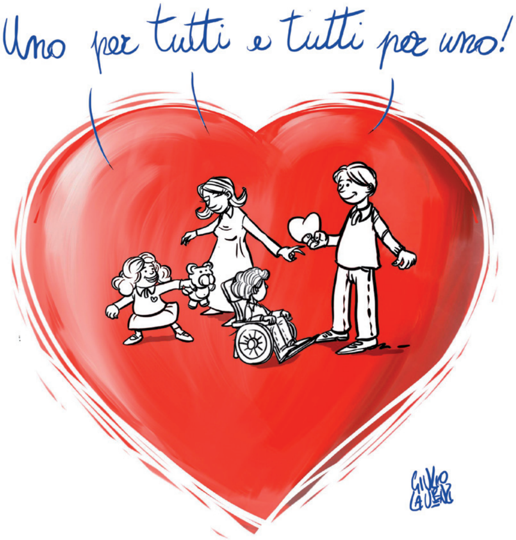
FONDAZIONE ALESSANDRA BISCEGLIA W ALE ONLUS
PER LO STUDIO E LA CURA DELLE ANOMALIE VASCOLARI

Towards the **possible harmony**

GUIDE FOR CAREGIVERS AND THEIR RELATIVES



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INTRODUCTION

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The guide with the suggestive title "Towards the possible harmony", that the WALE Foundation published ten years after its birth, is a tangible sign of how its activity has been working valuably over the years, always in the service of the sick and their families, to whom this guide is addressed.

The publication, in fact, is not meant to be only a solid scientific popular review which correctly informs us about the pathology but it has also been designed to be a tool guiding the communication of the diagnosis and supporting those who must face the burden of the disease along with the patient, it is usually the family according to all the data available in the literature, and in particular women, who represent the real welfare net, sometimes the only form of welfare support available to the sick.

It is a precious aid because it is a practical tool built with an interdisciplinary vision, incorporating the contributions of the scientific, psychological, juridical and social expertise, but also because it comes from the experience of those who live next to a sick person. Living and understanding the illness from the patient's point of view as well as from those who surround them, those who make a fundamental contribution to the care of the sick person and everyone should pay attention to this, especially doctors, health care professionals and public administrators, all those charged with the planning, providing and managing of the social assistance. It is this voice coming from those who are able to better grasp the situation of the patient, seize the families' needs and read them empathically, as well as understanding the role that the family has, especially in these situations of fragility with a person who is sick and where they often find themselves both completely flattened and infinitely crushed by the situation.

With its activity, the Foundation underlines the urgent need to avoid leaving the families alone when they are touched by the disease, but to support and help them. They alleviate their hardship and suffering, they highlight the irreplaceable role of the family on this pathway of care that a patient with severe disabilities must face throughout their life. The Foundation also has the merit of being a Guide towards possible autonomy, which is one of the most difficult challenges facing a family with respect to a disabled child. A path which requires courage and the ability to guide and support the person with disabilities, trying not to make them completely dependent but instead working to develop their abilities towards the autonomy, even if not fully achieved.

It is very important that this guide talks about "possible harmony", a state of balance that does not remain blocked with regret towards the lost abilities but instead stimulates the growth of residual potentialities, triggering with both suggestions and concrete paths the possibility of a vital metamorphosis and of a reversal of the perspective of pain.

Pope Francis, in his speech addressed to the participants in the Conference "Catechesis and people with disabilities" affirmed that: "In fact, we all know many people who, with their frailties, even the serious ones, have found, albeit with difficulty, a path towards a good and meaningful life. On the other hand we know people who are apparently perfect and desperate!".

Alessandra was a person who never gave up even until the last and did not allow the suffering and increasingly serious limits caused by her illness, to extinguish her sweet smile.

The possibility of "a good and meaningful life" also for the family members and for those who were close to Alessandra is the spirit that animated the birth of the Foundation. It is the "miracle" that has changed her loss into an opportunity, transforming pain into a choice of solidarity and gives real help to those who find themselves in that pain feeling as lost as if they were lost in a maze from which they cannot come leave.

This is also why we owe a special thanks to the Alessandra Bisceglia Foundation. For not having given the last word to the pain with the loss of Alessandra. For having had the courage to re-visit that experience and put it at the service of others and thereby making it a gift of love for everyone and especially for those who are living that same pain today. For the daily commitment to building active ways of sharing, caring and supportive paths for many of the sick and their families.

Seeds of light, signs of hope, to say once more that there is the strength in life and to discover that, by helping each other and living together until the end, even a time of illness, we can all become richer in humanity.

The image with the family at the center recalls the myth of Ariadne and represents, graphically, the spirit of the Foundation: helping families to get out of the maze of illness, disinformation and anguish of not knowing.

THE MISSION

In time, our activities have been more and more focused on patient's family problems. First of all because the family bears the same pains of a person affected by a destructive, rare and not completely known desease, then because the family is often the only effective resource close to that suffering person. For this reasons, giving support to this fundamental entity of our society, also means helping to improve the quality of life of the patient.

Strongly motivated by this awareness, we have initially chosen to focus on the figure of the caregiver. He is the one who, by choice or because unable to find another solution, assumes, within the family, the task of continuously assisting, all day long, every day of the year, the sick, disabled or almost disabled relative.

Our thoughts are totally addressed to these people, women or men, more frequently women, who charge themselves with this duty, paying an unbelievable personal high cost.

It must not be forgotten the uninterrupted storm they face, with painful or even dramatic consequences, on the personal and affective sphere, as they often lose personal relationships and, due to the alteration of the daily rhythms, they are frequently overwhelmed by the situation.

It must be also mentioned the employement, that is frequently lost, or impossible to obtain, because of the impossibility of combining both work and assistance, causing further trauma related to the renunciation of personal achievement and/or income lowering.

Looking at the family as an entity, it is immediately noticeable that his members are obliged to a new way of behave, the illness acting as an earthquake that shakes their whole emotional and relational balance, while hitting, in particular, the one who get stuck with the most fragile person and, for this situation, he also become a fragile person.

> Taking care of families, accompanying them, not making them feel alone is the basis of all our actions.

In this difficult situation a family should act as a team, able to distribute the tasks, thus sharing responsibility, and to organize the spaces of emotional recharge. On the contrary, who devotes himself to the psychologically and physically imprisoning role of the caregiver, he remains often isolated, without significant support and with recovery spaces that become increasingly inadequate and suffocating.

It is essential to give a recharging and regenerative space to the caregiver, as this role requires, not only physical and psychological resistance, but also lucidity and farsightedness, according to the fact that the one, who assists a patient with disabilities, is constantly faced with increasing high stakes, such as promoting the autonomy of the sick person despite the limitations imposed by the illness.

This last commitment is a really difficult challenge, that requires great courage in order to learn a new way to love, expressed not only as protection, but as an help stimulating the assisted to find his own freedom and to develop as much autonomy as possible, even where the goal may seem unachievable.

The pages you will read, dedicated to the harmony of the patient's family, are the ideal and logical continuation of those, directly addressed to the patient, collected in our previous publication “Towards the possible autonomy”.

TO
KNOW
MORE

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The two volumes are imbued with the philosophy that animated our activity since the very starting andt hat constitutes the core thought at the base of our actions.

Since the beginning we wanted to take care of the patient and his family at the same time. That’s the reason why the spaces where we welcome people are not aseptic medical offices but places that, in memory of Alessandra who inspired us, are called “Room of Ale”, where experts listen, understand and give every possible assistance, not only medical but also psychological. We felt, however, that the simple diagnostic indication, even if psychologically supported, was not exhaustive of the task we had decided to take on. So we also give indications of the centers where to obtain the correct treatment, support in the relationships with doctors and, everytime there is a special need, whe flank them in person.

> If the family is at the center, then the patient must be at the center of the family, since those who suffer from a rare disabling disease are inextricably linked to the protection of their family members. Building a network around families therefore means strengthening it around the sick who, in turn, must return to the world with their family.

It is not by chance that our friend Giulio Laurenzi symbolised our Foundation drawing a labyrinth, that surrounds a family which is clinging to a thread carried from an external hand, which represents the guide that helps to find the exit.

This drawing is now a logo and the hand is the one that takes the hand of our friends in sharing a path of condivision of life. Diagnosis, guidance, accompaniment are the pillars of our activity that are indwelled on a common base made of dialogue. Dialogue that, unfortunately, is frequently missing in the phisician-patient relationship, more and more characterized by persons that prefer the expert imposition rather than the comprehension of a sympathetic doctor.

In our view, communication is essential, particularly when dealing with the health and when touching very deep emotional spheres. In order to contribute to the improvement of social comprehension of the problem, we have established an annual journalistic award, reserved to young professionals, on the topic of an information correct for the public and able to protect patients, at both civil and health level.

In conclusion, going back to the aims of this guide, we wanted to fill the empty space around the family of the sick, indicating how to recognize positive potentials to be strengthened and the potential risks to be faced.

Our desire is to make it clear that the patient "is" the surrounding family and that it's impossible to assist one without, at the same time, take care of the others. It must be given to everyone time and a space, hopefully full of relationships, opportunities and attention, as we are sure that under most suitable conditions human sensibility can overcome pain even when pain cannot be annulled.

THE DOCTOR

Harmony is a word evoking tranquillity and well-being, and it may seem out of place if referred to very serious illnesses.

Nevertheless, the term was strongly desired by the staff members of Alessandra Bisceglia Foundation, who chose it as a result of their experience of years of involvement in the life of their "friends".

A previous work, "towards the possible autonomy", had been focused on the figure of the patient who, having to face a continously worsening long path of functional incapacity, was supported in sustaining and overcoming the problems.

The logic was constructive and aimed to help him to make full use of all the residual potentialities, rather than to console him for the lost possibilities.

The obvious subsequent step, despite of a general little attention to this aspect, was to examine family problems helping their members to rediscover the quiet of a peaceful life.

The message, for all the specialists who cure a chronic disabling disease, is that it is necessary not only to consider the technical path: damage/therapy/recover, but it is also mandatory to predict the alterations that, in time, could cause further damage within the patient's family.

It must be underlined that the emotional earthquake resulting from this kind of situation, with its continuous tremors, generates a significant change in the equilibrium of family relationships, with a high risk of added overposed pathologies.

In fact the emotional earthquake resulting from this kind of situation, with its continuous tremors, generates a significant change in the equilibrium of family relationships, with a high risk of additional pathologies.

Today we see the first laws related to the protection of the"caregivers". By this name are called those who, without adequate preparation, because of a new dramatic situation, are forced to devote their lives to the care of a loved one.

This work is dedicated, not only to these new "non-professionals", but to all the members of the family, with the idea that love, constructive towards one, must not turn into a cause of pain and suffering for the others around him.

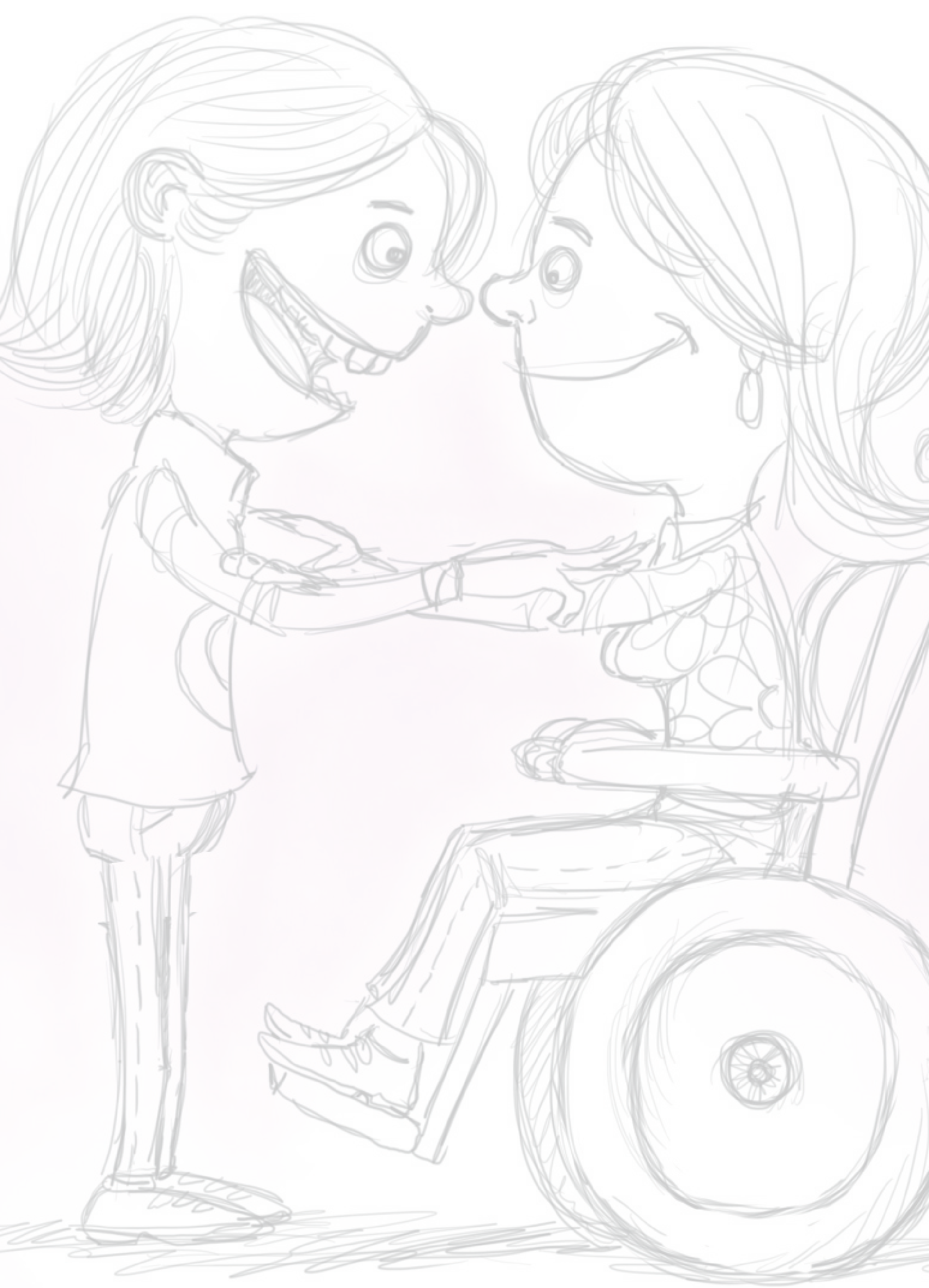
THE PSYCHOLOGIST

When a disease occurs in one of the family members it is an important event. If then this discovery is burdened by an unfortunate diagnosis, with prognosis of functional difficulties often progressing up to the disability or in some cases to the death, the event becomes destructive, with consequent emotional upheaval in all family members.

With this guide we want to enter a scarcely explored field, that of the harmony of those living with the patient. This idea is, for us, so important and significant that we wanted to include it in the title of a guide that aims to help those who may be involved to approach, in a functional and synchronic way, the dimension of pain and suffering.

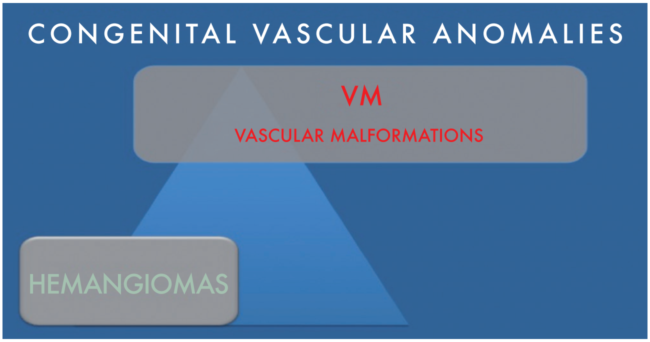
In this sense, through various steps, we want to touch all the facets of a family organization, outlining the dynamics, up to the complex network of relationships between the caregiver and those around him, trying to help them to find a coherent functional adaptation to the stress to which they are subjected.

In addition we wanted to give help also outside the narrow field of psychology and psychopathology, explaining what the laws in force provide in terms of official recognition of the figure of the family caregiver.



THE PATHOLOGY

Vascular Anomalies, what they are



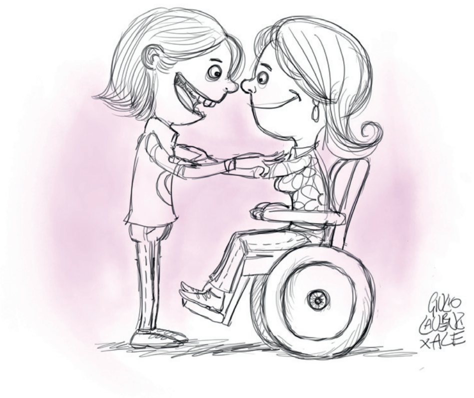
CONGENITAL VASCULAR ANOMALIES

VM

VASCULAR MALFORMATIONS

HEMANGIOMAS

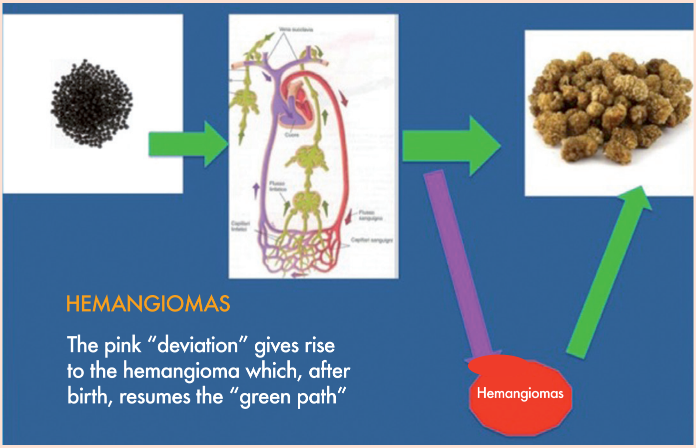
Vascular abnormalities are still not universally and correctly known in all their variations.
The difficulty lies in the fact that, in the same family of diseases, there are two variants: the angiomas, very frequent and scarcely dangerous, and the vascular malformations, rare, progressive and potentially lethal.



HEMANGIOMA

Hemangioma is the “good” component of the vascular anomalies family, caused not by a structural defect, but related to a mistake during the pathway of developement. During the embryonic period, from the angioblast, a mass of specialized cells, it will origine the entire vascular system: heart, arteries, veins and lymphatics.

At the end of the formation of the vasal net, located all around the whole organism, the not used remnants of angioblast, lose the “vasal” connotation and turns into fibroadipose tissue. Sometimes, for unknown reasons, the process does not reach its completion and leftovers of angioblast skip the final transformation.



HEMANGIOMAS

The pink “deviation” gives rise to the hemangioma which, after birth, resumes the “green path”

These residual portions are, in most cases, invisible at birth but, soon after, due to an aspecific proliferative push, they swell tumultuously in reddish cutaneous subcutaneous masses. Subsequently the growth stops and we assist to a spontaneous regression.

The described process runs out in the course of childhood and, if usually completed around the fifth, seventh year of life may, in some cases, finish later.

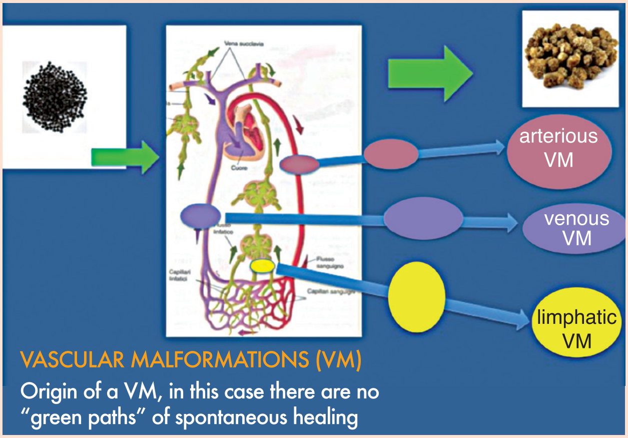
The hemangioma is therefore, in the vast majority of cases, a minor problem, destined to a natural solution, except in particular situations that do not allow a passive waiting. In these eveniences targeted medical and/or surgical therapeutic strategies are needed.

VASCULAR MALFORMATION

Unlike hemangiomas, vascular malformations (VM) are intrinsic structural errors of portions of the angioblast. This causes that the tracts of vascular system, arising from those sections, will be irredeemably compromised.

The involved anatomical region undergoes continous structure alterations, due to the unrelenting increase in number of the blood vessels and enlargement of their diameter, with the added damages related to the altered hemodynamic balance

The process is unstoppable and, though in most cases slow, it is always inexorably progressive, with outcomes ranging from local damage to general flow disorders that can lead to death.



VASCULAR MALFORMATIONS (VM)
Origin of a VM, in this case there are no "green paths" of spontaneous healing

TO KNOW MORE

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THE COMMUNICATION OF DIAGNOSIS

When dealing with vascular anomalies, a detailed knowledge of the pathology and its evolution is essential, in order to put both patient and family into the right conditions, so that they are able to face the illness.

Let's start from the Haemangiomas. As said before, in the vast majority of cases hemangiomas solve spontaneously, but the healing process typically lasts years and it is crucial, throughout this period, to control the natural anxiety of parents, helping them to wait. It is important to avoid any unjustified fear that could make them fall prey to "imaginative" and useless -if not harmful- therapies.

On the other hand, when it comes to particular cases, which require invasive therapies, we have the opposite problem, because we have to make these treatments acceptable to the patient. We must take all needed time to explain why, different than normal strategies, are used.

When affected by a vascular malformation, the patient must face the difficulties related to progressiveness and aggressiveness of the lesion. In this situation considerable experience and sensitivity is needed to explain how, an apparently banal situation, can cause impotence or death, therefore obliging to drastic therapies.

It is difficult to make patients understand how, "important" therapies are often undertaken only to delay the evolution of the disease, and it is even more difficult to explain that "definitive" therapy means total removal, often impossible and, very often, unacceptable.

It is like to be in a minefield: or the surgeon's proposal involves the drama of a mutilating intervention, or it is the patient who asks for a definitive solution that the surgeon cannot give, because of an anatomical situation impossible to deal with.

It is a question of finding a balance between "possible radicality" and "bearable radicality". In the latter case, the operator must carefully evaluate the "price / benefit" ratio between anatomical sacrifice and improvement of quality life. For example, amputating a limb to resolve an uncontrollable pain.

The situation to be explained is that of a disease, that differs from a malignant tumor, only by the inability to give distant metastases.

From here, to taking the methods of communication of diagnosis "on loan" from oncology, the step was short.

Basically, it is necessary for the pathology specialist to realize that he is not giving voice to his "knowledge of the expert", often an echo of his ego, but that is making a diagnosis that can represent a death sentence.

This means getting in touch with patients and family members and being able to find the right words, in order to thoroughly explain the disease, without adding unnecessary pain.

In this process, the natural partner is a trained psychologist, who knows the medical problem, the possibilities and the therapeutic limits of the case, and how to identify the strengths and weaknesses of the patient and all his family members.

The purpose of such a combined action is to be able to communicate, without throwing the listener in despair of fear and incomprehension.

OUR OWN APPROACH TO PATHOLOGY

The Foundation, born from the experience of Alessandra and her family, choosed the mission of giving a technically valid response to all applicants, combined with an empathic presence along the entire path of the disease.

Since the beginning, the psychological aspect has been looked at with the same attention dedicated to the more strictly medical one.

An example among all: the locations where we meet our patients, have never been classified as clinics or offices, but have immediately taken the name of Stanze di Ale, to signify and underline concepts of familiarity, comprehension and share of problems.

As already mentioned above, the communication of diagnosis is a fundamental moment and for this reason, in our rooms, at the time of the first contact, patient and relatives are welcomed by trained specialists and psychologists experts in the pathology.

Together, in a peaceful dialogue, they explain the situation, without any unduty brutality, for a communication of diagnosis which, even if sometimes dramatic, must not be made worse by misunderstandings and coldness.

The Foundation is not a hospital, this must be immediately made clear to those who look at it from the outside and ask for help. It has the logic of giving assistance, within the sphere of its own competences, to those who find themselves lost in uncertainty for a doubtful or, worse, not elsewhere obtained answer.

Most of the families who have so far turned to us, along with a desire to understand, have expressed the fear of being abandoned and the need for closeness

> It's not so much what we do, but how much love we put into doing it. It's not so much what we give, but how much love we put into giving.
>
> MOTHER TERESA

So, to support those who rely on us, we offer to guide them through the national welfare (SSN) maze, identifying the SSN centers able to treat their problems. In addition, as far as possible, we support them in person, when a particularly stressful occasions occur, either because of the invasiveness of the procedure, or because of the psychological situation.

All the team members of the Foundation draw strength from the union of their activities in addressing the needs of patients. The aim is to spare them, as far as possible, strenuous, expensive and often frustrating research odysseys, also with the help of the institutions and specialists of the SSN we work with. These management logics have a very strong value in reducing the anxieties and stress of families, helping to prevent possible disharmonies.

We are sure that our approach protocol, although born from the experience in a specific, rare pathological area, is applicable in dealing with any type of chronic and disabling disease and we realized how difficult it is to be able to cope with the patient's problems if we focus only on the purely medical aspect.

A HOPE AT LAST

“My wife Paola suffers from a vascular malformation of the lumbar area”, when she realized the problem, her first reaction was of a terrible fear, because she didn’t know what it could be.

Before meeting the W Ale Foundation, our trip had been very difficult, not only from a practical point of view (travel, unclear medical visits, incomplete interventions) but also and above all, from an emotional one. In fact, the lack of clear information or a well-defined diagnosis had only increased her sense of fear and amazement.

One day, thanks to a television program, which hosted prof. Cosmoferruccio De Stefano, a specialist in vascular anomalies, from the Foundation, we had heard him discuss these pathologies, unfortunately still unknown, and we decided to ask for help.

We had the feeling that in the end there was hope for us and we felt a great sense of relief

The only difficulties were of a logistic order and about organization of work, having to move to Rome from Sperlonga. We were helped by the Foundation and Campus teams, who together created an highly efficient collaborative group.

We felt immediately welcomed and supported since we met Professor De Stefano and the whole team, especially with regard to the psychological sphere, of which we felt the greatest need. Being able to talk about our situation and feel understood has strengthened our bond with the Foundation, which today represents an important referral for us

Being able to talk about our situation and feelings to be understood, has strengthened our bond with the Foundation, which has become an important point of reference for us today”.

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THE POSSIBLE HARMONY

> True joy comes from
> a deep harmony among people,
> which everyone feels in their hearts,
> which makes us feel the beauty
> of being together and to support each other
> in our life path.
>
> POPE FRANCIS

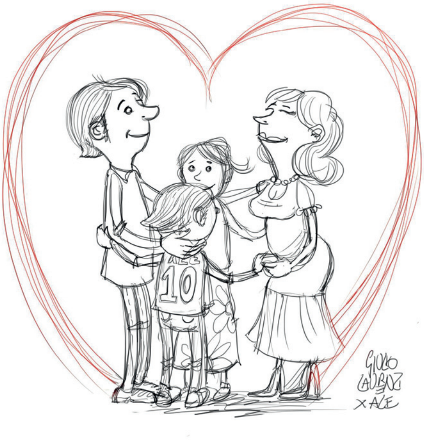
THE FAMILY DIFFICULTIES

"What do we do?", "Which specialist should we speak to?", "Will it be a serious illness?".

These are just a few examples of frequently asked questions, or simple thoughts expressed while following winding paths, when we are faced with serious and scarcely known pathologies.

Hence the tormented search for a diagnosis that obliges, in some cases, to extra-regional or even extra-national odysseys, with the family inevitably overwhelmed by a vortex of anguish and negative emotions.

This situation of difficulties represents one of the main obstacles to the development of that "Possible Harmony", necessary for a good coexistence and a functional adaptation to the illness.



Placing moments of sadness, anger or fear in the right context, recognizing and accepting them, is the first step we need to take when assisting a sick relative.

However, it is a difficult transition and, first of all, it is necessary that all family members know how to communicate with each others and with their own emotions. The emotional world is a world of multidimensional experiences and emotions, which are based on a complex chain of events, which determine the brain's responses to specific stimuli and in turn motivate the person affected to act accordingly.

There is no doubt that the illness of the single represents a painful stimulus and, in his presence, even if involved by the same experience, different individuals will have different evaluations and they will express different emotions.

The personal responses due to different perceptions and reactions to pain, if not managed correctly, will negatively influence the patient's parents, spouses and siblings, creating the conditions for possible conditions for possible divisions within the family. In this type of scenario it is possible to witness a sort of diaspora, with the actors moving away from the epicenter of pain, abandoning the one who, out of love or the impossibility of finding another solution, will have to bear alone the greatest part, if not all, of the psychic and physical weight of the assistance.

Whose members, as a sort of diaspora, will move away from the epicenter of pain abandoning those who, out of love or the impossibility of finding another solution, will have to bear alone most, if not all, of the psychic and physical weight of their assistance.

> Family teaches how not to fall into individualism and balance the "I" with "we". That's where "taking care" becomes a foundation of human existence and a moral attitude to promote, through the values of commitment and solidarity.
>
> POPE FRANCIS

In facing pain, we are faced with a series of questions, whose answers, are linked to the expectations of the outside world and our previous experiences of it, which in turn will lead to different individual behaviours.

THE PATIENT'S ISSUES

Considering the above, we can now understand how the whole family can be affected by the diagnosis of a chronic illness. In fact, changes in the life of someone who falls ill, added to the impact on his life experience and his subsequent upheavals, can also have violent repercussions on the people around

For a patient with chronic disease with an uncertain and ruthless course, such as vascular malformations, the component of unpredictability adds an overwhelming emotional load to the progressive functional incapacity, flanked by the realization of the loss of control over what is happening

Several studies have found that, under such conditions, there is a higher incidence of anxiety and mood related disorders, leading to an increased risk of suicide.

The patient faces a sort of redefinition of his identity, in terms of self-esteem, self-efficacy and body image. He must face his emotions such as anger, shame, sadness while, on the other hand, he must face the physical changes that he could experience, which can cause alterations in the relationship with the environment and the community in which he lives.

The attitude of patients, which varies according to their education, sensitivity and ability to manage emotions, significantly affects the tranquility of their relatives and, in severe cases, can cause family disintegration

THE CAREGIVER'S DIFFICULTIES

Technical definition of caregiver is: someone outside of the professional setting and generally free of charge, who offers support and assistance to a loved one or to his or her own family member, with a specific illness and/or in a condition of non-autonomy",

Euro-carers1 .

Data reported by the European Union tell us that most of the assistance given to people with chronic illnesses and disabilities is provided by relatives and friends, for about 80% of the cases. In Italy the role of the caregiver has not been made official yet and, as a consequence, there are no updated data regarding their number.

In a multipurpose survey in 2010, ISTAT counted over three million people in the family, regularly caring for the elderly, the sick and the disabled.

Cargivers are mainly women (74%), 31% of whom are under 45, 38% 46-60, 18% 61-70 and 13% over 70. The tasks performed by the family caregiver are continuous and burdensome as they are dedicated to the care of the other as a whole, guaranteeing the psycho-physical well-being of the person being treated.

FAMILY CAREGIVER
The person who provides support and assistance to a loved one with a specific illness and/or lack of self-sufficiency, outside of a professional context and generally free of charge.

It is a very hard activity which, in the absence of the required preparation, often produces a significantly negative impact on the patient's quality of life.

If no corrective measures are implemented, the caregiver could face a number of problems, potentially destructive for himself and those around him. First of all the moods deriving from having to face a new situation, finding oneself completely unprepared, with the consequent fear and anger due to the sensation of feeling inadequate or impotent.

There is a growing fear of making mistakes, both from direct and indirect actions, such as the choice between two or more different therapeutic paths.

In a situation like this, the caregiver often feels abandoned and progressively loses trust in others. Complete dedication to the sick also makes the caregiver a stigmatized person in the workplace, as it becomes progressively more difficult for him, to cope with work and family commitments.

It should not be forgotten that, according to a survey by the Italian Alzheimer's Association, 66% of Italian caregivers are forced to leave work. It is again this dedication that becomes the reason that leads to the progressive disintegration of the family, because the caregiver must face an increasingly active and passive isolation.

Active, as he will devote less and less time, affection and attention to other family members, often preventing them from sharing assistance, faced with real or presumed incapacity; passive, because relatives, feeling excluded, will find it easier to run away.

The loss of mutual trust, with all its negative outcomes, is around the corner. In addition, caring for a problematic patient can also be the cause of physical ailments in the caregiver, such as exertion-related trauma, gastrointestinal complaints or drug abuse.

Psychic problems can also occur, such as sleep disturbance or stress which, sometimes associated with a growing depletion of financial resources, can lead to depression and / or consumption syndrome in the worst cases.

The caregiver's internal pain is a deep, continuous conflict of choice between one's own well-being and that of the person that assists.

Situations, such as those shown, indicate a disharmonious context in which the caregiver is isolated. He thus lives a rainbow of moods, ranging from initial enthusiasm, guided by the personal desire to help, to the feeling of weight due to the overload of responsibility, to the resignation, to a loss of strength up to the possible consumption syndrome already mentioned.

We are witnessing a change in feelings which, from an initial gratifying commitment, quickly turn into a huge heavy load to bear and a transition from the solar "I want to do it", to the desperate cry of "I must do it".

It is at this point that the free choices become renunciations, with all the implications that will negatively influence not only the quality of the caregiver's intra and extra-family life, but also the quality and effectiveness of his care. This is demonstrated and confirmed by some studies showing that there is a 20% higher percentage of mental health problems among family caregivers than the rest of the population. (Colombo et al., 2011).

In this regard it must be considered that, in 66% of cases, additional medical expenses can represent an unsustainable economic burden for those who have difficulties in maintaining their jobs and professions, as previously indicated. In Europe many countries have already officially recognized the role of family caregiver (England, France, Holland, Sweden, Luxembourg, Malta).

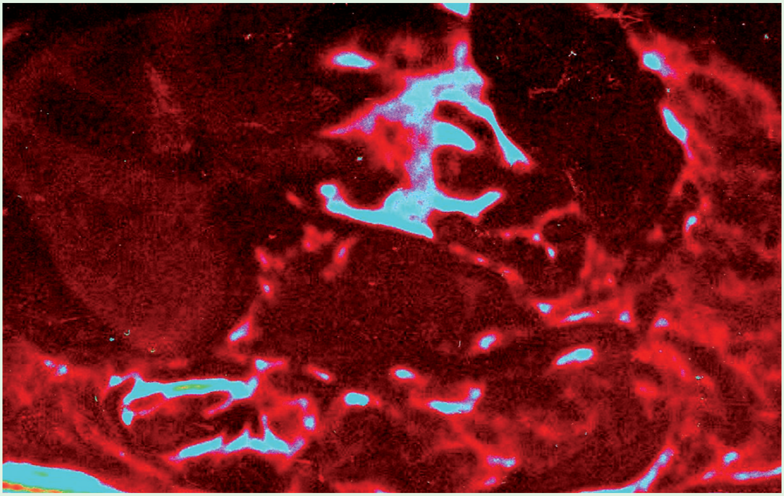
In Italy only in October 2018 a bill was discussed on the subject, so as soon as it is ratified, it should be an aid for the preservation of the well-being and quality of life of these people.

THE DISEASE OF A CHILD

The diagnosis of a serious and disabling disease is a critical moment because, in addition to the difficulties of acceptance, it involves a sudden and radical upheaval of the homeostasis of the family. The event is therefore particularly dramatic when it concerns young children and the idea of a child's possible disability brings with it feelings of anger, sadness and loss of confidence in any type of "justice".

It is a very delicate transition phase because it involves the reorganization of the family balance for which the parents are responsible: the priorities have changed and all energies must be redistributed according to the needs of the sick component.

Suddenly life is turned upside down by a new way of considering the "disease" which, from an "occasional event", turns into a "daily condition", thus causing impor-



MELTING POT

tant behavioral changes.

We see a variation in relationships between family members, with significant modification in the control of unexpressed emotions, not to mention the anxieties related to the need to maintain a continuous, no longer episodic, relationship with doctors.

If, as we have seen, definitive diagnosis is a dramatic milestone in the history of the family, the previous period is no less painful. In fact, from the moment of perception of the disease, the parents perceive changes in the image of themselves and their child, so they begin to live in an atmosphere of anxiety and fear mixed with hope. These feelings of inability and uncertainty will strongly influence the adaptation to a diagnosis, obtained after a frustrating and long wait for an answer.

What has just been described is what happens in the late diagnosis of a disease and is the most frequent in the case of congenital vascular malformations that, due to the rarity and insidious course, are generally misunderstood and underestimated when the first symptoms appear.

... what weighs more...
is the lack of love.
It is hard not to receive a smile,
not to be accepted.
Certain silences are heavy,
sometimes even in a family,
between husband and wife,
between parents and children, between siblings.
The effort
becomes heavier, intolerable without love.

POPE FRANCIS

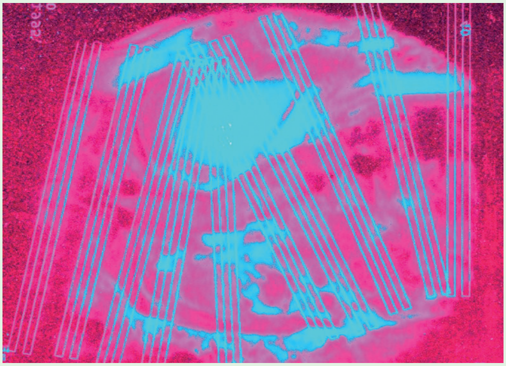
THE ILLNESS OF A SIBLING

If parents are the ones who bear most of the burden of the illness, siblings also live the drama of an upheaval of the family structure, both in practical and in emotional terms.

Initially they must face the feelings of anxiety and pain that, even if involuntarily, are transmitted by other family members and, in this uncomfortable atmosphere, they seek their parents for help, loading them with an additional psychological problem.

If requests are underestimated or, worse, completely ignored, a dramatic process is generated because feeling neglected leads to an increase in requests which become progressively more urgent and which are increasingly difficult to satisfy.

Brothers and sisters thus experience a feeling of exclusion, which generates anger towards the sick member who monopolizes the attention, to the detriment of others and towards the parent / parents who deprives them of what is perceived as "due", regardless of any eventualities.



JAIL

If this is added to the alterations of their daily routine, such as after-school care, the sharing of games and social activities, or if it is necessary to ask for help from relatives or external friends, the anger and the sense of exclusion and abandonment are consolidated and the situation can create conditions for significant future damages.

“All this inner tangle, led me to reflect on what I could do as a mother

The most difficult task for a parent is not to educate his children but to educate himself. Since I became a mother, I have been working hard to try to raise my children based on their real needs and not on my expectations.. However, even having a child with a disability questions this because the commitment is total and the rational ability to act according to a logic is often tested. This continuous and necessary dedication often adds the risk of not paying the right and necessary attention to your surroundings, including other children.

Thus begins an internal war, a war made of guilty feelings, from having to neglect everything, in contrast with the awareness of having to react to avoid the risk of creating irreparable damage where everything is fine or towards healthy children.

All this inner tangle has led me to reflect on what I could have done as a mother for my children without taking anything away from any of them. Among the many strategies, among the many attempts, among the thousand uncertainties, I continued, day after day, to consider disability as a source of great inner wealth that could have made me and all those who stood by me, stronger or even more “enlightened”.

At that point I realized that to prove my theory, I had to show my son that there are so many people who live with disabled brothers and sisters and in each of them there is an inner world made of pain and joy making them special. I have lived a life before and after disability ... brother and sisters no. In fact for them there is an "now and always" because it will be up to them to take our place when we are no longer there.

"THROUGH YOU" is a journey from an early age assumed by who is and has been son and brother above the "normal" standards. Is a journey through the refusal, the unconsciousness, the pain, the joy, the acceptance, the renunciation and the love of a boy who became great too soon and felt alone too many times.

I wanted this film to show the world the importance of the role of a brother or sister of a person with a disability, to show my son that he is not the only one to live an extraordinary situation and, above all, to remind everyone that to help those who take care of the most fragile, it is as important as taking care of the fragile themselves.

Pamela Pompei (mother of an alien and sibling)


GIULIO
LAURENZI
X ALE

THE PSYCHOLOGICAL CONTRIBUTION

For the patient:
we must not forget that, when looking for a new family equilibrium, the pivot point is the patient. It is therefore necessary to start from him, with a careful evaluation of his level of awareness of the disease and of the resources necessary to face the causes of stress.

AIMS:

- Promote the acceptance and redefinition of the self-image.
- Facilitate adaptation to the new condition.
- Help him to face the therapeutic paths, which are sometimes very difficult to support, for example when they need repeated invasive interventions or treatments.
- Support him on the level of psychological suffering linked to the disease, not only on a personal and physical level, but also as regards the alterations it can cause in terms of relations with his environment and his family.

- ✓ Support it in case of role reversal. This situation occurs when the patient-child takes care of the anxiety of his mother or father, taking on the task of being a strong person to try to protect the family. This phenomenon can mean that fear and anger are experienced by the patient not as "normal" emotions, but as a threat to the protective role he has decided to play. Therefore they become misunderstood or repressed emotions with possible dangerous consequences.
- ✓ Prevent anxiety, depression or food disorders.
- ✓ Prevent any risky conducts, such as alcohol abuse or taking other psychotropic substances.

For the caregiver:

"LUCKILY" I can't leave ... I can't go far from home ... These are words that come from a person who cared for his mother with love and dedication and lived this commitment as a fortune

This thought is the starting point to reflect on the figure and the role of the family caregiver. An important figure who, despite the heavy task, could achieve a better balance of life if, surrounded by family members involved rather than troubled, engaged rather than obliged, loved rather than neglected, he could find, with them, a way of living an environment of "possible harmony ".

OBJECTIVES:

- Help him to establish techniques of collaboration and sharing in the family, in order to better face the psychological burden in managing the disease.
- Turn him from solo into conductor, who guides the redistribution of activities among all family members, helping them in their choices with full awareness of their respective roles. According to this logic, the caregiver does not oblige anyone to tasks that can be interpreted as coercion or renunciation, but regulates the activities of family members, based on the skills and sensitivity of each of them
- Help him to accept what is offered by other family members, guiding them in sharing the assisting tasks and leading everyone to collaborate, for the maximum common good interest, with the least discomfort for their respective personal spheres.
- Help him adapt to new conditions.

In our vision, the family caregiver who, according to the literature, is the one who is in charge of supporting the patient's well-being, often even at the cost of his / her own psychophysical integrity, is the fulcrum of the WHOLE family for the sharing of activities and the distribution of the burden of pain.

And it is precisely to protect the pillar of family serenity that we spend so much energy for the caregiver, with the primary objective of teaching him to recognize his needs and emotions, as well as his limits, helping him to accept and respect them.

We believe it is essential to prevent a consumption syndrome, with the possible consequences of depression and anxiety, to avoid difficult dynamics to manage, which could lead to a failure in the process of achieving the desired tranquility

For parents:

For them the action focuses on the resources that each parent has, in order to guide them in the most functional way to manage pathology and pain. It often happens that parents feel overwhelmed by the suffering caused by the disabling event. In these cases the emotions of anger, fear, shame and guilt, if not elaborated and recognized, can enlarge the extent of their suffering, thus canceling any possibility of improving the quality of life for the whole family.

For siblings:

Psychological support for siblings is an important resource, since it helps to elaborate and understand dysfunctional relational dynamics, which can induce states of anxiety and / or depression.

PSYCHOEDUCATIONAL GROUP THERAPIES

These actions include a series of meetings, organized in different sessions, focusing on the analysis of the disease, its treatment and the different types of approach to the problem.

They can be addressed to patients, parents, siblings and caregivers and aim to improve the management of the disease, so as to reduce its impact on the patient's quality of life and on the family itself. The general objective is to encourage the development of functional coping skills.

TOWARDS HARMONY WITH MINDFULNESS

Over time, family members forced to endure the stress of caring for a seriously, chronically and / or disabled relative, could be brought to emotional closure as a defense against others' suffering or excessive involvement.

By enabling them to interact correctly with the discomfort, from a position of stability and presence, it allows a better adaptation to the treatments. This reduces family stress and the risk of exhaustion of internal resources, especially in the figure that mainly deals with the sick. It should also be considered that when the whole family group seeks serenity, there is a better sharing of tasks and more valid mutual support.

WHAT IS MINDFULNESS

It is an ancient practice, born about 2500 years ago from Vipassana meditation, which means "looking inside, looking deeply" and consists of a continuous search for reality, which allows clear and exact awareness of what is happening, at the exact moment in that is happening, getting the result of deconstructing the wrong mental patterns, through which people normally see the world and the reality around them.

Mindfulness cleanses the thought process from what we might call psychic irritants, such as impatience, dissatisfaction, anger, hostility ..., which keep the individual stuck in emotional slavery.

When, following this process of "cleansing", the energy of awareness is correctly applied, one remains constantly in a state of calm and vigilance, the mind will not be weighed down by worry or overexcitement and will return to a state of tranquility, of concentration and understanding.

It is a very accurate technique, which has as its object the exploration of the body and mind, which uses meditative contemplation, attention to the breath and internal and external sensations, as well as the understanding of "mental objects" (emotions, desires, thoughts, judgments, etc.), which inevitably leads to a change of character and a personal transformation, making the individual who is moving towards this type of experience very different.

It sets up a process of awareness, which enables people to become deeply aware of what they think, say or do.

In recent decades, scientific literature has demonstrated the validity of Mindfulness, confirming that a daily meditation practice structurally shapes the brain, thus demonstrating how constant, contemplative, activities can have a substantial impact on biological processes, leading to better mental health.

We are faced with a form of meditation, universally accessible and independent of types of beliefs and / or ideologies that, to date, has received a general consensus in Western culture.

In a situation of continuous stress, learning to take care of yourself and to control anxiety and stress, is essential for everyone's well-being and is the first step to help others.

For this reason, Mindfulness, which makes possible a correct awareness of the experience and related events, could be a powerful and very effective means that each individual can learn to manage such situations.

Without going into the description of the technical modalities of the practice, it should be underlined how a lasting "training" produces more stable and positive emotions, a better ability to face the phases of life, a reduction of tension, fear and worry and helps for a better mastery of difficult situations

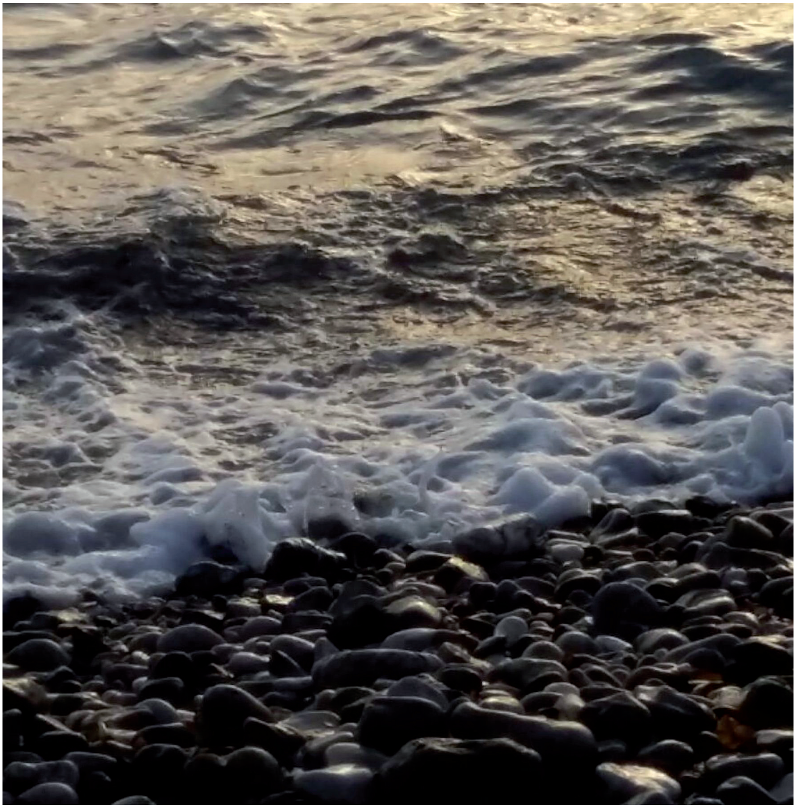
This will lead to an acquisition of awareness which, over time, will become a stable mental habit.

By applying Mindfulness it is possible to see family barriers fall: the "I" and the "you" will leave room for "us", all the members will be on the same road and, traveling together, in the same direction, the path will seem more pleasant and less challenging for everyone.

The goal is to make the family a safe haven and it is precisely the power of the group that, once learned the meditation practices, will be able, thanks to the teaching of an expert instructor, to continue the training independently, allowing you to maintain levels of personal and family balance, avoiding conflicts, bad moods, envy or other negative emotions that, over time, could destroy the family.

In summary, you become able to choose the behavior to be followed in every situation and you are able to not react automatically to negative impulses, allowing you to reach and maintain the maximum level of harmony possible within the group.

The most common clinical training protocol is, currently, the MBSR (mindfulness Based Stress Reduction), devised by Jon Kabat-Zinn, used since 1979 at the Medical Center



of the University of Massachusetts and, subsequently, exported all over the world.

The eight-week program, consisting of a deep immersion in mindfulness practice, aims to teach how to cultivate a state of awareness of one's own mental and emotional processes, how to recognize the source of stress and how to respond to it adequately, thanks to the use of meditative practices.

THE ROLE OF REHABILITATION

Rehabilitation is a problem-solving process that allow individual with pathology to attain the best possible standard of living into the physical, functional, social and emotional levels with the objective to limits the possible restriction of its operational choices. Rehabilitation is often useful to improve function also in rare patients.

Rehabilitation of rare and in most cases chronic diseases, requires continuous and appropriate quality actions to limit handicap and subsequent disability and involves family and the caregivers in association to hospital and territorial social services.

Despite the genetic nature of the single pathology, many rare diseases can benefit from rehabilitative action, which allows patients to have a better quality of life and a more active participation in social life, reducing the burden of dependence, especially if there is a good integration with hospital and territorial social services.

The Individual Rehabilitation Project (PRI) applies the parameters of impairment, limitation of activity and restriction of social participation listed in the International Classification of Functioning (ICF); PRI defines prognosis, expectations and priorities of the patient and his family; it defines the suitability of the different actions as well as the taking in charge. The formulation of the PRI allows to identify the appropriate rehabilitation setting for patients considering the phase of the treatment and allow an integrated assistance path based on the multidimensional sanitary and social evaluation.

Rehabilitation Project must define the specific areas of intervention, objectives, professional figures involved, settings, methodologies, rehabilitative methods and the timing of implementation and verification of the interventions; all these elements constitute the rehabilitation programmes.

Within the rehabilitation

project, the rehabilitation program defines the specific areas of intervention, the short-term objectives, timing and modalities of delivery of interventions, operators involved and the interventions verification.

Congenital vascular malformations are characterized by a multiplicity of neurological, orthopaedic, vascular and maxillofacial involvements and there Is a great variability of the lesional sites; these aspects need an individual approach to better manage complications such as hemorrhagic stroke, chronic venous insufficiency, joint rigidity and soft tissues infiltration.

Rehabilitation can be seen as management and treatment of the specific problem (e.g., dysphagia by speech therapy or peripheral vascular involvement with management and treatment of oedema by functional bandages), as a supplement to drug therapy in the management of chronic pain and in the evaluation of autonomies and function for prescribing aids such as prams and posture systems, as tools to promote autonomies.

In conclusion, rehabilitation should be define as a route to reach desired outcomes, using all the available instruments (clinical valuation, functional, physical means, rehabilitation, occupational therapy, orthoses and aids).

“We have found the right way to go at last”

I am the mother of a beautiful 10 month old baby.
As soon as he was born, he had a pink spot on the eyelid, then, after about a week, I noticed that the eyelid started to swell and thicken, not allowing the baby to open his eyes.
I immediately started contacting doctors, specialists, the department in which he was born, ... to find out what it was and what needed to be done.
The neonatologist of the ward where he was born told me about “angioma” and immediately sent me to your Foundation, where we finally found the right way to go.
At the Foundation I felt “at home”.
The child had to undergo beta-blocker therapy and, with the Foundation’s specialists, we faced the fears related to the use of the drug more serenely, evaluating the costs and benefits together. They explained to me that, after a phase of evolution, the angioma would have been reabsorbed but that, due to its position, it could have compressed the eye or obstructed its visual field compromising its vision and that, for this, it was necessary resort to such therapy.
An important strength was the psychological support received by the Foundation: in particular, Dr. Restaino was always ready to reassure me and encourage me to know better the problem and to identify the best way to deal with it.
My relationship with my little Andrea (Leo) is very positive today. I fill him with cuddles and try to do everything possible to pass this phase in the best way.


GIULIO
LAURENZI

THE ROLE OF THE FOUNDATION

> *"The family today is despised, mistreated,*
> *and what we are asked is to recognize*
> *how beautiful, true and good it is to form a*
> *family and to be a family today;*
> *how indispensable this is for the life of the world,*
> *for the future of humanity."*
>
> POPE FRANCIS

WELCOMING AND ORIENTATION

As already explained in the section dedicated to our approach to pathology, the family and patients are welcomed, at the first contact, in an initial orientation interview, by a team of vascular disease experts and psychologists.

In this first and fundamental step, the united medical staff will analyze the problems and suggest a strategy scheme to deal with them.

Aside from pure medical indications, psychological support can be suggested and, if accepted, performed directly by our team. Always based on the needs of each clinical case, family situation and / or special requests, the foundation offers targeted courses, both for individual and group training.

THE TRAINING

From our point of view, training is an important moment of sharing and exchange and also a sort of lifeline, for those who need to acquire specific tools to face difficult situations, which are often more onerous than initially imagined

First of all, our protocol aims to provide the basis for understanding the various specific situations and their development over time, and we consider this a fundamental step to proceed towards a more adequate therapeutic path.

If dynamics of a disease are not deeply known, there is a high risk of worsening an already difficult psicological situation, thus endangering not only the patient, but also the well-being of those who "care for" and of the othe members of the familyt, incessantly undermining the chances of achieving a proper balance in the life of the group

The knowledge provided will concern how to deal with disease, stress, how to manage the facets of the relationship within the patient / whole family system and how to organize everyone's activities, according to the specificity of the case, in order to promote the "Possible Harmony" to that we care so much about

Bureaucracy difficulties and relationships with social care services will also be explained and patients will be instructed on how to get what they are entitled to.

THE TRAINING OF THE FAMILY CAREGIVER

Focusing on the importance of the family caregiver, the Foundation offers training courses, specifically designed to limit the risks to psycho-physical integrity, linked to taking on such a delicate role.

We pay particular attention to him, because the family member who chooses this task, rarely if ever, has a specific preparation and, in most cases, has to face complex and unknown diseases, finding himself thrown into a complicated situation, which forces him to new, complex and tiring lifestyle.

TRAINING OF THE OTHER FAMILY MEMBERS

Not only the caregiver, but also the rest of the family, as already outlined, can suffer from the new problematic situation, in a context in which the illness changes the relationships and experiences of each member of the family.

As we have seen in the previous paragraphs, parents (when they are not a caregiver) and siblings also suffer from the difficulties of situations, often experiencing opposite emotions, which often lead to the decline of homeostasis and internal conflicts.

In light of the above, the Foundation intends to offer specific information / training meetings for these people who, even if not directly involved in the care process as much as the caregiver, observe, participate and absorb tensions, then dysfunctionally transfer them to their own lives.

Subsequently, the training will be aimed at making them aware of the fact that, as regards care, everyone must play a necessary role, for the development of correct harmonious family relationships in assistance activities.

The training will be addressed to how to recognize and verbalize intense emotions, such as anxiety, anger, sadness, teaching how to manage them, through specific behavioral strategies, promoting the ability to tolerate pain and suffering.

The Foundation of... a help in all directions

My daughter suffers from lymphatic-venous malformation of the face”, and from the first moment I saw her, after giving birth, I felt dismayed because the doctors with my daughter, gave me a paper that said something I didn’t quite understand. We all felt lost as we didn’t even know what it was. The doctors at the hospital immediately advised us to go to Milan where they would probably have clarified the diagnosis and then said what to do.

In all this my daughter always smiling, sociable, affectionate, playful, I did not see suffering in her face and in her way of living life, at least until adolescence, when she wanted to take matters into her own hands and search for a solution to the problem, asking me to go to a number of doctors.

After many trips from Milan to Pavia, Parma, Florence and then back to Milan, which not only cost us a lot of physical effort and unresolved interventions, but also, in some situations, poor understanding of the problem and a sense of scarce acceptance, we finally found the Foundation.

We felt immediately welcomed. A welcome we needed so much and the Foundation has helped us in every sense. We also experienced the opening of the Foundation doctors to collaborate with those who had already treated my daughter.

We felt supported. For us it is a referral point where we can, not only get the right care and the right information, given their knowledge of the disease, but also simply advices or indications when we feel the need.

G.S.

ANYWAY

People are often unreasonable, irrational, and self-centered.
Forgive them anyway.

If you are kind, people may accuse you of selfish, ulterior motives.
Be kind anyway.

If you are successful, you will win some unfaithful
friends and some genuine enemies.
Succeed anyway.

If you are honest and sincere people may deceive you.
Be honest and sincere anyway.

What you spend years creating, others could destroy overnight.
Create anyway.

If you find serenity and happiness, some may be jealous.
Be happy anyway.

The good you do today, will often be forgotten.
Do good anyway.

Give the best you have, and it will never be enough.
Give your best anyway.

MOTHER TERESA

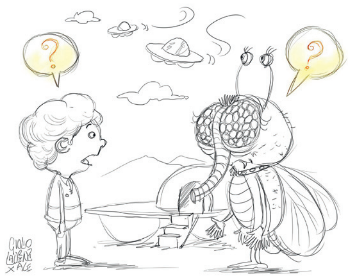
THE CAREGIVER, LEGAL ASPECTS

The figure of "Family Caregiver" was considered, for the first time, by the 28 March 2014 n. 2 law of Emilia Romagna region.

According to this law, article 2 paragraph 1, the "Family Caregiver" is the person who voluntarily, freely and responsibly, in the context of the individualized care plan, takes care of a loved one who is willing, not self-sufficient or who in any case needs long-term assistance, unable to take care of himself.

With this legislation and related resolution of implementation of the Regional Council ER of 16 June 2017 n. 858 (published on BURER on 12 July 2017 n. 198), the Region wants to support training in care and recognize the skills acquired for new job opportunities, wants to guarantee psychological support and participation in groups of mutual aid, orientation to services, financial support through disbursements such as, for example, care allowances, home health services in case of inability to move the patient, substitutes that offer moments of relief or allow Familiar Caregiver to deal with emergencies.

The law aims to make family caregivers share the care choices made by social and health services, provide adequate



information and training, as well as raise local communities' awareness of the social value of the family caregiver.

In the wake of Emilia Romagna, several regions have dictated rules on Family Caregiver.

Subsequently, it took three years, for the figure of the family caregiver to be taken into account by state legislation with the law of 27 December 2017 n. 205.

Paragraph 255 of article 1 of this law identifies the family caregiver in the person who assists and takes care of the spouse, the other part of the civil union between people of the same sex or the de facto cohabiting partner pursuant to law 20 May 2016, n. 76, of a family member or similar within the second degree, or, in the cases indicated in article 33, paragraph 3, of the law of 5 February 1992, n. 104, of a family member within the third degree who, due to illness, infirmity or disability, even chronic or degenerative, is not self-sufficient and able to take care of himself, is recognized invalid as in need of global assistance and long-term continuous pursuant to article 3, paragraph 3, of law no. 104, or is the holder of accompanying allowance pursuant to the law of 11 February 1980, n. 18.

The amount of the investments was foreseen in the previous paragraph 254: the Fund for the support of the caregiver role of the family caregiver is set up at the Ministry of Labor and Social Policies, with an initial allocation of 20 million euros for each of the years 2018 , 2019 and 2020.

***

As of possible interest of the family caregiver, it must be remembered that law no. 6 of 9 January 2004 established, for people who lack all or part of their autonomy in exercising the functions of daily life, the figure of Supporting Administrator, in order to protect them with the least possible limitation of their ability to act, through temporary or permanent sustaining interventions

The Supporting Administrator is appointed by the

Guardian Judge of the place of residence of the person concerned, who establishes powers and charges: indications, procedure and fac are available in the section of the website of the Court of Bologna dedicated to this.

SOCIAL SERVICES

L. n. 328/00. "Framework law for the implementation of the integrated system of interventions and social services", of which:

- Article 14 on individual projects for people with disabilities, concerning school integration and "after us" program,
- the articles. 9 and 11 relating to the minimum structural and organizational requirements for the authorization to operate residential and semi-residential services and structures, followed by the **D.P.C.M. n. 308/01** ("Minimum structural and organizational requirements for the authorization to manage residential and semi-residential services and structures).

The art. 7 classifies the structures into the following types, determining their characteristics:

a) Community structures;
b) mainly hotel accommodation structures;
c) protected structures;
d) daytime cycle structures.

In addition to the provisions of the previous articles, these structures must meet the requirements specified in the synoptic framework referred to in paragraph A).

In the previous art. 3 were identified family structures and communities for the reception of minors w (for a maximum of 6 users). With **L. n. 55/19** to art. 5 septies c. Until 2024, 2 funds have been allocated to equip video surveillance systems with "closed circuit social and health facilities for the elderly and people with disabilities, whether residential, semi-residential or daytime.

With L. n. 55/19 all'art. 5 septies c. 2 funds are allocated until 2024 to equip video surveillance systems with closed circuit "social and health care facilities for the elderly and people with disabilities, whether residential, semi-residential or day-time."

TO KNOW MORE

scan

scan

If

If you can keep your head when all about you
Are losing theirs and blaming it on you;
If you can trust yourself when all men doubt you,
But make allowance for their doubting too;
If you can wait and not be tired by waiting,
Or, being lied about, don't deal in lies,
Or, being hated, don't give way to hating,
And yet don't look too good, nor talk too wise;

If you can dream-and not make dreams your master;
If you can think-and not make thoughts your aim;
If you can meet with triumph and disaster
And treat those two impostors just the same;
If you can bear to hear the truth you've spoken
Twisted by knaves to make a trap for fools,
Or watch the things you gave your life to broken,
And stoop and build 'em up with wornout tools;

If you can make one heap of all your winnings
And risk it on one turn of pitch-and-toss,
And lose, and start again at your beginnings
And never breathe a word about your loss;
If you can force your heart and nerve and sinew
To serve your turn long after they are gone,
And so hold on when there is nothing in you
Except the Will which says to them: "Hold on";

If you can talk with crowds and keep your virtue,
Or walk with Kings-nor lose the common touch;
If neither foes nor loving friends can hurt you;
If all men count with you, but none too much;
If you can fill the unforgiving minute
With sixty seconds' worth of distance run-
Yours is the Earth and everything that's in it,
And-which is more-you'll be a Man, my son!

(Rudyard Kipling)

OUR HISTORY:
TEN YEARS OF COMMITMENT AND LOVE

The Foundation Alessandra Bisceglia W Ale Onlus was born in 2009 with the aim of promoting the study and cure of vascular anomalies.

It is dedicated to Alessandra Bisceglia, journalist and television author, with great professional and human skills, as well as talent and courage out of the ordinary.

Alessandra left us a great legacy, teaching us that every difficulty can be overcome.

Affected since birth by a very rare vascular malformation, which in the teenage phase forced her to stay on a wheelchair, Ale showed us that with commitment, determination and tenacity it is possible "make it in spite of everything". She challenged the traditional way of living disability, fighting physical and cultural prejudices and indulging her dreams, her ambitions… and with harmony and awareness she reached goals that would, normally, have been denied to her.

This is the precious message that she has given us along with love and friendship between people, and we do not want this message to be dispersed. She is the one who now invites us to do something for the others, she is the one who has never "worked" only for herself and who, thanks to her family harmony, achieved all her possible autonomy.

Below is a summary of the activities in which the Foundation is engaged daily, alongside the families, helping them to accept and deal with the burden of the disease, promote access to care and help them improve the quality of their lives.

WHAT WE DO

STANZE DI ALE (ALE'S ROOMS)

Diagnosis centres and therapeutic address.
The treatment and care process includes:
Free of charge medical advice
Multi-specialist medical assistance
Free psychological assistance to help patients and families.

TRAINING

ECM earning conferences, as well as training and information conferences for doctors and health personnel in order to spread knowledge of the pathology and the activities of the Foundation.

RESEARCH

Scientific research with PhDs, research grants and scholarships in the field of vascular anomalies.

HELPLINE

Helpline
SERVIZIO DI ASSISTENZA TELEFONICA PER LE ANOMALIE VASCOLARI

Free telephone assistance service.

Information on exemptions, diagnosis and treatment centres, disability and social aids.

PUBLICATIONS

Scientific and informative publications.

ACCESSIBLE MOBILITY

3570 MOBILITÀ ACCESSIBILE

Taxis for disabled guests. Service established in Rome in 2010,
promoted with the collaboration of Radio Taxi 3570 and ANGLAT.

THE WARMTH OF A SMILE

Project addressed to upper secondary school pupils. The vision of the documentary «Alessandra, the strength of a smile» is aimed at reflecting on how to face difficulties of life.

PRIZE FOR JOURNALISM

Journalist prize to promote social communication, information and awareness-raising on rare diseases.

HOW TO SUPPORT US BOTH

➤ WITH A DONATION::

c/c postale n. 99285512

bank transfer BCC Gaudiano di Lavello
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by cheque for:
“Fondazione Alessandra Bisceglia W Ale”

VISA PayPal MasterCard American Express Aura Discover

➤ AND DONATING YOUR 5X1000

Signing to give us strenght!

Add our **fiscal code**
into your annual Tax Return

97566810582

This is completely free for you, but it can change the future of a disease that doesn’t have a cure yet.

To know more

www.fondazionevivaale.org

All donations to the Foundation Alessandra Bisceglia benefit of tax relief except for contributions paid by cash.

Registered in the Register of non-profit organizations and in the National Register of Legal Persons, the Foundation Alessandra Bisceglia W Ale Onlus pursues the statutory aims of social utility in accordance with current legislation.

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THE TOOLS

THE FOUNDATION PART

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