectly representative of the spirit that informs the generous work carried out by so many in the Alzheimer Cafés. More specifically, they emphasise that when difficulties arise, the help given to those who are most vulnerable leads to the salvation of all of us.
Organization of services for people affected by cognitive deficit

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1.A NETWORK

In few areas of the health organization have so many words been spent as in that of the therapeutic continuity to be constructed around ill and no longer self-sufficient elderly patients, including those suffering from compromised cognitive functions. There are many critical aspects that interfere with the possible construction of a support system that is appropriate for the complex dynamics produced by the current crisis in family relations, the fact that family members nowadays often live at considerable distances from each other, economic difficulties, the process of ageing itself, which occurs in an absolutely individual manner, accompanied by expectations and hopes that cannot be comprised within pre-constituted schema.

Even in the recent past rigid, functionalistic organization models were used, with services management systems planned in schematic fashion, inside which people affected by invalidating chronic illnesses had to navigate their lives. One could say that none of these systems proved successful, and even less did they offer the chance to evolve relative to demographic and epidemiological dynamics. One cannot exclude from this overview the combination of interventions that are implemented by society to try to meet the needs of the ill. Care and assistance services must therefore be characterised by a high level of integration between each other, as well as with the rest of services for people in a specific territory, avoiding functionalistic schematizations and simplifications.

Their organization according to these principles is difficult and - as a result - there are few examples that can be cited of services that are able to meet growing needs, in terms of both quantity and quality. Indeed, as already extensively explored in this book, the increase in the number of elderly persons also automatically comprises an increase in the number of people affected by dementia. In addition, social and cultural progress has increased our awareness of the right of citizens to have appropriate responses when in difficulty, and to have the most critical aspects recognised as those that most merit high level interventions.

The problems exhibited by dementia require a panoramic view of the issues involved, not least because their development is so rapid, with a continual change in the clinical picture, with the patient (and those who assist him) being subject to interventions to help him which may be continually updated, avoiding inconsistencies, delays or even the absence of responses. In a relatively short period of time (Alzheimer's lasts on average 5-10 years) the patient experiences the switch from a condition characterised by slight memory deficits and difficulties in carrying out more complex activities to a progressive diminishing of cognitive abilities, a radical modification of his personality (almost invariably accompanied by behavioural modifications), with a deterioration in functions that is increasingly evident, through to complete disa-
bility and the appearance of grave neurological and somatic complications. In this process there is the profound and often dramatic involvement of the family, which first experiences anguish on learning of the diagnosis and the unstoppable future path the illness will take, then the difficulty of managing behavioural and cognitive problems, as well as the burden due to ever-increasing assistance requirements.

In the light of what is stated above, the organization of services, as with the care of individual patients, must over the coming years make a considerable degree of progress on a cultural level, relative to today’s approach, in order to avoid those models that involve rigid organization, where everything occurs in phases, as though every human event is always foreseeable and the fruit of a strict cause-and-effect logic. It is necessary, on the contrary, to embrace a dynamic approach to life, open to the unexpected, able to understand relationships which develop between people in ways that are sometimes not traditional. At the heart of this view there is an interpretation of biological (and hence clinical) events open to the reality of living people that goes beyond mere rigid schematizations, such that one event can be the result of interactions with many others, in turn generating new equilibria. It is not a smooth road, given that adopting predictable itineraries is certainly more reassuring. However, in the near future we can hope to overcome economic and organizational (and also human!) difficulties only by accepting a model that profoundly reflects the features of real life, placing technological progress at the service of a dynamic vision, according to which there is rich variety and variability in the world, which cannot be confined within robotic mechanisms. Those who wish to simplify, imposing schematic limits on the variety and liberty of individual behaviour, may seem to have the right solutions, and may well be approved by some myopic observers. In the end, however, such solutions do not achieve any useful results because the interface between the rigidity of a solution system and the need for more articulated definition - which varies over time, and is influenced by psychosocial as well as somatic conditions - is never very effective.

The subject is of general interest and regards many areas of organized life in addition to those of medicine and assistance. One only has to think of the diffusion of medicine based on evidence as an operational instrument founded on rigid lines and protocols, and the conflict that arises with the clinical reality of the person affected by dementia, which does not lend itself to any schematization within rigid boundaries. This situation requires equilibrium and openness, in search of middle ground, which has to be identified in the various intervention situations. At the same time, the search for a modality that brings together individual variability with the need to organize services that have to follow preset
standards and behaviours is anything but easy. Indeed it is one of the most significant challenges that post-modernity has to tackle. Relative to rigidity and anarchy - where does one position the organization of services? Do we not perhaps have to accept a certain level of conflict, an inescapable feature of today's world, the progress we are experiencing, which we hope to see further extended? Conflict impedes any turning of the collective in on itself, with the disappearance of rich social variety which is such a feature of our historical period. History - including small histories constructed by vulnerable people - has not come to an end, but is open to our ability to innovate, starting from a recognition of the complexity-conflict duality, and the dynamics generated by the same.

Today we are experiencing a moment of crisis because we are aware that the traditional services model for vulnerable people is in difficulty. At the same time we do not yet have any mature alternatives. This situation, though on the one hand it causes concern, on the other it stimulates and commits all those of good will (operators, citizens, decision-makers) to find new and more appropriate approaches. Many are inspired by a profound ethical sensibility, which is often described as a “sense of responsibility towards one’s fellow man”. A humane perspective that has always characterized the growth of civil society. If the preference for conservation is practically and morally negative, innovation too must pursue precise rules. It cannot be the product of specific and non verified ideas. Above all, it is important that we constantly seek to measure results. Though this is a difficult undertaking, especially when various dynamics are at work, any innovation that does not lead to results in terms of somatic health, psychic or practical health quality, improvements in community relations etc., is of little significance. Regarding such matters, in Italy it is necessary to proceed with considerable prudence, given that it is all too easy to destroy even partial services, which nevertheless play a certain role, while it is extremely difficult to construct alternatives that truly operate effectively.

**Patient and family needs**

The first essential element for a rational organization of solutions to meet patient needs is a recognition of the illness and its features. Only in a third of cases do those affected by the illness receive a diagnosis in the initial phases. More frequently it is the appearance of rather obvious symptoms or complications that leads to the recognition of a dementia syndrome. The late recognition of the nature of the symptoms generates increased suffering on the part of the patient, difficulties within the family and delays in starting treatments. All of which impedes correct planning of support interventions, risks prevention (management of finances, car driving etc.), and postpones the taking of important legal decisions.
Following the diagnostics phase, the patient requires targeted care for the various clinical manifestations of Alzheimer’s and other dementias. Although there are no resolutory pharmacological treatments, an integrated combination of interventions, carried out continuously, can lead to a significant improvement in the quality of life of the patient and his family members. Often it can slow down the progressive manifestation of symptoms. It is essential to involve a number of professional figures (general practitioners, specialists, psychologists, social assistants, nurses, rehabilitation therapists etc.) who, at different times and in different locations (home, specialized diagnosis centres, day centres and day hospitals, specific nuclei in protected care homes, rehabilitation wards etc.), collaborate in providing appropriate treatments. Even in the most advanced stages of dementia it is possible to intervene, exploiting the patient’s residual capacities and family resources, as well as limiting the effects of co-morbidity, sensorial deficit, environmental obstacles and stress.

Such needs must be provided for in the network of socio-health and health services comprising an integrated system of centres for diagnosis and therapy management, home assistance services (including semi-residential structures like day centres) and for the support and education of caregivers, rehabilitation services of various typologies and long term care services. The central aspect is the relationship between centres that have to guarantee, on the one hand, services specificity and, on the other, connections between various levels, in order to permit the patient to move from one to the other in relation to specific needs.

A crucial discussion point is whether dementia is a condition that requires an autonomous network of services or whether responses can be found in the ordinary services structure. Numerous national and international experiences have shown that through dedicated and specialized services it is possible to respond in a more specific and appropriate way to complex problems. Notwithstanding this, the Italian network is extremely varied. In some areas almost nothing has been done, due to grave failures on the part of political and administrative organs and the prevalence of less than transparent interests that all too often do not match those of the general population, especially those affected by serious health problems.

Some central nodes in the services network will be analysed below. However, one must first state that no organization, even the richest and most advanced, can ever offer completely satisfying responses to the family, which remains the main interpreter of patient needs in the face of a progressive loss of cognitive capacities. For example, even when the patient is accepted in an institution, and hence the family is exempted from management tasks, some psychological aspects continue to be dramatic, with services having to tackle
them with prudence and attention. Furthermore, if the ill person remains at home there are aspects of the assistance, such as its duration (someone has defined the commitment of families as equivalent to “a 36 hour day”), work and organizational load, psychological burden (including the solitude of those who provide assistance) that are only partially reduced by improved services organization.

One of the crucial aspects that affects all services problems is represented by the ability of the family to play a central role relative to the various interventions which, even when they are adequately coordinated, nevertheless require the family to be at the centre of the activity, if they are to be effective. There are situations in which this is not achieved and hence a decision has to be made to admit the patient in an institution. There are however times and conditions in which it is possible to help the family to carry out its central function, thereby permitting the overall assistance system to operate optimally. As regards the practical modalities needed to realise this objective, there have been considerable discussions, without arriving at any decisive conclusions. More specifically, there has been a lot of debate on the role of economic support given directly to the family, as a way to facilitate its autonomy and ability to deal with difficulties, including through a direct contractual relationship with those offering services, with higher and non bureaucratic control over quantity and quality.

This is not the place to express any definitive opinion regarding such matters. It is however important to reaffirm the need to find operational instruments that make it possible to reduce the risks - always present - of service self-referentiality. Even more important is the creation of conditions such that assistance given to the person affected by long term illness - which therefore interact with the vital dynamics of the men and women who live with these problems - becomes a stimulus to attention on the part of the community, exploiting the natural energies existing within it. For too long the indiscriminate delegation of services, even when they were not high quality services, has impeded the growth of more widespread generosity on the part of the community, since many found it difficult to express themselves within bureaucratic structures that were all too often unwilling or unable to listen to them. Today’s change in sensibility has opened up new prospects. It is however necessary to exhibit considerable elasticity in order integrate within the care system - without any loss of dignity - the family, neighbourhood, volunteers and services offered by protagonists who accept the fact that the patient they serve must be at the centre of their attention. The experience gained through Alzheimer Cafés fully confirms this approach. Without any exaggeration, one must reaffirm that in specific situations like chronic illnesses, which radically turn the life of the person affected and his family upside down, the care intervention must display compassion and a willingness to listen, not as
merely additional elements accompanying the technical aspects of care, but as absolutely essential components of the same.

To confer meaning on the various points set out above, it is necessary for the system to be able to construct a strong innovative culture for operators. Indeed the new commitment areas risk producing frustration for those who work in them, with the inevitable generation of pessimism and cynicism, if an incisive approach is not implemented, one that transmits the motivations of the service and at the same time helps people to understand the efficacy of the interventions and the most appropriate means to be used. However, training is anything but simple. The current system in force in Italy is little more than an economic-bureaucratic strait-jacket as regards ongoing training, while universities have not always been able to prepare an adequate class of trainers, able to combine technical information with indications as to work processes, the need for collaboration between various cultures and sensibilities, or the need to measure results obtained, comparing them with pre-set targets.

It therefore falls to the specific qualities and characters of individuals in each territory to find adequate solutions - solutions that must not be considered luxury add-on activities (and therefore realisable only when one has large economic resources), but structural moments in the life of services. Adequate training is also essential in permitting effective team work. It must be understood by workers that this aspect is not an accessory, linked to specific sensibilities, but an essential condition in obtaining results in complex situations. On the other hand, reality clearly shows how difficult it is to encourage different professional groups to collaborate on a clinical-assistance problem, both within the same service and via integration and contact interfaces.

To concretely tackle the problem of managing the services network for people affected by dementia it must be noted that throughout the world, but above all in Italy, there are very few research studies able to guide programming choices. One must therefore entrust the same to subjective observations or to group analyses which, however, have not realised any controlled studies able to provide definitive solutions. One must therefore ask in regard to the same: is it truly realistic to implement research work in a complex situation such as that which characterises the clinical, psychological, relational and social condition of an elderly ill person living in an advanced society?

The first modality - and, unfortunately, often the most frequent - adopted to tackle the management of services for elderly people affected by dementia is defeatist in character: the system has to make its own adjustments, citizens flow into the various segments of the network without being filtered, except by parameters such as proximity, availability of places, adequate financing,
desire for personal involvement on an economic and organizational level etc. This solution will never be openly accepted by anyone - yet in reality it is the most widespread. Its most serious limitation is that it exposes the most vulnerable and their families to a search for solutions that they are not able to identify and achieve due to conditions generated by economic, cultural and relational poverty etc.

The second possible response is positioned at the extreme opposite pole i.e. absolute functionalism, in accordance with a network model where everything moves under strict control, each movement is pre-planned, accompanied and certified in its efficacy. Some years ago this model was very widespread on a theoretical level and many recall the interminable lessons given by those who considered themselves the champions of such a rigid model - where the patient entered at a certain moment, in line with his initial needs, and was then closely guided for the rest of his life.

A third solution is obviously that of mediation. However, to avoid being merely a banal compromise it requires a number of firm points: when the elderly enter the network they must be studied analytically via multidimensional assessment which, by means of a somatic, psychological, functional and relational evaluation, is able to indicate and define a certain degree of need. On the other hand, the programmer undertakes, at the moment a new service opens, to clarify a precise profile of the relevant user and, albeit in a more elastic way, the location of the network relative to other segments. Starting from these two fixed points, the citizen can then “navigate” his way and now approach one, now the other option.

1.B SERVICES

Health and assistance authorities in recent years have proposed the most varied evaluation unit “formats” to regulate the system. However, they are too often bureaucratic-prescriptive entities which do not carry out any actions associated with defending the wellbeing of the citizen (obviously these considerations do not apply to particularly meritorious exceptions). Matters would be different if one could count on the activity of an efficient district, active 24 hours a day, able to smoothly regulate the various levels of assistance, with control over appropriateness, results evaluation and costs. Within a functioning district, including where there is a change in the level of intensity of the required intervention, there would be no need for so many different services. Only a few would be required, provided they are staffed by particularly well trained teams and are able to embrace differentiated activities in terms of quality and quantity.

Once the evaluation phase has been carried out, ill citizens enter the services system. As regards the latter, three aspects will be described below relative to persons affected by dementia. They concern the acceptance of the person with the condition (Alzheimer Evaluation Unit), somatic pathology management
hospitalization for acute cases), advance phases of dementia (dedicated nuclei in nursing homes).

**Alzheimer Evaluation Units**

The centres specializing in diagnosis of dementias (variously referred to as: Memory Clinics, Dementia Clinics, Alzheimer Evaluation Units), through the implementation of diagnostic evaluation protocols and specific care programmes, are able, relative to traditional services, to carry out early identification of the illness, accurately differentiate illnesses that lead to dementia, improve the quality of life of patients and caregivers and ensure targeted treatment.

The decisive elements in the definition of the quality of a service offered by specialized centres are: capillary diffusion and high accessibility, the presence of a wide variety of professional figures (geriatricians, neurologists, psychiatrists, psychologists) and a connection with diagnostics exploration services (neuropsychology, neuroradiology), the possibility of providing non pharmacological and rehabilitative interventions, connection with territorial and residential services.

In Italy the year 2000 saw the start of a national project focusing on the organization of a network of services for the diagnosis and treatment of Alzheimer’s called the “CRONOS project”, aiming to standardize the prescription of drugs and evaluate the effect of treatments. Approximately 500 specialized centres (called Alzheimer Evaluation Units - AEU) were instituted throughout Italy, with capillary though somewhat non-homogenous distribution. The definition of AEU organization criteria was left to the Regions without any real coordination between them. One therefore witnessed imbalances in both the distribution of the centres and in their organization (territorial, hospital, neurological, psychiatric and geriatric centres with or without support services etc.).

Although the non-homogeneity of the AEU was clearly evident, in terms of both composition of personnel and activities carried out, in the majority of cases these are not limited to being “prescription” centres for medicines but carry out a role as responsibility takers for patients. Those structures linked to recovery and diagnosis services and those with multi professional skills succeed best in guaranteeing satisfaction of the complex needs of patients suffering from Alzheimer’s disease. Unfortunately, the lack of agreed guidelines (concerning specific tasks, organization and distribution) and adequate support, including cultural, in some cases risks nullifying the contributions of operators in these centres which represent, including on an international level, a unique services network model for the territorial management of patients diagnosed with dementia.

The main role of AEUs is to accompany the patient and his family. There are particular critical moments during which targeted, intelligent and technical-
ly qualified support can modify the experience of those suffering from the disease. One of these is represented by the first phases of the illness, often characterised by the solitude of the patient and his family. Those who are in difficulty do not find any immediately available and reassuring answers that would help them understand their condition in order to be able to calmly analyse it and hence take the necessary decisions, accompanied by the advice of those who have greater knowledge, enabling them to indicate the correct approach to take in terms of life and care procedures. Relative to the more delicate problems concerning some phases in the relationship of the patient and his family with the illness, a study has recently been carried out by Censis on people affected by multiple sclerosis which has highlighted the fact that 48% of those affected by the disease see various specialists before arriving at a correct diagnosis. Moreover, 40% had to struggle, not without difficulties, in order convince the said doctors that their symptoms were real. Finally, 29% have received various treatments for pathologies other than multiple sclerosis. The survey continues by analysing the subjective response of patients to the appearance of the first symptoms, a response that tends to deny the existence of the said symptoms and hide them from others. The disability is difficult to accept, not least because - and notwithstanding widespread public generosity - there is always a certain number of family members (30%) who do not understand the patient’s suffering and tend to minimise it. Furthermore, the family exercises an absolutely predominant role in both the control and execution of care. However, families also persistently ask for functioning care centres they can work with, not just for the prescription of therapies, but for support over time, allowing them to find the right answers at the right time to many questions that make the provision of assistance uncertain and hence more burdensome.

Relative to the above, it is interesting to note that in the advanced phases of the disease, when the need for counselling is more intense, access to specific services is reduced. In other words, when medicines are no longer of any use, the function of the centres ceases too, because they focus their energies on medicines prescription, instead of on an overall management of the disease, through to the moment when palliative procedures are adopted.

This data, though the product of a survey that concerns another chronic illness that is extremely debilitating, assumes particular significance because from many points of view it is similar to what those affected by dementia, and their families, have to face. Within this scenario AEU have a significant role to play, responding to the most serious critical situations, which include:

a. Difficulties in arriving at a diagnosis with the support of doctors within the territory who are not always open-minded and often inadequately informed. Hence patients have to explore many routes to receive answers that correctly explain their suffering. The socio-health organization lacks
personnel able to construct “bridges” over which patients can transit, moving from their previous health condition to the new one - an illness that constrains them to come to terms with radical changes in their life experiences;
b. Difficulty in communicating the subjective nature of the disease to health operators and family members. In the phase of greatest pain and uncertainty, solitude is made even more acute due to a lack of understanding. One has only to think, for example, of the crisis that has to be faced by a person who for the first time experiences an intimate and personal condition of inadequacy due to an alteration in his cognitive functions;
c. As an indirect consequence of the above condition, the person affected tends to hide his crises, further intensifying his experience of solitude. A vicious circle is therefore generated that is difficult to break and which, in the end, also leads to further damage to health, after devastating the quality of life of those suffering from the disease;
d. The solitude of the patient is accompanied by that of the families, which have to provide assistance on their own (i.e. without any or with inadequate practical-organizational support, but above all without any support to help them interpret the present situation and suggest possible future scenarios). However, the majority of the AEU are able to respond to requests relative to the clinical and psychosocial aspects of patients and their families. While lacking any specific financing and hence often facing serious personal problems, they carry out an irreplaceable role. Arising initially as locations deputed to prescribe medicines, they progressively become vital centres and reference points for those persons affected with cognitive deficit, offering the latter answers to various questions and guidance in the difficult phases of their illness.

The person affected by dementia in a hospital for acute cases
Approximately 20-30% of patients older than 65, recovered in medical wards, exhibit clinically observable dementia and in 60% of cases it is possible to observe cognitive decline. Dementia represents for hospitalized patients an independent predictor of an increase in the duration of hospitalization, functional loss, risk of complications (infections, falls, iatrogenic damage), mortality and greater frequency of institutionalization.
Recovery in hospital for a patient with Alzheimer’s represents a crucial event for survival and functionality. It requires a specialist approach, able to provide, on the basis of patient prognosis, the most adequate level of care which can sometimes be intensive, sometimes limited to palliative interventions, with attention focused on social and family problems.
The outcome of many acute pathologies (pneumonia, myocardial infarction, fracture of femur) is worse in the patient suffering from dementia, regardless
of the specific gravity of the underlying illness. For these reasons hospitals should be able to recognise patients suffering from dementia as soon as they are admitted, providing specific assistance procedures to manage the acute phase, and specialise some wards for the said acute phases (geriatrics, medicines), having functional connections with surgery areas (orthopaedics, surgery, intensive therapy) and with the critical area. Moreover, it is essential to activate protected hospital release processes, to avoid both inappropriate ongoing hospitalization and the discharge of a patient into an unprepared environment. The most delicate aspects for the person affected by dementia include access to emergency services i.e. a bridge in the emergency phase between the activities carried out within the wider territory and in hospitals, which see a constant increase in admissions on the part of the elderly, especially those over 80 years of age. Emergency services constitute a safe place where those in difficulty, together with their families, can always obtain a response to match their needs, at any moment and in any condition.

It is therefore the place where effective responses have to be located on a clinical level, able to quickly understand the complexity and gravity of an illness and the suffering it causes. With this goal in mind, the construction of a Short-Stay Observation ward (ISO) with optimum geriatrics skills could allow the elderly suffering from dementia to receive the maximum attention and at the same time avoid – where possible – hospital admission, unless strictly necessary. (It is important in this regard for citizens to know that the primary concern of health operators at all levels should not be respecting hospitalization indexes but preventing any negative consequences for the elderly due to hospital admission, where the dangers exceed possible advantages, especially as regards the risk of disorientation and the manifestation of intense fear and anxiety levels due to sudden and profound changes in the patient’s environment).

Short-Stay Observation also carries out an important role as regards relations with nursing homes by preventing, on the one hand, admissions from leading to stress for residency guests, especially if they are affected by dementia, and, on the other, too short a period of observation, with the consequent risk that the clinical needs of vulnerable elderly patients are not satisfied.

Hospital activities that involve a particularly delicate and complex intervention include orthogeriatrics i.e. a system for networking integrated interventions on the elderly following a fracture. This is an increasingly more widespread model on an international level, one that has produced important results relative to the survival of ill people and their functional recovery. It is based on a rigorous integration of surgical and geriatrics activities, accompanying the patient through the various care phases, from the pre-intervention period - to be reduced as far as possible - to the rehabilitation phase. The patient’s clinical fragility requires continual observation in order to avoid the generation of adverse clinical events that can have a considerable affect on the final outcome.
Another particularly critical aspect is represented by a service that is at the other end of the spectrum relative to hospital emergency services i.e. post-acute care. Criticisms relative to this area are well known, not least because there has been a lack of experimentation indicating any clear approaches to be adopted.

In the near future there should be a clearer definition of the patient typology that most benefits from this intervention, more specifically clarifying the interface, on the one hand, with rehabilitation and, on the other, with interventions that are programmable in the territory through home activities. In this regard one must carefully analyse the possible role of these innovative services relative to people affected by dementia, together with the concrete possibility that they may facilitate the return of patients to their homes after a period of hospitalization, at the same time reducing the number of people that have to be institutionalized.

**Special units in residences**

The admission of people with dementia in special residential nuclei for the elderly (Alzheimer Nuclei) has demonstrated that it is able to reduce the frequency and intensity of behavioural disturbances without any (or with limited) use of psychotropic medications and physical restraints, slowing down the loss of functionality, preventing some complications (falls, malnutrition, immobility syndrome, delirium) and improving the quality of life of the patient, family members and assistance personnel.

The decision to hospitalize a person affected by dementia in a nursing home is almost invariably dictated by the presence of high levels of behavioural disturbances. Indeed, whereas at home some 40% of patients are in a low level phase, 40% in a moderate phase and the remaining 20% in a severe phase of the illness, in those who are institutionalized 80% are in a severe or very severe phase. It has been calculated that 60-70% of residents in institutions exhibit cognitive decline; approximately 40% exhibit severe level dementia; and 50-60% significant behavioural disturbances.

Specialized nuclei for dementia are based on some key elements in terms of their specificity:

a. personnel, which must be specifically trained to be able, in terms of operational contents and psychological capacity, to carry out the management of gravely disturbed patients, and in adequate numbers;

b. environment, adapted to patient needs, with specific attention devoted to architectonics and the organization of spaces. The living space of a person with dementia must be considered as an integrated system, one that comprises architectonic aspects and components linked to organization and social context;

c. activity programmes adapted to the specific condition of the person with
dementia, able at the same time to offer stimulation and prosthetics where appropriate;

d. family members, who must be actively involved as a source of information relative to the clinical history of the patient, his routine and habits at home and his ability to communicate with other ill patients, both as an active participant in group activities and as support in everyday assistance activities.

Within the context of Alzheimer Nuclei activities, various original modalities have been implemented as part of the treatment of patients suffering from severe stage dementia (music therapy, work therapy, validation therapy, soft corner, snoezelen room etc.). These have proven to be efficacious in terms of behavioural symptomatology and slowing down functional decline, and can also be applied in traditional nursing homes.

**Home assistance**

The pages that follow are dedicated to a review of the role of Home Assistance within the context of services for people affected by dementia. The Cafés too are part of this approach, as a support for the commitment made by various assistance structures on behalf of ill people who are living at home. The 1995 Objective Project For Protection of the Elderly laid down as its goal, at the end of a five year period, the activation of integrated home services (IHS) in order to assist at least 2% of non self-sufficient or partially self-sufficient elderly people over 65 years of age, or those subject to a grave risk of invalidity.

The main objectives of IHS focus on satisfying many needs correlated with partial or total non self-sufficiency, through assistance integration and continuity, with specific attention centring on patient quality of life, to be achieved by maintaining and protecting his living environment and his most important relationships.

Services assigned to home assistance management are variously denominated in Italian regions: Home Assistance Centres (HAC), Home Services, Primary Care etc., through to the most recent definitions of Home Care provided by the Health or Socio-Health District. Schematically, a correct use of home assistance satisfies the following conditions:

a. Base admission on verification of predefined eligibility criteria for the patients needing assistance;

b. Guarantee thorough and coordinated interventions management;

c. Concretely evaluate implemented interventions.

The correct and appropriate selection of assisted persons and a stable connection with hospital wards or semi-residential and extra-hospital residential structures (rehabilitation institutes/centres, RSA, Protected Residences, Hospices, Day Centres etc.) makes it possible to quickly and efficiently respond to
demands for assistance and above all to guarantee assistance continuity, the primary aim in the non self-sufficiency area. Home assistance, however, has never concentrated solely on persons affected by dementia. This remains one of the most critical aspects of the overall network and one which the greatest efforts could be focused on in terms of models to be applied and the relative experimentation.

Within the context of territorial services a particular role is played by Day Centres (DC). These represent a support for families and enrich the opportunities and flexibility of the network when equipped with specific features:

a. A specific socio-health orientation in an appropriate environment: the role of the environment in the management of patients affected by dementia is essential; at the same time the DC must also be able to deal with health needs;

b. Good urban location: the DC must not be isolated from the everyday life context of the patient and must encourage relationships with the wider society;

c. Adequate provision of qualified personnel and individualized activities programmes: socialization, education, reactivation activities requiring specific programmes for people with dementia; personnel must therefore be prepared for relationships with such patients;

d. Flexibility in management and opening hours: a wide time band must be available (up to 10/12 hours) for at least six days a week;

e. Availability of an equipped transport service, to encourage access and reduce the burden on families.

Day centres can be specifically dedicated to patients with dementia, or mixed in type. In dementia-specific centres, in addition to basic everyday activities, some rehabilitative activities are guaranteed, both cognitive and motor in character, in addition to clinical observation and the administration of medications. Day centres offer the following: catering service, meeting place, social secretariat, consultancy, recreation and cultural and health activities, especially those that are rehabilitative in character. In some cases day centres develop relations with Alzheimer Cafés, which can constitute a useful addition to their activities.

In general, patients affected by dementia who use day centres are the most “difficult” for families because they exhibit the greatest level of functional limitations, high frequency of behavioural disturbances and somatic co-morbidity. Day centres are located throughout Italy although there are no precise estimates. According to a recent survey, approximately 25% of patients with dementia that live at home attend a DC. For example, in Lombardy there are 232 accredited DCs, for a total of 5,143 places (0.6% of subjects over 75 years of age). However, there are only 7 DCs dedicated exclusively to patients with dementia, for a total of just 154 places.
**1.C INFORMAL SUPPORT**

Direct assistance for the elderly and people of all ages who are not self-sufficient is a difficult task on a human level, complex on an organizational level, and requires skill, physical and psychological “strength”, available time and sufficient economic resources. What can be done to make the generous commitment of many hundreds of thousands of citizens more effective in their devotion of time on behalf of those who are affected by major illnesses that drastically compromise self-sufficiency (with considerable negative effects on quality of life)? This is a world of generosity that is often hidden and largely unrecognised, one that must be encouraged to emerge from the marginal role to which it has been relegated. It is simply not acceptable that such an important part of social organization, in formal terms, goes unrecognised!

Caregiving is essential in helping non self-sufficient people - often affected by polypathology which directly affects their self-sufficiency - to remain in their own homes. It therefore represents a function that approaches that of an institutional service, together with those that are more strictly speaking clinical (relative to which it acts as an ancillary service, since no pharmacological or rehabilitative prescription or life style can be successful if it is not sustained by a caregiving system).

Relative to this growing need which exhibits increasingly diverse dynamics, one notes today a progressive difficulty in carrying out the caregiving function due to the fact that the number and clinical-assistance gravity of persons needing care has increased (pursuant to the structural modification of medical interventions, more prone to define illnesses as chronic) while at the same time the structure of the family has also changed (until a few years ago it comprised a larger number of caregivers but more recently the size of nuclear families began to decline, though the main caregiver still bore much of the burden; today, however, we have a situation characterised by substantial solitude on the part of both care-receivers and care-givers).

More recently the caregiving system has experienced a reduction - affecting many sectors - in public support services, as a result of the economic crisis. Those that offer assistance often find themselves carrying out technical tasks that are not part of their remit, tasks which circumstances demand they carry out. The present economic crisis has, among other things, led to change - albeit still limited - in the typology of caregivers, as a result of many women returning to the home environment after losing their jobs, thereby generating a possible new source of support within the family context.

Parallel to the services system there is also the care area assigned to caregivers. The economic crisis is also introducing elements of change in this sector, with a trend among Italian women that sees them returning to domestic work. As part of this trend the importance of home help cheques is being re-evaluated and in the light of a reduction in family incomes it is assuming a more
significant role. In the past some superficial commentators have defined the level of 9.5% of over-65s being the receivers of cheques as excessive. Today this percentage is considered adequate. Above all, the contribution to non self-sufficient persons has become a central factor for the human and economic equilibrium of many families.

With respect to this problem, the situation as regards dementia is particularly delicate because for some time there have been discussions on the significance of invalidity with purely “motor” interpretations that penalise persons affected by cognitive alterations together with their families, constrained to undertake what are often long hours of accompaniment which is not recognised by the State and is therefore not paid for. It is a further indication of how it is still difficult to make the services system understand the problems that have to be faced in the lives of those who are affected by dementia, and the need to provide such people with adequate support on a clinical, assistance and economic level.

The above evolution in the caregiving system has its limitations because it has been imposed and not freely chosen. This creates, within the family, increasingly more significant levels of stress with the generation of strong tensions. As a result, care work loses, among other things, part of its value in terms of the organization of the community and hence the possibility of creating social capital.

The caregiving scenario highlights the substantial fragility of the compartment, in which various areas are active, many often lacking protection and external to any organization. As a result the individual actors - both belonging to the family and personnel who are for the most part non-Italians - are exposed to a host of difficulties on a psychological (solitude, uncertainty about the future, contact with long-term and often very serious levels of suffering), technical (lack of information on the main geriatrics nursing - and other - methodologies relative to conditions that require specific interventions) and regulatory level (employment modalities, work hours, insurance etc.).

The suffering of family caregivers assumes different aspects over the long course of the illness: from waiting for the diagnosis to communication of the same, to everyday difficulties, to accompaniment in the advanced and terminal phases of dementia, to the moment when the most dramatic decisions have to be taken (institutionalization, choice of artificial alimentation, use of specific treatments etc.) and finally the death of their loved ones. Relative to these matters, caregiving for people affected by dementia does not have any formalized intervention models. The response must be constructed day by day, through crises, successes, pain and uncertainties.

Increasingly there is therefore a clear need to structure payment mechanisms for work carried out and for support given on the part of assistant-organizer-nurse-psychologist figures relative to various levels of need i.e. practi-
cal-technical, relational, organization of time and finally regulatory-national insurance-economic. However, in today’s society no interventions can be identified that address such complex needs in a coordinated manner. To meet this need it would be of great human and practical significance if the role of caregivers was recognised on an institutional level via the following:

a. Recognition on a cultural and social level of the importance of caregiving, in order to achieve, on a national level, basic homogeneity relative to the evaluation of this important human and assistance function. The subsidiarity role of the family must be defined relative to public services not as a concession, but as a central factor in civil society development;

b. Full recognition on the part of the Government, Regions and Local Authorities of the family as a service function for non self-sufficient people. This recognition must in turn be reflected in modifications to current non-remunerating regulations with the institution of homogenous economic benefits that are appropriate relative to the “weight” of the assistance provided. One of the first interventions that must be implemented is a revision of law 104/92 which makes it possible to take leave from work. Abuses have been discovered that have led to calls for an intensification of checks, while at the same time many situations involving real needs have not received adequate attention;

c. Definition of caregiver tasks and duties. Obviously within a strategic plan aimed at formally valorising a function it is necessary to indicate its limits and remits, although any increased rigidity must be avoided within bureaucratic schema relative to a function that always has a significant voluntary component to it and hence tends to be self-organizing. Assistance at home is structurally connected to the recognition of a high level of freedom on the part of the various protagonists involved in providing care. One specific aspect is represented by the relationship of the caregiver with the support administrator. Often the two figures do not coincide, with the risk of negative conflicts compromising the harmonious delivery of a given assistance project;

d. The right to have adequate training on a technical and relational level. In many local areas there are increasing numbers of “family schools” where, through the use of adequate didactic instruments, nursing techniques are taught for non self-sufficient people, together with ways to deal with and manage stress, as well as intra-family and services dynamics;

e. Structuring on the part of health companies of assistance plans that provide for the organic inclusion of caregivers. In this approach one must consider both the home and hospital level as well as that of any nursing homes. In each location the rights of caregivers must be formally recognised, encouraging their work and reducing restrictions on a practical level (e.g. access limitations for caregivers in some nursing home struc-
tutes, hospitals etc.). Using assistance plans one must define the tasks of caregivers, diversifying their use and as a result the interventions relative to the needs of non self-sufficient people;
f. The organization of adequate support services for the work of the family within the home (day centres, temporary relief admissions etc.). As part of a systematic approach these services must be available relative to real needs and hence be available and in line with the needs of a given territory.

1.D A POSSIBLE AND SUSTAINABLE FUTURE
To conclude, it is useful to delineate some features of organized interventions in favour of people affected by dementia.
The first is the coordination of work carried out in various contexts, under precise strategic and technical guidance. Interventions must be carried out within a unitary logic expressed through various approaches that are coherent with each other. This must not involve any increase in bureaucratic structures, with their relative costs and delays. Each intervention protagonist, however, is aware that he acts within a network that valorises his contribution. This aspect is important because it increases both the value of the results and the satisfaction experienced by individual care operators relative to the work they carry out.
A second feature of services for the vulnerable, including citizens affected by dementia, is that they are constituted by many small activities which taken together assume considerable importance. Small things which can become “gigantic” if placed together, forming a network which people can rely on in times of difficulty.
A third feature of services involves managing the problems of the elderly while taking into account the multidimensionality of their needs. Hence it is important never to forget that, regardless of how activities are initiated, those who are ill express their vulnerability through an intensely intricate group of somatic, psychological and socio-relational conditions.
The intervention that is truly useful is the kind of intervention that rejects the notion that any activity is the work of individual operators, replacing it with a collaborative concept of work, without straining the system and without any prevarications. For those who remember the endless discussions that took place in the past as to whether it was the clinical, assistance or relational aspects that should predominate, there is reason for satisfaction in noting that these kinds of attitudes, which blocked the realisation of improved results, have gradually disappeared.
The dialectic between hospital and territory, which has recently occupied the front pages, often with less than significant results, has been transcended, as have other “key words” (which all too often risk becoming nothing more than
“empty words” like “therapeutic continuity”, “sole access doors”. Often a good shared basic idea makes it possible to overcome, in practical everyday terms, the kind of difficulties that are normally described relative to these matters. A little more of the “real world” relative theoretical constructions that claim to provide for everything, regulate everything, is the solution that has generated the best results.

A further feature of organized systems must be a commitment to always measure any results achieved, so as to avoid the kind of subjectivism that has in the past characterised the weakest sectors, as regards both health and assistance. To state today that “what cannot be measured does not exist” constitutes a solid basis for the construction of a cost-benefit analysis, increasingly necessary in a society experiencing economic difficulties. However, and above all, measuring results is a sign of civil and human respect towards the person who is the subject of an intervention, because he has the right to know the results of any actions carried out on his behalf. The attitude of those who do not consider such an approach to be necessary reflects either pessimism (i.e. there is no point doing it) or the presumption that the intervention carried out must necessarily lead to a result. In both cases vulnerable people are not valorised as having the right to receive the maximum commitment possible in any given circumstance.

To conclude these pages on the importance of services for the quality of life of those who are ill we set out a fragment from a poem by the great poet Andrea Zanzotto. It expresses the force of light (human solidarity?), even in the face of the most terrible conditions. Just as the sun combats Alzheimer’s, so we hope that the commitment of so many in favour of the elderly can represent a light illuminating the road of those who suffer, a light characterised by the generosity of human commitment and the wisdom and intelligence of medicine: “Benches stupefied, Offering two still healthy elderly people to the sun, To the sun, With a violet in memory’s hand, Anti-Alzheimer sun”.

This section presents the data gathered from seven Alzheimer Cafés which are listed in Table 1. They are considered significant for their respective territories, both in typology of activities and in the number of users involved. Analysis of the Cafés has made it possible to efficaciously contextualise theoretical models, noting their advantages and, sometimes, limits. Overall, and notwithstanding the various contexts, they have adopted a general structure inspired by that proposed by Miesen for the constitution of an Alzheimer Café, intelligently adapted to satisfy the needs of their users. The data was collected on the basis of a protocol which the organizers of the Cafés participating in the study agreed to respect.

**Table 1. List of Alzheimer Cafés Taking Part in the Study**

<table>
<thead>
<tr>
<th>Café</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amarcord al Café</td>
<td>Cesena</td>
</tr>
<tr>
<td>Alzheimer Café</td>
<td>Cremona</td>
</tr>
<tr>
<td>Alzhauser Café</td>
<td>Saronno</td>
</tr>
<tr>
<td>Casa Guidi Café</td>
<td>Sesto Fiorentino</td>
</tr>
<tr>
<td>Alzheimer Café</td>
<td>Roma</td>
</tr>
<tr>
<td>Alzheimer Café</td>
<td>Oderzo</td>
</tr>
<tr>
<td>Alzheimer Café</td>
<td>Treviso</td>
</tr>
</tbody>
</table>

Sometimes the Cafés are included in the network of provincial or regional assistance services, together with other Alzheimer Cafés or entities that focus on dementias. The Cafés in Rome, Treviso and Oderzo are complex structures that have further internal subdivisions:

- Alzheimer Uniti Roma Onlus manages the Alzheimer Cafés in three districts of the capital: Monteverde, Prenestino and Bologna. The three Centres display some variations in their organization and management of activities.
- The Cafés in Oderzo and Treviso are subdivided on the basis of their intervention typologies, determined by the degree of cognitive compromise of the persons with dementia and the caregivers’ information and educational requirements. On the basis of these criteria there are two groups for each Café: the ACM Group (Ill Persons Alzheimer Café) and ACF Group (Family Members Alzheimer Café).

**2. founders and current partners**

Alzheimer Cafés are often created to counter a lack of information and adequate services relative to support for the family members of patients. Various studies have indicated that the caregivers of people affected with dementia are not sufficiently informed as to the assistance problems the sick person may have to face and the bureaucratic procedures that have to be followed to obtain any external support. A significant part of them therefore require
further information on prevention programmes and dementia symptoms and characteristics. Some institutions and entities, to respond to a growing need for knowledge and information on how to manage dementias, have promoted the foundation of Alzheimer Cafés. The years of activity have demonstrated not only the success of the initial idea but also positive collaboration between the different protagonists involved in care and assistance for the elderly in a given territory (table 2).

<table>
<thead>
<tr>
<th>Table 2. Alzheimer Café Years of Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Café</td>
</tr>
<tr>
<td>Amarcord al Café</td>
</tr>
<tr>
<td>Alzheimer Café</td>
</tr>
<tr>
<td>Casa Guidi Café</td>
</tr>
<tr>
<td>Alzheimer Café District Monteverde</td>
</tr>
<tr>
<td>Alzheimer Café District Prenestino</td>
</tr>
<tr>
<td>Alzheimer Café District Bologna</td>
</tr>
<tr>
<td>Alzhauser Café</td>
</tr>
<tr>
<td>ACM</td>
</tr>
<tr>
<td>ACF</td>
</tr>
</tbody>
</table>

Each Alzheimer Café is the product of the synergy of various subjects that are particularly sensitive to the needs of both patients affected by dementia and their family members.

When analysing the history of the birth of each Café one discovers that the promoters are subjects already involved in assistance for the elderly. More specifically, the founders of the centres analysed were: for Café Amarcord di Cesena, the Opera Don Baronio Foundation; for Café di Cremona, AIMA Association (Associazione Italiana Malati di Alzheimer); the initiating subject for Casa Guidi Café was Cooperativa Sociale Elleuno. The Cafés in Rome were founded in line with a project proposed by Onlus Alzheimer Uniti Association. In Saronno the Café was started up thanks to Onlus Auser Volontariato, while for Oderzo and Treviso the initiator of the Alzheimer Cafés was Ente ISRAA, Istituto di Ricovero ed Assistenza agli Anziani, a Public Assistance and Charity Institution, which in 2008 conceived and financed the pilot Alzheimer Café project for those suffering from the disease. To develop the initial idea, some centres involved further entities, listed in table 3. They compromise multiple models: Café di Cesena, for example, included among its initial partners ten entities comprising, the only one to do so, a university - the University of Bologna - while other Cafés were promoted by a single structure.
As already indicated, there have been various solutions proposed for starting up an Alzheimer Café, both in terms of typology and the subjects involved. Generally speaking, voluntary associations constitute the majority of co-founding entities. In other cases cooperatives have been actively involved, especially those which, even before the start-up of a Café, managed services for the elderly.

After the start-up Cafés have been able to create and optimise further contacts, with both public structures and other organizations, in order to optimally develop their potential. The search for new protagonists, for the organization, the management and financing of the Café, is a process that is always open to further interlocutors. Table 4 sets out, in addition to founding subjects, entities that have started to collaborate since the start-up. It is also important to note that all the promoter entities are currently partners in the Alzheimer Café project, even if, in some cases, they have a different role from the one they initially carried out.
### Table 4. Entities Currently Partners of Alzheimer Cafés

<table>
<thead>
<tr>
<th>Café</th>
<th>Partners currently involved in AC management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Amarcord al Caffè</strong></td>
<td>Cesena: AUSL di Cesena; Fondazione Opera Don Baronio; Università di Bologna; ASP distretto di Cesena-Valle Savio; Associazione “Amici di Casa Insieme”; Associazione CAIMA; Associazione GAIA; Associazione AUSER Territoriale di Cesena; Comune di Cesena; Centro Servizi per il Volontario Ass.1 prov.V; CAD Società Cooperativa ONLUS</td>
</tr>
<tr>
<td><strong>Alzheimer Caffè</strong></td>
<td>Cremona: AIMA, collaborations with: CISVOL-Centro Servizi per il Volontariato; Forum del Terzo Settore per Cremona; Associazione “Donatori del tempo libero”; Associazione “Nido dei nonni”</td>
</tr>
<tr>
<td><strong>Casa Guidi Caffè</strong></td>
<td>Sesto Fiorentino: Cooperativa Sociale Elleuno; Associazione AIMA; Società della salute della Zona Fiorentina Nord-Ovest; Associazione Comunale Anziani di Sesto</td>
</tr>
<tr>
<td><strong>Alzheimer Caffè Q.re Monteverde</strong></td>
<td>Rome: Associazione Alzheimer Uniti Roma, with the patronage of XVI Municipio and Coop Sociale “Medici di medicina generale 16 Onlus”</td>
</tr>
<tr>
<td><strong>Alzheimer Caffè Q.re Prenestino</strong></td>
<td>Rome: Associazione Alzheimer Uniti Roma, with the patronage of VI Municipio</td>
</tr>
<tr>
<td><strong>Alzheimer Caffè Q.re Bologna</strong></td>
<td>Rome: Associazione Alzheimer Uniti Roma</td>
</tr>
<tr>
<td><strong>Alzheimer Caffè Q.re Saronno</strong></td>
<td>Saronno: AUSER, collaboration with local Associations</td>
</tr>
<tr>
<td><strong>Amarcord al Caffè</strong></td>
<td>Oderzo: ISRAA; Associazione Perdut’amente; Azienda Sanitaria ULSS 9; Residenza Anziani Oderzo</td>
</tr>
<tr>
<td><strong>ACM</strong></td>
<td>Oderzo: ISRAA; Associazione Perdut’amente; Azienda Sanitaria ULSS 9; Casa di Riposo di Motta Livenza; Comune di Oderzo; Comune di Motta di Livenza</td>
</tr>
<tr>
<td><strong>ACF</strong></td>
<td>Treviso: ISRAA; Associazione Perdut’amente; Azienda Sanitaria ULSS 9</td>
</tr>
<tr>
<td><strong>ACM</strong></td>
<td>Treviso: ISRAA; Associazione Perdut’amente; Azienda Sanitaria ULSS 9; Comune di Treviso</td>
</tr>
</tbody>
</table>

#### 2. B Environment

The location of the Café relative to the city and its setting are important factors making it possible to establish the typology of users and their numbers,
the activities they can offer and which, due to lack of space, it is better to avoid. Alzheimer Café locations are often environments made available by or shared with other organizations operating within the territory (table 5).

<table>
<thead>
<tr>
<th>Café Location</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amarcord al Café</td>
<td>Cesena</td>
</tr>
<tr>
<td>Alzheimer Café</td>
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<tr>
<td>Casa Guidi Café</td>
<td>Sesto Fiorentino</td>
</tr>
<tr>
<td>Alzheimer Café Monteverde</td>
<td>Rome</td>
</tr>
<tr>
<td>Cafè District Prenestino</td>
<td></td>
</tr>
<tr>
<td>Alzheimer Café District Bologna</td>
<td></td>
</tr>
<tr>
<td>Alzhauser Café</td>
<td>Saronno</td>
</tr>
<tr>
<td>ACM</td>
<td>Oderzo</td>
</tr>
<tr>
<td>ACF</td>
<td></td>
</tr>
<tr>
<td>ACM</td>
<td>Treviso</td>
</tr>
<tr>
<td>ACF</td>
<td></td>
</tr>
</tbody>
</table>

The location within a social structure encourages the involvement of a greater number of users. In some cases Cafés are located in structures that already focus on the elderly (RSA, Day Centres, Associations). If, on the one hand, this facilitates contact with patients and family members that could become future users, on the other the Café runs the risk of being considered an extension of the first and not as an autonomous entity.

In addition, to increase its visibility within its urban setting, the greater part of the Cafés are positioned within a known context, in the centre of the mu-
nicipality, for the most part provincial capital cities or smaller towns. This location guarantees greater consideration on the part of all citizens, users or possible users of Alzheimer Café services. For big cities like Rome, the definition of centre and suburb is defined more narrowly: Alzheimer Cafés become a service for a ward or a district (table 6).

**Table 6. Location of Alzheimer Cafés in Cities**

<table>
<thead>
<tr>
<th>Caffè</th>
<th>Location in the city</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amarcord al Café</td>
<td>Cesena</td>
</tr>
<tr>
<td>Alzheimer Café</td>
<td>Cremona</td>
</tr>
<tr>
<td>Casa Guidi Café</td>
<td>Sesto Fiorentino</td>
</tr>
<tr>
<td>Alzheimer Café District Monteverde</td>
<td>Roma</td>
</tr>
<tr>
<td>Alzheimer Café District Prenestino</td>
<td>Oderzo</td>
</tr>
<tr>
<td>Alzheimer Café District Bologna</td>
<td>Treviso</td>
</tr>
</tbody>
</table>

The organization and subdivision of space also has a notable effect on the life of the Café. Areas range from a minimum of 40 sq.m. to a maximum of 250 sq.m. (table 7). The environments available are for the most part intended for activities with patients and family members: each Café includes a meeting room. It is not always possible to divide family members from patients, assigning a separate room to each of them. In some Cafés there is a space for the secretariat. In others there is a kitchen for the preparation of food and drinks so that people can sit down and enjoy sharing a meal together. For meetings during the summer months, some Cafés use gardens and balconies.
### TABLE 7. SPECIFICATIONS OF PREMISES

<table>
<thead>
<tr>
<th>Café</th>
<th>Sq.m.</th>
<th>No. rooms</th>
<th>No. toilets</th>
<th>No. toilets accessible to disabled</th>
<th>Carparking near structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amarcord al Café Cesena</td>
<td>40</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>yes</td>
</tr>
<tr>
<td>Alzheimer Café Cremona</td>
<td>106</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>yes</td>
</tr>
<tr>
<td>Casa Guidi Café Sesto Fiorentino</td>
<td>63</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>yes</td>
</tr>
<tr>
<td>Alzheimer Café District Monteverde Rome</td>
<td>40</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>yes</td>
</tr>
<tr>
<td>Alzheimer Café District Prenestino</td>
<td>60</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>yes</td>
</tr>
<tr>
<td>Alzheimer Café District Bologna</td>
<td>100</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>yes</td>
</tr>
<tr>
<td>Alzhauser Café Saronno</td>
<td>250</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>yes</td>
</tr>
<tr>
<td>ACM ACF Oderzo</td>
<td>106</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>yes</td>
</tr>
<tr>
<td>ACM ACF Treviso</td>
<td>125</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>yes</td>
</tr>
<tr>
<td>ACM ACF</td>
<td>90</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>yes</td>
</tr>
</tbody>
</table>

An aspect that cannot be undervalued is accessibility to the structure by patients with motor difficulties, via the presence of lifts and facilitated entrances as well as modified toilets, present in almost all Cafés. In addition, especially if transport has to be provided by the caregiver, another element to be considered is the possibility of parking near the structure. All the Cafés analysed are located near car parks and, above all in medium size cities, they can also be reached using public transport. Transport of patients and caregivers, where required, must be a service that is always guaranteed and free of charge, as occurs in the three Cafés which have activated it, even if the same constitutes a significant cost item in terms of money for vehicles, petrol and insurance, as well as in terms of volunteer commitment or paid personnel. The possibility of using transport made available by the Café also encourages the presence of users at meetings who would otherwise not take part.

A final consideration concerns Café decor - informal and welcoming, very different from hospitals and clinics. The choice and arrangement of furniture recalls that of a bar or true Café or, again, depending on the structure, that of a home. Inside the Café it is possible to find, at times, “information corners” with material available to users on Alzheimer’s and on the services offered within the territory.
Café opening times for the public try to satisfy the needs of caregivers and patients on the basis of the typology of intervention involved. For example, meetings programmed during the morning or in the afternoon benefit caregivers that do not work, while for meetings of an informational kind concerning patient management, different times during the day can be chosen. The Cafés are generally open on a weekly basis (table 8).

**Table 8. Opening Times**

<table>
<thead>
<tr>
<th>Café</th>
<th>Weekly opening hours</th>
<th>Monthly opening hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amarcord al Cafè Cesena</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Alzheimer Cafè Cremona</td>
<td>6</td>
<td>26</td>
</tr>
<tr>
<td>Casa Guidi Cafè Sesto Fiorentino</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Alzheimer Cafè District Monteverde Rome</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Alzheimer Cafè District Prenestino</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Alzheimer Cafè District Bologna</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Alzhauser Cafè Saronno</td>
<td>4,5</td>
<td>182</td>
</tr>
<tr>
<td>ACM Oderzo</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>ACF</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>ACM Treviso</td>
<td>4</td>
<td>16</td>
</tr>
</tbody>
</table>

Only one Café indicated diversified opening hours on the basis of legal time and solar time, to satisfy the needs of patients who seem more agitated “after sunset”. As regards the period of closure, it should be noted that the majority of Alzheimer Cafés suspend their meetings for the summer period, normally only for a few weeks.

**2.C PERSONNEL**

A multiplicity of professional figures take part in the training of Alzheimer Café staff. Overall, some 123 people collaborate in the 11 Cafés. Comparing the data for each Centre one notes significant differences: some structures have more than thirty people, while others only a few. The organization of activities depends, obviously, on the quantity of human resources available, their profile and their competences.
In detail those who collaborate with the 11 Cafés are as follows:

- 53 Volunteers
- 23 Trainees
- 15 Psychologists
- 11 Technicians for patient activities
  (music therapist, art teacher, rehabilitation therapist etc.)
- 4 Nurses
- 3 Doctors
- 4 Professional Educators
- 2 Coordinators
- 8 Other figures

Of 123 people, 65% work as volunteers. Paid personnel comprise, usually, psychologists and specialist doctors, as well as patient workshop personnel. The volunteers, including therein both university and Higher Institute trainees, carry out various tasks: helping in the management of the group and in activities, carrying out secretariat work, purchasing etc. To take part in the activities, especially in response to caregiver information requests, the Alzheimer Cafés organize courses for their training.

Among those specialized in the treatment of problems associated with dementia, the psychologist is certainly the figure most present in the Café, with the twofold function of support for patient activities and psychological help for family members. The approach to the patient is realised through cognitive evaluation, affect-behavioural evaluation and relational and communication aspects, while as regards interventions, psychologists particularly focus on affect and cognitive aspects of the ill person and as a support for operators.

Café personnel also include therapists who concentrate on activities aimed at patients e.g. specialists in music therapy, the activity that is most widespread after cognitive therapy, art therapy, pet therapy and oriental gymnastics.

Alzheimer Cafés often also require the presence of a professional educator who collaborates with the psychologist and other caregivers in the management of meetings and various activities.

Doctors and nurses participate for the most part in meetings aimed at caregivers, as consultants for family members and informal assistants who have to acquire useful information regarding the development of their family member’s illness and the management of the patient at home. Personnel and volunteers are guided in their activities and specificities by a figure officially assigned the role of Coordinator. Only in two Cafés is this figure clearly distinguished from the others, while normally a collaborator is assigned who, in addition to his own function, also carries out that of supervisor.
To carry out the various activities and define Café guidelines monthly or bi-monthly meetings are organized with various members of the team. In almost all Cafés one noted the importance of immediate feedback from operators following each meeting in order to examine and resolve, as of the next meeting, any new problems that may have arisen.

2.D USERS: WHERE THEY COME FROM

Patients that attend Alzheimer Cafés are for the most part women, with around 60% aged between 80 and 90, with a dementia diagnosis having been already carried out, in the majority of cases at an AEU clinic or by a specialist doctor.

Overall, during the period of observation, 170 patients and 190 caregivers attended meetings at the eleven Cafés. As with other data collected, there are considerable differences from Café to Café: from centres with an average of 6-7 users to others with some 30-35 people attending.

Turnover among patients and caregivers is approximately 12 units per year. This is due to a variety of reasons: from institutionalization of the ill person, to the impossibility of caregivers continuing with the meetings, to the worsening of patient state of health. Data is however extremely variable, including relative to the typology of activities proposed, at times structured in cycles, which allow caregivers to attend some of the meetings, interrupting their attendance for a period, to later start attending them once again.

Admissions to nursing homes communicated by each Café involve a limited number of patients: only one Centre registered 6 institutionalizations per year, the highest number recorded, while in three Centres no admissions were registered.

If one also considers the average attendance per user, over a period of approximately 12 months, one notes the presence of “core guests” i.e. habitual frequernters of the Café. This clearly indicates the level of success of the initiative, further confirmed by good results relative to user opinions on the quality of service. Even though only three Centres use customer satisfaction data, during meetings operators directly receive informal feedback from users which also helps to establish future Centre objectives.

All the Alzheimer Cafés promote their activities using various communication strategies. In addition to standard communication channels, patients and family members learn about the Alzheimer Cafés above all through health structures that focus on dementia, or from specialist doctors, geriatrics doctors and neurologists (table 9).
### Table 9. Patient Information Sources

<table>
<thead>
<tr>
<th>Typology of entities/professional figures that tell patients about the Cafés</th>
<th>No. of Cafés in which information is provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family member organizations (AIMA; Linealzheimer etc.)</td>
<td>3</td>
</tr>
<tr>
<td>AEU Centres</td>
<td>3</td>
</tr>
<tr>
<td>Specialist doctors</td>
<td>5</td>
</tr>
<tr>
<td>Municipal social assistants</td>
<td>4</td>
</tr>
<tr>
<td>Café founders</td>
<td>2</td>
</tr>
<tr>
<td>Public relations (Council, ASL etc.)</td>
<td>3</td>
</tr>
<tr>
<td>Territorial Nursing Homes</td>
<td>3</td>
</tr>
<tr>
<td>Altro</td>
<td>2</td>
</tr>
</tbody>
</table>

The voluntary associations too, as well as telephone lines dedicated to problems associated with dementia, inform people that the Cafés are meeting centres. Collaboration with territorial social assistants is also important together with, in general, the public authorities. Finally, it is important to note that, for a Café, promotion also spreads via “word of mouth” in collaboration with local pharmacies.

As regards communications by the AEU, it must be emphasised that although there is fertile collaboration concerning patient care, there are no agreements or protocols that formalize relations. In some cases the existence of the Cafés is notified via official communications from the relative Area Health Authority, sent out to all those “working in the field”.

Alzheimer Cafés have been created as free access locations. Only two Centres, those in Oderzo and Treviso, select entrance patients, advising attendance at the Ill Persons Alzheimer Café or the Family Members Alzheimer Café on the basis of the typology of intervention, the degree of cognitive compromise of the patient and the caregiver’s information and educational needs. The Ill Persons Alzheimer Café (ACM) is intended for those suffering from dementia with slight or medium cognitive decline, while offering their caregivers the chance to take part in psycho-attitudinal meetings on the subject of dementia and its symptoms.

Patients are involved, during the meetings, in non-specific cognitive stimulation. On the other hand, the Family Members Alzheimer Café (ACF) focuses above all on caregivers, with the possibility of involving ill family members in recreational activities. The aim is to create a safe and friendly environment where family members can receive adequate support. Caregivers are not obliged to follow the group that is indicated to them: if for various reasons they prefer a different choice they are not excluded from the Café’s activities.
It should also be noted that in a Café participants are not selected. Each family member with their ill relative who asks to be allowed to use the Café is accepted for a test period, during which initial tests and observation evaluations are carried out.

2.E ACTIVITIES FOR PATIENTS AND CAREGIVERS

The duration of each meeting at Alzheimer Cafés is approximately two and a half hours. Volunteers and operators prepare the hall approximately half an hour before the arrival of guests and get ready to welcome them. All Cafés generally divide their meetings into three phases:

- welcome phase
- activities for patients and, for some, caregiver consultation
- meeting closure phase.

The welcome phase plays a fundamental role in the management of the entire meeting since it determines the mood of the group. It can last from 15 to 30 minutes.

The activities proposed for patients can last from one hour to one and a half hours, and are often broken up by phases that include dancing and animation. In the meantime, caregivers can exploit the services made available or – though not in all Cafés – they can leave their family member until the end of the workshops.

The interventions focusing on patients affected by dementia have as their main objective the stimulation and maintenance of cognitive and motor capacities and are carried out to encourage relational and communicative abilities which may have deteriorated due to the illness. The range of activities that has been developed for patients is very extensive and as well as informal cognitive stimulation and ROT it also includes physiotherapy interventions, dance therapy or pet therapy. The activities proposed by the Cafés, listed in table 10, stimulate various functions: cognitive stimulation, for example, occurs above all informally and is substantially transversal to any proposed activity; other activities, such as music therapy, dance therapy, art therapy are also used as instruments to involve patients from a communication and relational point of view. Physiotherapy and Tai-Chi help those who are ill to maintain their motor functions.

Socialisation and animation phases are provided in all Centres. The socialisation phase, which also encourages interaction among the various caregivers, often coincides with the moment when patients and those who accompany them come together again for the final phase before the conclusion.
### Table 10. Patient Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>No. Cafés in which they are offered</th>
</tr>
</thead>
<tbody>
<tr>
<td>ROT (Reality Orientation Therapy)</td>
<td>3</td>
</tr>
<tr>
<td>Cognitive stimulation</td>
<td>11</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>3</td>
</tr>
<tr>
<td>Pet Therapy</td>
<td>1</td>
</tr>
<tr>
<td>Dance</td>
<td>2</td>
</tr>
<tr>
<td>Music therapy</td>
<td>4</td>
</tr>
<tr>
<td>Tai-Chi</td>
<td>1</td>
</tr>
<tr>
<td>Art therapy</td>
<td>3</td>
</tr>
<tr>
<td>Animation</td>
<td>11</td>
</tr>
<tr>
<td>Socialisation phase</td>
<td>11</td>
</tr>
</tbody>
</table>

As already indicated, two centres divide patients, at the moment the offered services are presented, into homogenous groups in terms of cognitive deterioration, while others carry out the said division only when the activities are carried out and in an informal way, in order to guarantee optimal management of patients. In some Cafés, as occurs with caregivers, the exercises intended for patients are subdivided into cycles, aimed at stimulating, on a case by case basis, various functions. Alzheimer Cafés do not just help in the management of patients affected by dementia, they also represent an instrument to provide caregivers with support and ensure they do not suffer from social isolation. To pursue this general objective a series of activities is offered that focuses on the patients' family members (Table 11).

### Table 11. Activities Focusing on Caregivers

<table>
<thead>
<tr>
<th>Intervention typology</th>
<th>No. of Cafés where promoted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussions with psychologist</td>
<td>11</td>
</tr>
<tr>
<td>Information on the search for caregivers/domestic help</td>
<td>4</td>
</tr>
<tr>
<td>Meetings with specialists (doctors, psychologists, nurses etc.)</td>
<td>3</td>
</tr>
<tr>
<td>Memory training</td>
<td>2</td>
</tr>
<tr>
<td>Self-mutual-help group</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>

The most widespread service is the discussion with the psychologist. In some Cafés the activity for family members involves, in addition to the proposal of self-mutual-help work, insertion in a group therapeutic-training type course under the guidance of a psychotherapist. These activities are carried out for
the most part on the basis of 1 year or 6 monthly cycles. Four Cafés also specified among the services offered to caregivers contact with cooperatives and associations for the selection of personnel that carry out home assistance, no minor concern for family members, especially when the patient’s first behavioural disturbances begin to manifest themselves. In some Cafés family assistants are also the recipients of training meetings with specialists. Sometimes the services offered by the Café comprise a telephone line dedicated to information on Alzheimer’s disease. There is also the very important possibility of leaving one’s ill family member for a few hours, entrusting him or her to the Café. This allows caregivers some free time, at least for a few hours, from the responsibility of managing their ill family members. Finally, it is important to note that the said family members also ask for advice on how to identify the very earliest symptoms of Alzheimer’s and how to exercise the patient’s memory. None of the Alzheimer Cafés indicates any support activities for caregivers after their loved ones have died. In addition to activities aimed at caregivers and patients, the Cafés often promote initiatives aimed at other users, such as seminars for health professions, information meetings with citizens, meetings with high schools, in order to make all citizens aware of the problem and informed as to the nature of the same.

2.F BUDGET
The budget available to the Café is usually the result of contributions allocated by various subjects. Often it is the public authorities, such as councils, Area Health Authorities and Provinces that assign to the Cafés parts of the funds intended for improvements in the assistance provided for elderly patients. In other cases the Cafés take part in public tenders for the provision of financing. Private entities and citizens also contribute with their donations to help meet Café requirements. At times financing for Alzheimer Cafés can also occur in an indirect manner, for example by providing free of charge personnel who already collaborate with a financing entity, paying for volunteer travel expenses, with the donation of materials required for activities with guests or, again, offering a location where meetings can be held free of charge. The annual budgets made available can vary considerably: from approximately € 600 to almost € 27,000 (table 12).

<table>
<thead>
<tr>
<th>TABLE 12. BUDGETS AVAILABLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Budget</td>
</tr>
<tr>
<td>-----------------------------</td>
</tr>
<tr>
<td>Cafés with budget up to € 5,000</td>
</tr>
<tr>
<td>Cafés with budget from € 5,000 to € 10,000</td>
</tr>
<tr>
<td>Cafés with budget from € 10,000 to € 20,000</td>
</tr>
<tr>
<td>Cafés with budget from € 20,000 to € 25,000</td>
</tr>
</tbody>
</table>
Various factors influence the economic profile of the Cafés: the number of paid and voluntary personnel; the possibility of using services made available by other entities which, therefore, do not directly impinge upon Café costs; rent and management of spaces not directly assigned to the Centre. Relative to these kinds of costs each Café draws up its own annual expenditure plan, comprising various items. The main ones include:

- **Annual rent**
  Only three centres have to include in their annual budget the rent costs for the premises, on average € 2,000 a year. In the majority of cases the room or structure are offered free of charge.

- **General expenses**
  Costs for the premises and for management of activities involve, on the other hand, all centres. For seven Cafés general expenses are less than € 1,000; for others general expenses range from € 1,000 to € 3,000. Only one Café spends, for the purchase of various materials, more than € 3,000.
  General expenses include various items: from the secretariat to the purchase of materials for workshop activities, for Centre utilities and socialization activities. All of which constitute approximately 10% of the total budget.

- **Personnel payments**
  For various Centres these constitute the majority of the expenses that the Café incurs. In this case too there are considerable variations and it is difficult to assign any significance to an average figure. The Cafés spend for their personnel amounts ranging from € 2,600 to € 17,000. The budget allocated depends on the number of activities proposed, personnel used, typology of professions at work, Café opening hours. As already noted, in some cases, all personnel carry out their services free of charge.

- **Transport service**
  There are three Cafés that have indicated transport service as an expenditure item: on average, in a year, the cost of the said service comes to € 1,500. In another 2 Cafés the service is activated on the basis of family requests.

- **Insurance**
  Only two Centres have specified this item, which constitutes an annual cost of approximately € 550.

### 2.G COMMUNICATION

Alzheimer Cafés promote their activities through an online strategy, for the most part using an Internet site or at least an information page on other institutional sites; and off-line, with the printing of information material and leaflets.

In the social network era Cafés too have opened their profile, aimed not so much at information exchange as at the sharing of the emotional “states” of
caregivers. Certainly not a secondary aspect, Facebook is becoming the main vehicle for the promotion of events and initiatives.

Paper material is distributed through various channels, from subjects that focus on Alzheimer’s disease to various partners that collaborate with the Cafés, to businesses in the district and to parishes: each Café has succeeded in involving different actors in their communities.

Relative to information for family members, the methods most used are: telephone lines dedicated to the problems of Alzheimer patients and meetings with specialists. These intervention typologies on the one hand support caregivers in the management of their loved ones; on the other they encourage a diffusion of information on dementia.

Some Cafés also carry out more targeted training interventions, aimed at health professions, for which they organize, in collaboration with other structures, seminars and updating courses. Other scientific-divulgation type activities include participation in congresses and conventions, publication of articles in sector journals, Alzheimer’s disease studies.

Meetings are also held that are open to all citizens, students in high schools, potential informal assistants, with the aim of spreading awareness of Alzheimer’s and other dementias.

The divulgation of information and periodic visibility in local information media help to maintain relations not just with the network, understood as users and structures that collaborate with the Café, but also with all citizens. This connection is also fundamental for the acquisition of new volunteers to work with the Café: only one Centre offers annual meetings for their “recruitment”. In some entities a projects and ideas comparison and exchange strategy is adopted with other Alzheimer Cafés: this could develop into an interesting incubator of new ideas.
INTRODUZIONE

LA DEMENZA: UN FUTURO DI SPERANZA?
Chapter 3

Alzheimer Cafés: benefits for people affected by dementia and their families

3.A Evaluation methods 58
3.B Guest characteristics 61
3.C Results 63
This section sets out the characteristics of the people that frequent the Alzheimer Cafés examined during the course of the study. In a subgroup of subjects it was also possible to analyse modifications of clinical and functional parameters after attending a Café for 3 months.

The study was carried out in the period between December 2011 and March 2012. For the collection of data widely validated evaluation scales were used.

The sample considered comprises 116 patients, with relative caregivers. Of these 62 are new users of the Café, with evaluation scales administered to the same at the start of attendance and 3 months later, in order to determine any beneficial effects of the meetings.

3.A EVALUATION METHODS

Instruments for multidimensional evaluation in the elderly make it possible to construct an image of the life experience of the person and follow its evolution over time. The following domains were taken into account relative to the Cafés:

- Cognitive functions (via administration to patients of the Mini Mental State Examination- MMSE).
- Mood analysis (using the Geriatric Depression Scale- GDS).
- Global somatic health (with the use of an instrument that collects available clinical information from the patient, family members or operators (Cumulative Illness Rating Scale- CIRS).
- The presence of behaviour disturbances due to dementia (with an instrument that systematically collects information provided by family members - the Neuro Psychiatric Inventory- NPI).
- The patient’s quality of life (with a scale, the Quality of Life AD-QoL, which involves an interview with both the patient and the caregiver. Given the extensive range of cognitive deterioration of the sample analysed and the presence of subjects with moderate-severe deterioration, only the part of the scale that involves the interview with the caregiver has been used).
- The assistance burden (measured using the Caregiver Burden Inventory- CBI, a scale that is administered to caregivers).

Cognitive functions (MMSE)

The evaluation of patient cognitive capacity was carried out using the Mini Mental State Examination (MMSE). This comprises 11 items, subdivided into 5 sections by means of which the various cognitive functions are evaluated, especially temporal and spatial orientation, immediate memory (fixation or registration memory), attention and calculation, recent episodic memory, language (name, comprehension of messages, both oral and written, and
writing of a phrase), as well as constructive apraxia. The maximum value of the test is 30/30. Scores equal to or above 25/30 are considered normal.

The sample was subdivided on the basis of the following scores:
- 25-30: cognitive processes within the context of normality
  (24 is the threshold score)
- 18-24: slight cognitive deficit
- 10-17: moderate cognitive deficit
- 9-0: serious cognitive deficit.

**Mood (GDS)**
Mood was evaluated using the Geriatric Depression Scale (GDS). The GDS minimises the somatic aspects of depression, considered confusing and not very specific in the elderly, while it explores the affective aspect. The maximum score is 30, corresponding to a serious degree of depression. It is not a scale that allows one to draw up a clinical diagnosis but it does permit graduation of depressive symptoms. The scores obtained can be subdivided as follows:
- 0-10=depression absent;
- 11-17=slight depression
- 18-30=serious depression.

The scale was administered only to subjects with MMSE greater than 10 to limit any interference due to cognitive deficit.

**State of somatic health (CIRS)**
The general state of patient health was measured using the CIRS scale i.e. Cumulative Illness Rating Scale. Considered a valid indicator of global health it defines clinical and functional severity of 14 of the most frequently observed pathology categories: cardiac pathologies, hypertension, vascular pathologies, respiratory pathologies, disturbances of the eyes, ears, nose, throat, larynx, upper GI apparatus (oesophagus, stomach, duodenum, biliary system, pancreas), lower GI apparatus (intestine, hernias), hepatic pathologies, renal pathologies, genital-urinary pathologies, muscular-skeletal-skin system, nervous system pathologies, endocrinial and metabolic pathologies, psychiatric behavioural pathologies.

Two indices are obtained:
- Severity index, which is obtained from the average of the scores of the first 13 pathologies (excluding the psychiatric/behavioural pathologies category);
- Co-morbidity index, which represents the number of pathologies in which one obtains a score greater than 0 or equal to 3 (excluding the psychiatric/behavioural pathologies category).
**Behavioural disturbances (NPI)**

The Neuro Psychiatric Inventory (NPI) is an instrument able to evaluate, on the basis of the information obtained by the caregiver, the frequency and gravity of an extensive range of behavioural disturbances such as: delusions, hallucinations, agitation-aggression, dysphoria-depression, anxiety, euphoria, apathy, disinhibition, irritability-lability, aberrant motor behaviour, sleep disturbances, alimentary behavioural disturbances. The score ranges from 0 to 144. The individual behavioural disturbances are explored using a questionnaire that makes it possible to both note their presence and obtain detailed information on their modalities of expression. The questions refer to the situation of the patient in the 4-6 weeks prior to the interview. The evaluation is carried out on the basis of information provided by a family member or by a person who knows the patient.

**Quality of life (QoL)**

The scale administered to the caregiver is the Quality of Life AD, comprising 13 questions that explore various aspects, such as social life or family relations, for each of which the caregiver must assign a score from 1 to 4. The maximum score is 52.

**Assistance burden (CBI)**

The Caregiver Burden Inventory or CBI is an assistance burden evaluation instrument able to analyse multidimensional aspects, elaborated for caregivers of patients affected by Alzheimer’s and related dementias.

This is a self-report instrument, compiled by the main caregiver i.e. the family member or operator who bears most of the assistance burden. Evaluation of the various stress factors is divided into 5 sections:

1. burden (item 1-5), describes the burden associated with restriction of the caregiver’s time;
2. evolving burden (item 6-10), understood as the caregiver’s perception of feeling excluded relative to the expectations and opportunities of his peers;
3. physical burden (item 11-14), which describes feelings of chronic fatigue and somatic health problems;
4. social burden (item 15-19), which describes the perception of a conflict in work and in the family;
5. emotional burden (item 20-24), which describes feelings towards the patient, which can be generated by his unpredictable and bizarre behaviour.

The maximum score for this scale is 96.
3.B GUEST CHARACTERISTICS

Alzheimer Cafés, as already set out in previous sections, are locations dedicated above all to elderly persons affected by dementia and to their assistants, both formal and informal. On the basis of the data obtained in the study it is possible to delineate an identikit of the average user of this service. Table 1 describes the main features of the sample. Guests have an average age of 80 (within a wide range: from 64 to 92) and are for the most part women: out of 116 guests 69 are female. Women, as one would expect, have an average age that is significantly higher than male subjects.

<table>
<thead>
<tr>
<th>TABLE 1. CHARACTERISTICS OF PATIENTS TAKING PART IN ALZHEIMER CAFÉS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample Total</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Gender (n (%))</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>MMSE</td>
</tr>
<tr>
<td>GDS</td>
</tr>
<tr>
<td>CIRS severity</td>
</tr>
<tr>
<td>CIRS comorbidity</td>
</tr>
<tr>
<td>NPI total</td>
</tr>
<tr>
<td>QoL</td>
</tr>
</tbody>
</table>

The data is presented as average ± DS
p: statistical significance calculated with two-tailed t-test for independent samples (for averages)

A further subdivision on the basis of age bands better describes the characteristics of Alzheimer Café users (figure 1).

The data is presented as average ± DS
p: statistical significance calculated with two-tailed t-test for independent samples (for averages)

FIGURE 1
Distribution of patients taking part in Alzheimer Cafés relative to age and gender

More than 90 years old
80-90 years old
70-80 years old
60-70 years old
Alzheimer Cafés are for the most part frequented by people aged between 80 and 90, some 50.7% of users, for the most part women (67% of cases). These are followed by people between 70 and 80, constituting 30.4% of the sample. There is a slight prevalence of males, with 55% of subjects. Finally, another significant datum is constituted by the presence of people older than 90, constituting 11.6% of the total, mostly female. The majority of Alzheimer Café users, approximately 60%, attended elementary school, 21% also attended junior high school, while only 10% attended a higher institute. The average MMSE score obtained by the subjects at the baseline is 11.4 ±8.9 (table 1). There are no significant differences relative to gender. Given the breadth of the range, from 1 to 28, an analysis of the data was carried out subdivided by level of cognitive deficit (figure 2).

Some 35.3% of Café patients exhibit serious cognitive deficit, 35.3% moderate and 24.1% slight. Male patients mostly have moderate cognitive deficit, while there is just one grave female. Female subjects with a score above 25 are, in percentage terms, greater in numbers than their male counterparts. Table 2 sets out the MMSE scores subdivided by Café: differences are limited and this indicates that users are substantially homogenous relative to the seriousness of their cognitive deficit.

### Table 2. MMSE Score at the Baseline in Various Alzheimer Cafés

<table>
<thead>
<tr>
<th>Café</th>
<th>MMSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cesena</td>
<td>10.2±9.3</td>
</tr>
<tr>
<td>Cremona</td>
<td>14.3±8.1</td>
</tr>
<tr>
<td>Sesto Fiorentino</td>
<td>13.2±10.8</td>
</tr>
<tr>
<td>Rome</td>
<td>13.8±7.0</td>
</tr>
<tr>
<td>Saronno</td>
<td>11.9±5.7</td>
</tr>
<tr>
<td>Treviso/Oderzo</td>
<td>10.2±10.1</td>
</tr>
</tbody>
</table>
The scores for the depression scale (GDS) indicate values that are substantially similar for male and female and low scores, indicating a limited number of depression symptoms (table 1): 93% of the sample have values that lie within the limits of normality, while the remaining 7% exhibit a form of slight depression.

As regards somatic health, the data indicates high levels of co-morbidity: 32% of the samples are affected by 3 or more moderate-severe chronic pathologies, and 44% by just one moderate-severe chronic pathology. The CIRS co-morbidity data (table 1) indicates higher scores in female subjects, in line with epidemiological data for this age.

As regards behavioural disturbances, total NPI scores are rather high (31.7±29), without any significant differences between male and female (table 1).

As regards the scale that measures caregiver assistance burden (CBI), the average total score is 31.6 ± 19.1. The analysis of individual items indicates those aspects considered more stressful for caregivers (table 3).

<table>
<thead>
<tr>
<th>Table 3. Distribution of average CBI scores at the baseline</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBI subscale</td>
</tr>
<tr>
<td>----------------------------</td>
</tr>
<tr>
<td>Objective burden</td>
</tr>
<tr>
<td>Evolving burden</td>
</tr>
<tr>
<td>Physical burden</td>
</tr>
<tr>
<td>Social burden</td>
</tr>
<tr>
<td>Emotional burden</td>
</tr>
<tr>
<td>Total CBI</td>
</tr>
</tbody>
</table>

Caregivers consider the objective burden to be the greatest source of stress. In this item the family member is asked how much the patient has to be helped in carrying out everyday activities, how much free time the caregiver has left, to what degree the patient has to be monitored. Another source of stress is represented by the evolving burden, which explores how assistance for a patient influences the present and future life of the family member. The physical burden exhibits a score that is not particularly significant: it analyses in what way, and to what extent, concentrating energies on a patient affects the caregiver’s state of health. No significant data was observed as regards social and emotional burden either. These respectively consider the extent of the said burden in the family and working life of the caregiver due to his having to look after a person affected by dementia, and whether the caregiver develops any resentment relative to the person receiving his care.

3.C RESULTS

The data is presented relative to 62 patients who started to attend Alzheimer Cafés during the survey and relative to whom it was therefore possible to ob-
tain follow-up data after three months, with the aim of evaluating the results of the intervention on psychological and behavioural symptoms associated with dementia.

### TABLE 4. COMPARISON OF CLINICAL CHARACTERISTICS OF PATIENTS ATTENDING ALZHEIMER CAFÉS AT THE BASELINE AND FOLLOW-UP AFTER THREE MONTHS

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>Follow up</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMSE</td>
<td>11,4±8,9</td>
<td>11,7±10,2</td>
<td>Ns</td>
</tr>
<tr>
<td>GDS</td>
<td>3,6±2,5</td>
<td>3,5±2,1</td>
<td>Ns</td>
</tr>
<tr>
<td>NPI total</td>
<td>28,8±19,3</td>
<td>23,5±18,6</td>
<td>&lt;0,001</td>
</tr>
<tr>
<td>NPI distress</td>
<td>13,8±12,3</td>
<td>11,1±11,4</td>
<td>&lt;0,001</td>
</tr>
<tr>
<td>QoL</td>
<td>18,6±11,8</td>
<td>22,8±12,4</td>
<td>&lt;0,001</td>
</tr>
</tbody>
</table>

The average score for MMSE and GDS remained substantially stable (table 4); analysis of the distribution of subjects on the basis of the MMSE score (figure 3) also did not show any significant variations.

Although the modifications observed do not reach a level of statistical significance, at follow-up one notes a percentage increase in patients with serious levels of compromise (+3%) and with normal score (+5%). Groups with a slight or moderate score decrease. One notes that 43 subjects, 69% of the sample, maintain modifications to the MMSE score within a range of +/- 1 relative to the baseline, while 17% register an improvement of 2 or more points at follow-up. The remaining 12% exhibit a worse score, relative to the baseline, by 2 or more points.

As regards NPI there is a statistically significant reduction in average scores on follow-up (table 4); behavioural disturbances decrease in 53.2% of subjects analysed, 14.5% remain unchanged and there is an increase in the remaining 32.2%. There is also a reduction in the score for the NPI distress scale, which
evaluates the impact of behavioural disturbances on caregiver stress levels. The perception of the quality of life is considerably improved over the three months (table 4), increasing from 18.6 ±11.8 to 22.8 ±12.4: the increase in the data represents a statistically significant change, of no little human importance, given the aspect which the scale is designed to analyse. Table 5 contains the data for the CBI subscales at the baseline and follow-up; it exhibits a significant reduction in the total score, to which the various subscales contribute in different ways; more specifically, the reduction in the emotional and social burden is significant. The caregiver has less difficulty in accepting his role and succeeds better in emotively managing the illness of his family member. Although the average for the CBI total score at follow-up decreases, the score suggests that Alzheimer Cafés carry out an important function, but that other interventions are also necessary to support caregivers in their provision of assistance.

<table>
<thead>
<tr>
<th>Sub scala CBI</th>
<th>Baseline</th>
<th>Follow up</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective burden</td>
<td>11.3±6.3</td>
<td>12.0±7.0</td>
<td>Ns</td>
</tr>
<tr>
<td>Evolving burden</td>
<td>8.6±6.7</td>
<td>7.8±6.5</td>
<td>Ns</td>
</tr>
<tr>
<td>Physical burden</td>
<td>4.6±4.9</td>
<td>4.4±4.3</td>
<td>Ns</td>
</tr>
<tr>
<td>Social burden</td>
<td>3.5±2.6</td>
<td>2.5±2.6</td>
<td>&lt;0.08</td>
</tr>
<tr>
<td>Emotional burden</td>
<td>2.8±2.6</td>
<td>1.6±2.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Average</td>
<td>32.7±20.5</td>
<td>29.01±17.3</td>
<td>&lt;0.04</td>
</tr>
</tbody>
</table>

Data presented as average ± DS
Significance calculated with Student two-tailed t-test for paired samples.
INTRODUZIONE
LA DEMENZA: UN FUTURO DI SPERANZA?
Chapter 4

A low cost service model with high social utility

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The data gathered from the survey of Cafés outlines an original and useful service. Original because it is a different assistance typology from many others; useful because it makes it possible to take care of the ill person and his family efficaciously, but at the same time without any need for significant investments. It is a convincing example of human high intensity interventions, adequate for a period of economic crisis in supporting formal services that risk progressive reduction. Support does not mean, however, substitution. To attempt to do so would be unrealistic and would also risk this experience taking on a misleading image.

The enormous development in the number of Cafés in recent years testifies to their role in contributing to the wealth of mechanisms protecting the vulnerable that characterises Italy and the positive response they have received on the part of the families of those affected by dementia. It is therefore not a response to an “assistance vacuum” that has been perceived and must be filled, but the opening of new spaces for care, such that those suffering from dementias can find places where they can spend some time, in a protected, serene environment, one that is adequate for the specificity of their needs and hence substantially therapeutic.

A recent review of the literature has shown that the majority of the guidelines that focus on dementia do not consider psycho-social interventions. This work therefore seeks to offer material for those who have to draft the next Italian and European guidelines to ensure that Alzheimer Cafés will be considered among the intervention typologies that enjoy considerable significance. We are fully aware that the collection of data, with regard to both functionality and results, has been carried out relative to a limited sample. The results merit further exploration, using greater numbers and methodologies that are more refined than those used here. However, we hope that - thanks too to this body of work - it will be impossible in the future to ignore the contribution of Alzheimer Cafés within a structured care project for those suffering from dementia, and without restricting the dynamic flow of spontaneity and innovation which has characterised the majority of these services during the 20 years of their existence.

This is not the place to retrace the history of the Cafés, which started in 1997 in Leiden, Holland, and which then spread to other European and extra-European countries, and which have also existed for more than a decade in Italy, where experience with the same has become progressively more widespread. Today the scenario is characterised by structures that are often very different from each other. In part the differences are also reflected in the data set out in this study, though this should not lead to their interpretation as a sign of inefficacy, and even less of inadequacy in terms of the work they carry out. The considerations set out below do not seek to provide rigid indications but support for those who wish to open a new Café or reanalyse any work carried
out to date, in order to achieve, each in his own territory, the maximum levels in terms of quality and results. At the same time, however, the data indicates that there are some features of the service that cannot be ignored. Spontaneity is not decreased by any dependence on indications of a general character. On the contrary, it is valorised in that some operational decisions can be facilitated and unnecessary errors can be avoided. We hope that these pages will be read and understood as part of this approach: a contribution among equals for the progress of many small enterprises which overall constitute a model that has generated important results and can continue to provide a useful function. It is therefore a contribution supporting the construction of many small free enterprises. A world of targeted generosity which we hope can develop still further in the coming years.

4.A Startup And Partners

The structures examined are a reflection of the wealth of our society, still able (and this is a positive sign!) to express commitment and innovation in favour of those who are less fortunate. It is interesting to note that the initiators belong to the voluntary sector in its various expressions and, even more, the rapid rate of growth among family member associations, as a response to an acutely felt need and to a request for help that is expressed directly. The associations that represent the group interests of vulnerable people constitute a network of interests and skills that should find increasingly more space in a modern and responsible welfare state. They are efficacious in their specific functionality and, more encouraging still, the great majority of them carry out their activities without any parochialism or egotism.

It is also interesting to note that during the course of their existence the Cafés have found new support, including among Councils and health companies. This is a de facto recognition of the utility of their activity and its social significance, even if sometimes one notes resistance on the part of those who do not recognise diversity and specificity of roles, and the need to create networks. Some Cafés grow by relying to some degree on larger structures such as nursing homes for the elderly. This contiguity offers advantages on a practical level (starting with the greater availability of qualified professionals). However, it is important to keep the two spheres of work separate, to avoid any identification of the Café with an environment that is often sad and segregating, and perceived as such by the wider population. Alzheimer Cafés, on the other hand, oppose the very idea of segregation, starting from that of a family which, burdened by its tasks, tends to close in on itself, reducing its contacts with the exterior world to a minimum.

In conclusion, if anyone today conceives of a new operation in this sector, especially if it is an association of family members, they must first ensure the support of strong voluntary work (e.g. the pensioners union has solid structures,
often equal to professionalized structures) and a reliable cooperative for the supply of the necessary support of an economic character (the social vocation of a reliable cooperative is a guarantee of a good level of homogeneity relative to the common activity carried out). This is the basis on which one must start and “risk”, with generosity and courage (the data set out, and other information collected in various environments, indicates that no Alzheimer Cafés have failed once they have been set up!). Obviously, it is necessary to have, alongside courage, an idea, a project, one that connects the specific needs of a territory, a group of people, with the “big” goal of replicating a model that has enjoyed success in various contexts. All of which leads to a progressive and firm consolidation of the Cafés, silently but with solid foundations. Another datum that is not openly declared, but one that can be deduced from various indications, is the function of leadership exercised by a person (or two-three people who work well with each other) who from the start acts as pivot for the activity. Such leadership succeeds in bringing together the needs of various types, transforming them into concrete work programmes. Leadership which must, however, be “delicate”, to avoid constituting de facto barriers, even if they are the product of good intentions, against those who are interested in this new experience and its potential integration. The question of leadership is one of the most sensitive in all Cafés. Often the background of whoever is the initiator of the enterprise (volunteer, social operator, family member) provides a strong orientation for the overall activity. Such strength must at the same time be accompanied by an ability to encourage collaborative goals, as general as possible and open to continual innovation.

4.B SPACES AND ENVIRONMENT
The environments in which Café activities are carried out are frequently made available by entities that support the initiative or promote it. A critical aspect is their location. Today transport by family members occurs in the great majority of cases by car. It therefore appears to be more important to have car parking available that a location in the centre of a city or town. In some Cafés transport is carried out against payment, in others via the contribution of organized volunteers. Obviously, the choice must be made carefully, to avoid heavy costs for families (from both an organizational and economic point of view).

Large spaces are not necessary (100-120 sq.m. appears to be adequate). However, good heating is a necessity in winter as is the avoidance of excessive heat in summers - bearing in mind that those who are ill often have very warm houses and hence their stay in a Café can offer them a chance to experience healthier, cooler and fresher temperatures.

The premises can be made pleasant by the work of volunteers, putting up photographs and ornaments. There are no rigid rules regarding the environment. It must, however, be well maintained, even if sometimes the building itself may
not be well conserved and may even require a few low cost interventions. This does not mean that it has to be rigidly organized, but it must be a place where the fundamental and immediately perceivable characteristic is that of warm and friendly acceptance. Informality and the implications of the name itself, “Café”, characterise the environment, which must be nothing like an institution (clinic or day hospital). On the contrary, it must convey the image of a place that is perfect for friendly meetings, without any predefined tasks to be accomplished, offering a pause in the frenetic rhythm of a “36 hour day” that is all too often full of essential duties and tasks. It is necessary to have an equipped bathroom, easily accessible. It is preferable to have spaces organized in two separate areas to permit, for example, in some moments, subdivisions between the ill and family members, and to make the performance of various interventions possible. A small cooking area where food and drinks can be prepared is also very useful. A particular aspect concerns the adoption of refinements to reduce noise levels in the environment using sound absorbent panels or other systems. It is essential that peoples’ stay in the Café does not become a source of stress, especially for those who are ill. This has concrete implications as regards the selection of Café users since it requires the separation, for example, of people with significant behavioural disturbances from the others. Lighting too must be arranged intelligently, to avoid any dark corners or excessive differences in intensity since the same may create shadows that worry those suffering from cognitive deficit. Decor must pleasantly convey the atmosphere of an informal location, while at the same time guaranteeing safety (no furniture with sharp angles and protrusions, or ornaments that might fall or break etc.). Specific care must be devoted to colours, to encourage the serenity of guests and facilitate the recognition and enjoyment of spaces. An adequate environment is very important in making it possible to introduce compensatory strategies that help to slow down the evolution of the illness - above all, time and space that is free of anxiety-generating factors, the origin of many behavioural disturbances.

4.C ORGANIZATION AND PERSONNEL
The organization of Alzheimer Cafés is usually “flexible”, like its personnel. The data obtained in the study indicates considerable variety relative to the number of meetings held per week and per month. Evidently this data depends on the availability of operators. However, too few meetings impedes the achievement of any significant results. A close relationship with people affected by dementias and their families requires a certain level of frequency (at least once a week, with the Café open for 2-3 hours). Such opening times can be reduced if the aim of the Café is solely that of providing information and offering practical advice, especially as regards family members. On the other hand, in some cases the experience generated by the Cafés has led to more committed services, with much more extended opening times that approach those of day centres (however-
er, the latter are particular cases, not a model to be replicated). The data from the survey indicates a strong presence of voluntary personnel. Approximately 70% do not receive any payment. These are often educated people, with experience gained in other services (in some cases they are the results of psycho-attitudinal selection, although this procedure is not very common). Paid personnel include doctors, nurses (for short time periods, for the most part dedicated to consultancy, to avoid any temptation to compete with other services) and some technical staff dedicated to specific activities, such as psychologists and educators (one notes that the low level of payment implicitly indicates that these professional figures too, in offering their services, are motivated by considerable levels of commitment and humanity). In some cases voluntary associations act autonomously alongside the Café and focus on specific tasks (transport, cleaning of premises, maintenance, preparation of food etc.). These contacts have great value, in addition to that of the service rendered, because they connect the Café with the external world, reinforcing its human and technical validity (in many cases the National Alpini Association generously and professionally carries out this kind of activity). The preparation and distribution of printed material, informing people how to deal with dementia (hundreds of such publications have been made available, for the most part of good quality) represents another useful instrument. In some cases connections have been experimented via web with the families of those who use the Cafés in order to maintain contact during those days when the Cafés are not open. The world of information and communication technology is expanding enormously, including in this field, and in the near future we will see the implementation of advanced care models, useful in maintaining contacts via the creation of spontaneous networks, for example around a Café. Mobile phones are a useful tool, open to many applications, enabling people to continue at home the exercises they may have started during their stay at a Café, or request further information. Cafés must focus their attention on society’s rapidly developing technologies. To this end the systematic presence of young volunteers, brimming with innovatory attitudes, can be useful, helping to construct and test small advances on an organizational and communication level.

4.D GUESTS
The selection of guests is a delicate procedure. Some Cafés choose patients within a certain range of gravity, others no. some feel that patients with less serious cognitive deficit can derive greater benefit from an intervention. The reason patients approach a Café (i.e. the sources that suggest using a Café) can vary greatly. It is important to note that in a certain number of cases the suggestion to attend a Café is made via the Alzheimer Evaluation Units, which constitute a network throughout Italy and carry out diagnosis, therapy, follow-up and counselling functions. In some cases the relationship with the AEU is main-
tained, with significant advantages in terms of information exchange, but also as regards targeted intervention indications. In addition, this connection reassures operators that they are working within a technically qualified care system, obviously with different tasks, but with the same fundamental inspiration. This is particularly relevant in countering the temptation to shut oneself off from the world, to embrace self-sufficiency, always present and sometimes justified in those environments that have suffered greatly due to social exclusion generated by the communities to which they belong. Café users are often non-homogenous from a clinical point of view, suffering from a range of illnesses including Alzheimer’s, vascular or mixed dementias, other dementias, psychoses, with cognitive functions compromised. Family members too cannot be inserted in homogenous groups since they vary in age, culture, resilience capacity (and hence ability to manage objective burdens) and the amount of support they have available to them. The average age of the Café users analysed is 80, with 60% of them being female. The significant presence of men testifies to the interest of female caregivers in the activities of the Café, aimed at patients of the opposite gender (it would be very interesting in this regard, in future research, to define the activity profiles that are most favoured by one or other gender). Only 6% of the users of the service are younger than 70, as occurs today for the majority of services, increasingly used by elderly persons (each epidemiological evaluation carried out on those older than 65 is therefore destined to lose value).

The average number of years in education - 10 years - is slightly above the education period for this age group in northern regions. The analytic data also indicates a somatic health condition that is not gravely compromised, in line with other studies carried out in Italy for the same age groups. The MMSE scores suggest that the majority of users have a medium level of compromise of their cognitive functions, while there is a high score relative to the presence of behavioural disturbances. Do the Cafés therefore constitute at least a partial alternative to the use of neuroleptic medications? Relative to this question, which is increasingly put forward as a consequence of restrictions on the use of these drugs imposed by regulatory authorities, there is as yet no precise answer, even if there are ever more studies that seek to open up new care prospects. The score noted for caregiver stress indicates quite a high burden, which justifies use of the Cafés by those who provide assistance, offering them an opportunity to enjoy some moments of relaxation during the week.

As set out in section 3, the turnover of users is not very high, indicating a strong relational connection between the Cafés and those who frequent them. On the other hand, a not insignificant quota interrupt their attendance because they are transferred to a nursing home. In these cases it seems clear that frequenting the Cafés represented a form of support for families that found themselves at the limit of their organizational and psychological ability to offer adequate care for the person affected by dementia.
Almost all ill users attend the Cafés accompanied by a family member or a caregiver (sometimes two: an indication that they particularly enjoy the activities carried out!). These are ill people who are no longer able to autonomously carry out any of the basic everyday activities, for whom life is de facto based on the reality of a couple (this is something that characterises many chronic illnesses and which should constitute one of the objectives of care, something that has never been explored to date).

Particular attention is devoted to the poorest guests. These are often isolated, have greater needs, live in unhealthy homes and follow inadequate diets (the medical-scientific literature has clearly shown there is a relationship between poverty and negative outcomes, such as increased recourse to health services, morbidity and mortality). The same grow very fond of the Cafés because they find, within its premises and hospitality, a warmer environment (in both physical and psychological terms) than they do at home. The increase in the spread of poverty among the elderly due to the current economic crisis will lead to a further valorisation of such free and high added value experiences.

When guests start to attend the Cafés their biographies are carefully noted. Knowledge of the events that have marked their lives and that of their families constitutes an important resource in understanding some of the attitudes assumed by patients and their residual capacity for relationships. It also helps to prevent and reduce any behavioural disturbances, as well as to organize activities that focus on individual ill persons (e.g. music therapy for those who have always had a passion for singing...).

4.E ACTIVITIES

The activities carried out in the Cafés vary greatly and are linked to the presence of local skills and sensibilities. It is therefore not possible to indicate a common approach, nor is it part of the aims of this document (on the other hand, it has been noted that the choice of one methodology or another is not the result of indications dictated by precise scientific findings, but by the specific training and information that characterises the operators, especially those with psychological training who form an essential nucleus in every Café). One must, however, emphasise that the various activities have to be strictly sequenced, to prevent anxiety and the frustration of waiting, on the part of users, and the confusion of personnel, who risk coming up with banal responses as a result.

The most significant aspects are hospitality, which must be clearly offered and charged with warm human intensity to ensure patients do not feel stress due to any changes in their environment; the involvement of users in the preparation of premises, which has a positive effect on their participation in activities; the concluding games section, with cakes and drinks, which is always much appreciated. At the end, users take part in cleaning and ordering the environment. Obviously, these activities are all voluntary. If in some situations patients display
little willingness to take part it is necessary to respect their condition, without applying any pressure.

The most frequent activities are those involving cognitive and rehabilitative stimulation, like ROT, whose purpose is therapeutic but also helps create a positive environment. An approach that also includes music therapy, dance therapy, arte therapy etc. Allowing patients to paint and draw has also become more widespread and generates a rich array of experiences. The way faces are reproduced is particularly interesting. As the illness progresses there tends to be a loss of details in the drawings of faces, until only the eyes can be perceived. Quite apart from the scientific implications of this type of production, it is useful to recall that such examples of “outsider art” arouse considerable attention in the wider public and hence represent an important form of contact with the world outside the Café environment.

With respect to caregivers, discussions with the psychologist represent the most widespread activity, both through a personal relationship and in small groups. Sharing problems experienced is in and of itself an aspect that is much appreciated. The exchange of experiences has a high added value. Obviously, one is dealing with delicate interventions that require preparation, sensitivity and experience on the part of group leaders. In some cases the presence of the doctor consists in a discussion in response to precise questions on the part of those who are ill and their family members.

The complex of support interventions, both direct and within the group, must not require an excessive investment of psychophysical resources, to avoid the paradoxical effect of the caregiver being weighed down by an excessive burden. Information on the health of a person affected by dementia and on what can be done must be communicated calmly and not be imposed. One must transmit the sensation that not all aspects of life are dominated by the illness, and that even in the most complex situations it is possible to explore preventive interventions, aimed at reducing any excess disability.

In general psychological support and practical information have a common objective i.e. to reduce anxiety levels relative to questions without any answers and the future as an unknown entity with respect to both the symptomatological evolution of the illness from a cognitive, behavioural, clinical point of view, and with respect to the role of caregivers and their ability to respond adequately to assistance requirements. General information is not a priority, since today many people are able to find it on the internet. Specific answers, however, are vital since they generate trust through a direct, safe and comforting relationship.

In traditional information meetings - which continue to play an important role - intense and trusting relationships are not created, as occurs on the other hand in the Cafés. During periods of solitude, a meeting place that is organized, periodic and safe represents an oasis during the difficult working day of every caregiver. Sharing experiences among people in similar situations removes any social em-
barrassment or shame in dealing with any subject, even the most private and
delicate. Moreover, the presence of the ill person in the Café reduces the car-
egiver’s level of anxiety because he knows that he/she is in safe hands.
Overall it is possible to contribute to the serenity of those who offer assistance
by ensuring that caregivers do not begin to feel that they too are ill. On the con-
trary, they must be helped to find and construct a daily routine full of care and
affection. In this regard we set out what has been written by an operator to ex-
press how he sees his work: “To see how natural it is for operators to share happy
and serene moments with ill family members serves above all to communicate
to caregivers that it is still possible to receive from people who are affected by
dementia. We teach them to look at the individuals we are relating with in a dif-
ferent way. We teach them to avoid trying to reorient, re-equilibrate and return
those who are ill to perfect health. Here is where the relational space of the
Café can become an enjoyable, playful area, where by using one’s imagination
it is possible to create entertaining and relaxing situations. And when, as if by
magic, healthy people merge with those who are ill we know we have achieved
our goal: quality free time and quality interpersonal relationships”.
It is important for Café organizers to keep a diary, in order to both document
the activities carried out and to analyse any modifications to the same over
time and, albeit in a non-structured way, to note the level of usefulness of
meetings for individual ill people and their families. A diary associated with
at least monthly meetings of the team constitutes a core work tool. Continual
monitoring of the level of attendance and active participation makes it possible
to correct, in real time, any unwanted critical situations, especially if they in-
volve persons who are more at risk. A “narrative” documentation is also useful
in the training of new volunteers and operators who begin to work in this sector.
This aspect is of particular significance because it permits a turnover of opera-
tors and the possibility of creating new activities, starting from a consolidated
base of acquired knowledge and experience. In addition, the presence of people
undergoing training (as occurs in some Cafés) enriches the group of operators,
injecting greater serenity and new experiences.
In some cases Cafés have launched training courses for assistance personnel such
as, for example, caregivers. While not being a fundamental activity, it testifies
to the link that is created in difficult situations experienced by the families of
patients and the level of respect that the Cafés have acquired. This also applies
to any other project activity aimed at the territory. Though in overall terms this
is a positive move, it is also important to ensure that it does not undermine
the main activity i.e. that of hospitality and convivial socialisation in the Café.
Overall, however, the collaboration between the Cafés and the territory must
be improved, to reduce prejudices and commonly held reductive attitudes. All
too frequently the surrounding population feels extraneous to what is happening
in the Cafés. Moreover, this psychological distance and the lack of any adequate

CHAPTER 4 A LOW COST SERVICE MODEL WITH HIGH SOCIAL UTILITY
information leads to delays in turning to the service on the part of families, who tend to wait until they have reached the limit of their strength and resources. It must be emphasised that in many situations there are no structured relations between Cafés and general practitioners. This deprives the service of an important source of support, while also depriving doctors of the chance to discuss with Café operators useful interventions for the wellbeing of patients and increase their understanding of the kind of conditions that most cause suffering. Moreover, such a connection would be useful in supporting those who frequent the Cafés with clinical competence whenever a situation that would benefit from specific treatment is noted. Cafés must not in any way resemble a health structure but, on the other hand, if perceptive operators note a clinical need it is necessary for a care pathway to be identified so as to guarantee an adequate follow-up. With respect to relations with external environments it is important to emphasise that only one Café has relations with a training structure - more specifically, with the University of Bologna. It would therefore be extremely advantageous to have widespread contact with training and research agencies, in order to improve the preparation of operators (old and new, volunteers and professionals), to train new personnel, and also to draw up original work modalities via mutual information exchange relations and their consequent elaboration. There are many university departments that could be involved in these activities relative to geriatrics, psychology, rehabilitation, nursing, social assistance etc. Collaboration on the methodological level and interpretation of results would be of great utility for the Cafés, and would also give the university a role in the analysis of transformation processes as regards assistance, under the pressure of constantly increasing needs combined with reductions in the availability of funding. Finally, activities also include evaluation of the service by users. In the cases that have been studied it was felt that the intense relationship between the organizers and the users makes it possible to achieve a continual mutual exchange of information and evaluation, avoiding any need for a formal structure though relative to this approach some problems remain. On the other hand, it is always important to be aware that relations can be modified between operators and users and that nothing can be considered stable in interpersonal and group dynamics. Sometimes habitual modes of thought hinder people from seeing crises and hence from appropriately intervening.

**4.F COSTS**

The costs of Café activities have on average been reduced. They range from 5 to € 10,000 per year for a Café with 20 guests, even if the latter vary greatly in their conditions. Their segmentation indicates that in the majority of cases one is dealing with costs that cannot be changed, such as, for example, the cost of insurance. However, in general one can state that in economic terms the use of larger services or structures permits considerable economies of scale.
Particular attention must be devoted to keeping costs below a certain threshold level. From this point of view one must avoid any rapid extension of activities e.g. under pressure from an increase in the number of volunteers or a certain temporary increase in financial funding. Only careful programming can permit - where considered appropriate - a slow extension of work. Thrift must characterise all activities, avoiding any unnecessary costs, where possible reusing any materials, encouraging guests and their families to take part in the life of the Café with non economic contributions (food, in particular). The latter is another sensitive issue. The Cafés never ask for money, because it would create difficulties for some families, already subject today to the negative consequences of the economic crisis, as well as unpleasant inequalities. The atmosphere of free exchange that characterises the majority of Cafés would be destroyed.

Sources of financing can vary tremendously. Since local authorities are being subject to continual funding reductions, it is appropriate to turn to the wealth and generosity of civil society, banking and private foundations, structured contributions (fiscal allocations) and the collection of targeted funds by initiating specific fund raising activities. Certainly the increasing amount of attention devoted to dementias on the part of the general public also favours donations. However, it is important for Cafés to be presented as a “positive” location, one that encourages wellbeing, not one that is seen as a secondary activity, perceived as a “last resort”, not least because donors are more likely to finance enterprises which they feel produce results.

4.G RESULTS
The survey carried out has made it possible to document the results obtained in various entities. As indicated in previous sections, not only quantitative evaluations have been carried out since atmospheres, adaptation capacities, positive stimuli, mood changes, re-conquered serenity cannot be measured quantitatively but only perceived by those who are involved in the enterprise. From this point of view it would be useful, for certain periods, to video record activities, in order to allow external observers to understand and properly evaluate the specific character and benefits of the service. This has exposed such evaluations to criticisms of subjective self-referentiality. However, it is necessary to repeat that the wealth of human behaviour cannot be completely summarised in evaluation scales, even if the latter constitute essential elements in organizing a service. The relationship between a series of actions and the relative consequences for behaviour is often impossible to define and hence one cannot deduce any general laws but only empirical indications - though the latter are of course useful in carrying out the work that needs to be done. Knowing, for example, that the MMSE for a certain guest is 24/30 and not 14/30 constitutes an important starting point in developing a significant relationship. In the same
way, noting that at a certain moment the population that frequents a Café has on average a slight or medium level of cognitive compromise constitutes information that can easily be shared by all personnel, and on the basis of which it is possible to construct a caregiving project. Moreover, it is significant that during the period under observation the guests with a higher level of MMSE, and hence a smaller degree of cognitive compromise, exhibited improvement.

If the datum is also confirmed in other studies it would indicate that people who are less compromised benefit more from the Cafés. This observation, however, does not take into account that, on the contrary, it is the caregivers that have to support greater burdens due to assistance needs resulting from the activities carried out. In point of fact the Caregiver Burden Inventory has a rather low score, which improves above all in components relative to the perception of subjective difficulty on the part of those who offer assistance. In this sense the positive results obtained via evaluation of the frequency and gravity of behavioural disturbances can be more clearly interpreted. In point of fact, behavioural disturbances are reduced, in turn reducing the psychological and practical burden in the lives of those who provide assistance.

The presence of such disturbances is the most frequent cause of an increase in disability and institutionalisation, as well as grave assistance difficulties (greater frequency of medical interventions, pharmacological prescriptions, greater illness management costs, higher stress levels in caregivers that leads, as a result, to an increase in the stress levels of the ill person, further reducing the level of autonomy in everyday life activities, already compromised by cognitive deficit). It is certainly the most significant datum on a practical level because behavioural disturbance is the aspect that most interferes with the life of the family, causing crises that are difficult to manage and increasing the risk of institutionalisation of the ill person. The improvement in the life quality score too is part of this overall picture, as indicated by the study, with a not insignificant effect generated by a stay in Alzheimer Cafés relative to difficulties generated by care tasks assigned to family members or other caregivers. It is interesting to note that the scores are slightly higher in the males relative to females, almost as though there is a greater psychological autonomy in men relative to the life environment. Overall, the low level is in line with high behavioural disturbance, which accompanies a population experiencing a high level of subjective suffering. Obviously the positive effects generated by frequenting the Cafés sometimes are not adequate relative to the gravity of the illness and the stress conditions of those who provide assistance. In such cases operators can facilitate the support of other services, such as relief recoveries or access to a day centre for dementias. Overall, however, one notes a net increase on the part of family members in acquiring greater ability to provide help for a long period, without the arrival of a crisis impeding their maintaining a high quality service over time. Such increase in empowerment on the part of those who
offer assistance is not always a conscious one. One notes, however, a progressive, even if slow, improvement in their condition, reflecting greater control on the part of the caregiver over his own life. The service is not merely a source of alienation, but of choices that lead to improved management of one’s time and improved control over procedures and results. The brevity of the period of observation has impeded the observation of any modification in the rate of institutionalisation of persons frequenting the Cafe. However, one did note stability in the frequentation itself, which indicates a strong connection with the service, certainly a reflection of the large and small results achieved.

The complex of above-mentioned indications makes it possible to conclude that the experience of Alzheimer Cafés, in their different realisations, is extremely positive. In effect, a new approach has been constructed that provides us with greater insight into those who are ill and their needs, offering us a “social” vision of dementias, one that does not deny the biological origins of the disturbance, but locates the same within an everyday dimension, in which symptoms develop and exercise an influence over the dynamics of everyday existence.

It is not possible to demonstrate using this data any direct relationship between frequentation of a Café and the improvements observed. However, there can be no doubt that an intervention in support of family members, which positively influences not just their quality of life, but at the same time the behavioural symptoms of the ill person and the maintenance of his residual cognitive functions, assumes a significant level of importance within the panorama of instruments available for the care of people affected by Alzheimer’s disease and other dementias.

The Cafés are neither a meeting place like a Social Centre, nor a social services office run by the local council or district, nor are they dementia information points, nor locations for booking examinations and checkups. On the contrary, if well organized, they can embody the strengths of each of the above to provide citizens with a useful and structured service. In this perspective, moreover, the evolution of the Café is open to the initiatives of managers and their possibility/ability to extend efficacious networks.

The advantages of the Cafés are evident both for patients and for those who assist them. The initial hypothesis of this section has therefore been confirmed i.e. that the service, at low costs, but intensely humane, is useful and therefore its spontaneous diffusion in recent years should be sustained and supported (as set out in the aims of this study).

The study reveals both advantages and disadvantages, but the aspects that merit attention far outweigh any critical features. This permits its effective defence by those who consider some Cafés inadequate due to the lack of structured activities and any connections with expected results. Although the Cafés analysed in the study do not belong to this typology it is useful to recall that a certain level of autonomy and creativity is necessary to arrive at significant
results. More specifically, it is important that each Café knows how to strike a balance between structured and spontaneous aspects, because only in this way can high quality assistance services be achieved.

The very significant differences among Café frequenters impedes the adoption of pre-set behaviour and requires a high level of informality, one that generates progressive improvement in communication and hence further benefits in terms of the standard and effectiveness of care.

One may therefore legitimately hope that “the Alzheimer Café enterprise” will develop further and that this text can help facilitate the task of those who wish to undertake a difficult approach but one that is replete with profound human and assistance significance.

The diffusion should identify contact and connection locations between the various entities, to generate practical information exchanges and create operational synergies. As part of this approach the Foundations have an important role, especially those that seek to flank non profit organizations to facilitate the exchange of information and care models in order to improve operations and the results that can be achieved. Recent attention focused on microrealisations represents an extremely significant change in perspective because it makes it possible to intervene where the distance between need and care action is least, avoiding waste, bureaucracy and sometimes even the construction of sand castles in the desert.

There has been a lot of discussion in recent years about the significance of and opportunities offered by pharmacological treatments but not about the people suffering from dementia. We have no wish to initiate a diatribe that moves away from the aims of this study, not least because we place “care” at the centre of our focus, a concept that has a wider meaning than any individual techniques used.

If constructing and managing an Alzheimer Café is an act of care for someone, as has been demonstrated in this book, it is our task as professional protagonists and, in general, as members of the collective, to sustain them and keep them alive. Alzheimer Cafés are not a space that stands outside everyday reality, in which people for a short time pretend that they do not have any illness. On the contrary, they are an important technique that offers a period of serenity in the difficult lives of those affected by the illness and those who take care of them. Serenity that is generated by clearly defined roles and tasks, by the ability to communicate using different but always adequate languages, by the possibility of preventing and cushioning extremely difficult situations, by belonging to a shared culture in which it is always possible to improve the lives of people who are suffering, including in the most difficult of situations. It is a serenity that tends to spread throughout the Café because it is built on solid relations between people. It represents a positive sign for those who have to face a period of illness which would otherwise seem both endless and hopeless.
The conclusions of this study are drawn from the previous section, where the possible role of Alzheimer Cafés was set out relative to people affected by dementia and their families. Some modalities to optimise the functionality of an original and innovative service have also been indicated, which can benefit from ideas and experience such as those set out in these pages. The following, on the other hand, focuses on some basic features which should inspire those who project and realise services for vulnerable elderly patients and more specifically those affected by dementia. This kind of action is always difficult, whatever the level. Which is why adhering to a methodological approach makes it possible to carry out one’s mission whilst being guided by useful outlines.

The care of vulnerable people is culturally based on some structural characteristics in the lives of people who are ageing, already extensively described in these pages, but which it is appropriate to further summarise here:

a. the multidimensionality of human and clinical problems and hence the need for an evaluation that is equally multidimensional, which takes into account different clinical and functional plans;

b. vulnerability as a condition specific to the subpopulation of elderly people which requires greater protection in a global sense as well as targeted and in-depth health interventions;

c. flexibility as a basic feature of the life (including biological life) of people who age; hence an extensive series of interventions that is also connected to lifestyle is important in controlling the state of health and can achieve significant results, albeit in apparently unchangeable conditions like those of people affected by dementia.

In the approach set out above some attitudes on the part of those who provide care and assistance guarantee the possibility of improved delivery of useful services for people who suffer from limitations to their autonomy. The following sets out some indications the blend both theory and practice, to better perform the tasks generated by our commitment to care within an organized system.

1. Avoid conservative attitudes. The now historic phrase by Robert Kane - “We have to adopt a collective spirit of creative intolerance towards the status quo in assistance provided for the chronic illnesses of the elderly” - must be adopted as a general rule. We must implement a decisive commitment to creativity because needs change quickly and only particularly flexible minds can meet the challenge. At the same time we must recognise that sometimes, on a practical and cultural level, our care actions are inadequate and need to be revised. Some time ago it was fashionable to affirm that our period would be characterised by its awareness of ‘the end
of history’. A theory defeated by macro phenomena on a planetary level, but also by our most modest everyday realities, like those characterised by the need to protect vulnerable people. “The poor will always be with you”: this well known evangelical text describes a history that is always on the move, that every day assumes new features, in an endless dialectic between the commitment to care and the need, as a consequence, for changes in our cultures, techniques, generosity and egotisms. Innovation also means courage and enthusiasm, true features for those who wish to undertake effective care actions. The Alzheimer Cafés environment has in recent years shown both courage and enthusiasm. Indeed without these they would never have taken off or survived for very long! An important way to avoid conservative attitudes is also achieved by changes in our style of communication when dealing with dementias. Terms like “loss of self”, “living dead”, “victims of illness”, “theft of memory” must be abandoned because they do not help us to understand the suffering of those who are ill. On the contrary, they create a halo of pessimism around them, a sort of social death that sees them as only “heavy burdens for caregivers” and discourages an attitude focused on care. Many Cafés have adopted this innovative approach in that they use a new language, less traditional, much “freer”, one that is derived directly from their basic motivation i.e. to reject merely waiting for death and to guarantee life instead.

2. Modern assistance and care of the elderly suffering from cognitive function deficit is not compatible with either being withdrawn and timid (those who see catastrophes without either remedy or hope) or superficial and theoretical optimists who feel they have the perfect solution to every problem. The demographic and epidemiological evolution has been so fast as to impede the maturation of innovative thought that is capable of dealing with the many and diverse human, clinical, psychological, social and organizational dynamics that have occurred in just a few years. This historical consideration makes it possible to maintain a balanced and practical vision during everyday commitment and when project planning major undertakings. Today we are at the threshold of major changes (the so-called third industrial revolution) which, through robotics, will drastically reduce the workforce. Energies will therefore be liberated for new professions, linked to the care of vulnerable people, whose financing will occur via an increase in the productivity of various sectors of industry and services. This prospect displays some darker sides, in particular as regards social justice, but at the same time it opens up large spaces for enterprises that still have a high intensity of human labour, like those offered in the Alzheimer Cafés, which in this context could benefit from appropriate financing.
3. Do not reduce clinical-assistance problems to their economic aspects, subjecting all behaviour to these and reducing any evaluation to the “cost of everything” and the “value of nothing”. The dynamics of life, in particular those connected with the defence of vulnerable people, place values independent of “evolutions of chance and fortune” at the centre of our focus. Human dignity is a higher scale of value than any other. Every decision, therefore, especially in extreme moments, must avoid the domination of mere economic, organizational or even psychological considerations. One must also avoid creating conditions where the chronically ill person, and hence objectively speaking a strong consumer of resources, feels he is an excessive burden on the collective, with negative effects in terms of his subjective life experience. This difficulty is particularly felt by the family members of people affected by dementia. The Alzheimer Cafés, on the other hand, are by definition environments where one does not feel any awkwardness due to one’s condition nor does one feel that one is a burden for the collective. The volunteer atmosphere generates, on the contrary, serenity, tolerance, listening, enjoyment. In a time of grave difficulties for poor families, which are being subjected to drastic reductions in public funds dedicated to social policies, low cost and high value interventions both in concrete terms and as psychological support assume progressively greater importance. This consideration, linked to specific conditions, does not reduce our concern for and evaluation of plans regarding the struggle against poverty. In the past such concerns were at the centre of public interventions - interventions which have in recent years experienced cuts of considerable intensity.

4. Assistance for the elderly is based on high and low technology interventions. We must possess the ability to use machines, because technology exercises a strong thrust towards progress in all sectors of medicine (e.g. the role carried out by ICT). However, it is also right to feel proud about those aspects of care that are less measurable i.e. the ability to transform into therapeutic procedures what is indicated by medical research, based on evidence, but also what is indicated by a “narrative” methodology: both contribute to an approach that embraces the multiplicity of the needs of elderly people affected by chronic illness.

Scientific progress must not be rendered banal or even nullified by being implemented in assistance environments that are unable to comprehend the specificity of the clinical condition of the elderly, unable to collect data in a multidimensional manner and to organise therapeutic-assistance responses in ways that are both “gentle” and incisive. The network of services for dementia, as a premise for an assistance continuity method, is not a theoretical model, but a complex of moments, characterised by the
same culture, able to accompany the elderly person down the long road of his chronic illness, adapting whatever is indicated by the latest research to the specific needs of the vulnerable.

5. Committing oneself to define care work results. The evaluation of outcomes is also essential in order to define the relationship between costs and benefits. It is essential to have focused effort on the part of those who have responsibility for defining benefits obtained, otherwise it will be difficult to ask society to generously provide funds for the most vulnerable. Results cannot always be achieved over the short term and are often limited to controlling some symptoms or slowing down the natural history of the illness. Small gains can therefore be achieved within this context, small advantages that can be generated in the vulnerable elderly as a result of appropriate care. These may be results that objectively speaking seem limited but which on the contrary are of significant value for the individual person whose life is strongly compromised as well as for the collective, which de facto recognises its duty to act for the good of the individual, without focusing the intervention on distant objectives, which all too often tend to be theoretical and unrealisable. It is necessary to provide value for any care segment, seeking to define, achieve and measure outcomes that are - realistically speaking - appropriate for the clinical situation of each ill elderly person. Similarly, it is also important to recognise that achieving small gains means avoiding small losses i.e. slowing down the patient’s evolving condition when exposed to difficulties without any protection.

6. Care therefore always has a twofold function, which one must evaluate as far as possible from a qualitative point of view. Realism and sensibility, however, suggest that sometimes the contents of human care can be more important than the “scientific” definition by which outcomes are defined. As regards the ethics of responsibility, the function of the care relationship is mainly expressed as an attempt to - as far as possible - save the identity of the person in his subjective and environmental dimension. Within this context, where on the one hand the priority of scientific evidence is unquestioned, it would however be illusory to think that this is able to provide solutions to all the problems that clinical practice observes. Finally, one must recognise that patient care is realised not only via interventions that are based on the current status of knowledge, but also on reasonable working hypotheses which the lack of knowledge itself demands, in the interests of ill people, subjecting any care provided to clinical verification.

The elderly ill person’s liberty must not be taken away from him. The
elderly ill person is already subjected, due to events, to a slow depriva-
tion of his ability to autonomously live his own life, whatever the level of
cognitive functionality. The risk of reducing the elderly (and our image of
them) to a series of parameters in decline is always lying in wait to ambush
us. The slogan, “ageing is not an illness”, quite apart from its clinical rea-
ism, is also of great efficacy in avoiding any expropriation of the ‘time for
life’ from those who are ageing, reducing it to nothing more than ‘time for
illness’. This attitude is particularly necessary relative to people affected
by dementia, whose liberty is entrusted to the decisions of those who have
care of them (professionally or in a caregiving relationship). Social life must
be open to the elderly with cognitive problems, encouraging their limited
but possible liberty. The Cafés represent islands set in a sea that is someti-
mes inhospitable, islands on which those who are ill and those who live with
them can find some support which, though only temporary, can help them
to “keep their heads above water”. And it falls to the collective to prevent
that island from being submerged by flood waters.

7. It is necessary to adopt a “prudent” medicine model for chronic elderly
people because no competence or specialisation has all the answers. It
is certain, however, that there will always be a need for those who know
how to interpret and care for the complex suffering of the elderly, adap-
ting practice to the specificity of their many different life situations. Pru-
dence also includes, in a wider sense, knowing how to accept limits in the
organization of services that one nowadays observes in many parts of Italy.
The rhetorical and often exaggerated claims made regarding the net-
work, understood as a perfect construction that regulates and controls
everything, have never been realised anywhere in the world. The culture
of care for the chronically ill, on the other hand, openly declares that
it belongs to non commercial medicine, that it has at its base profound
respect for the dignity and liberty of the individual and hence an appro-
ach that is inspired by gentleness and prudence. Within this context, the
evaluation of quality as expressed by the user represents an indication of
how and whether the patient reacts to the strategic choice - operational
and relational - of those who carry out the service. Although there are
significant methodological and interpretative problems, especially as re-
gards people with cognitive limitations, it is still essential to obtain the
evaluations of those who are the subject of the care service.
In chronic pathologies this is often difficult because they frequently coexi-
st with cognitive deficits, depression, the need to involve caregivers, with
the relative limits as regards reliability. However, a modern assistance
system must take into account the evaluation of those who live many
years of their lives within an organized service as well as those of the
people who continuously provide assistance. As regards dementias, the modality for gathering the evaluations of those who receive a service varies over time because the ability to express satisfaction changes relative to the quality of the assistance received. In the background, however, there always remains the need to create conditions in which a person feels he can control events that concern his future life. This is a profound desire that care operators cannot ignore in its various expressions, which essentially regard health and wellbeing conditions. An intense relationship between those who provide and those who receive, as occurs in the Cafés, makes it possible to construct some vital processes together and hence to give those who are assisted the perception that they are active participants in the construction of their own futures.

8. In apparently marginal areas, like those involving assistance to people affected by dementia, it is necessary to adopt major emphasis on training, on “examples” and on experimentation. The presence of locations where the care for dementias can be tangibly experimented is also important, every day incorporating the latest developments in biology, clinical practice, technology and science in care practices. It is important to have environments available where clinical practice, which is always the fruit of mediations (and sometimes significant compromises) works in synergy with the latest developments in medicine, based on evidence (for example the use of innovative drugs) and with new technological proposals as regards diagnostics, therapeutics or information and communication. Obviously, as regards these matters, operators at every level must be trained. In addition, one cannot forget the rapidity of evolution in customs and traditions and other sociologically relevant matters (family structure, modality of relations with services, availability of informal care etc.). These require analysis contexts and careful evaluation, in order to propose new formal contents and the experimentation of those assistance models that are suited to changing conditions in the lives of the elderly. It is important to avoid the kind of bureaucratic superstructures which, in the past, were sometimes privileged by a certain medical approach and tended to impose their slowness and rigidities on rapidly changing needs. One must also avoid moralistic analyses relative to the evolution of the social conditions of the elderly: we must act with realism within the present historical period, indicating intervention features that respect people, all the more so where adequate attention devoted to needs is not found in informal support contexts.

These points constitute a strong basis for constructing any project in the most vulnerable areas of life. In addition to these considerations of a general cha-
racter, the analysis of the experience of Alzheimer Cafés leads to an overall evaluation that can schematically be defined as “thrifty subsidiarity”. The Café is positioned in a space that respects all others within a network of services. It does not carry out direct health activity, but only the kind of support interventions that other services cannot provide. It does not wish to, nor can it, replace the family and its organization, although it represents a useful help in the life of families. The work of Alzheimer Cafés therefore respects the hierarchies that characterise interventions in favour of people affected by dementias. Hence they valorise their role, without interfering with that of others and therefore without creating any damage, even of an involuntary kind. Certainly those who design these services have no theoretical problems relative to subsidiarity. A positioning that de facto respects this fundamental principle of social organization is an index of sensibility and intelligence, all the more relevant the more they are natural and not generated by mere theoretical affirmations.

On the other hand, thrift is also a basic feature of these enterprises. Thrift induced by the decision to carry out mainly voluntary functions, to use low cost or free spaces, to develop activities that also use external support. Thrift in this field makes it possible - as repeatedly stated - to have a positive cost-benefit ratio, but at the same time it represents a significant example of how small amounts of money, used with intelligence and dedication, can generate excellent results. Thrift becomes a style and also a model for other actors in the network, unaccustomed to focusing attention on aspects which were considered irrelevant during the period of economic boom, but which now, in a period of economic crisis, have become essential in permitting the survival of specific services. The term thrift has been compared by some to that of down-sizing. There is, on the contrary, a fundamental difference, because in the first case there is spontaneous and convinced participation in a common decision, while in the second case imposed hierarchical decisions predominate.

This consideration must not be interpreted as an invitation to be contented with little, but to recognise that expensive structures and operations are often not necessary to obtain good results and that today the survival of some services is linked to the ability to make them cost less - without, at the same time, experiencing savings as a misfortune leading to pessimism, renunciation and self-devaluation. Furthermore, those who work in the field of dementias have, and have had for some time, experience of limited means - but with goals nevertheless achieved! The latter are sometimes independent of the quantity of the service (though not the quality) and a source of satisfaction that makes it possible to move forward. Funding cannot be defined as an independent variable but certainly any act of collective or interpersonal care cannot depend solely on money.
The crisis which today accompanies the provision of care requires solutions that differ from traditional ones. Increasingly we need more enterprises that produce not just economic but human value, through an ability to marry technology with relationships, efficiency with values, respect for both the individual and the organization. Once again, it is possible to state that Alzheimer Cafés represent a small example of a small revolution, one that is positioned at the centre of significant transformation in our organized systems, especially those that seek to guarantee wellbeing for the vulnerable in society. It will be interesting to follow this evolution as an example of a new way to offer care in a period that is apparently unreceptive to a more generous attitude towards the weak and vulnerable.

At the end of this study we would like to say that we hope the reader will find material in it that helps him to more serenely confront the problems facing people affected by dementia. More specifically, those who are involved in various interventions can find behaviour models that are useful and reproducible. In this sense this book offers significant added value. In overall terms, the Alzheimer Cafés represent an operational hypothesis for improving the quality of life of those suffering from illness which can be realised using limited resources. The hope of those who have carried out this study, and those who have made its supporting data available, is that they can facilitate the task of those who wish to explore new experiences in this subject or related areas. Assistance for people affected by dementia would receive a considerable boost and those who are ill would benefit from a significant improvement in their conditions.

However, in the end: “Reason can only talk, it is love that sings!” This quote from the writer, Joseph de Maistre, is often cited to youngsters who wish to undertake a care profession. Working for the vulnerable elderly cannot avoid technical-scientific approaches, founded on discoveries made by research, but it must also be characterised by a commitment to understand the ill person in his various dimensions, complex and difficult to identify, a sort of “song” that must be intuited, because reason and science must be accompanied by the kind of love that allows one to more deeply understand one’s fellow man in order to be able to offer him better care.

If the meeting between these two realities does not occur, care fails to express its potentialities and those who are ill cannot benefit from the kind of progress that is now possible. Today’s Alzheimer Cafés would not be such a dynamic enterprise without the love and dedication of so many volunteers and operators who have translated the great discoveries of science into the tangible everyday realities of their care work.


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