I realized that, perhaps, there’s a time for everything…but…to end like this, I’ve been fighting for all my life. Alessandra Bisceglia

The strength of a smile.

Make it, in spite of everything.

Alessandra Bisceglia “W Ale[1]” Foundation is a Charity Organization for the study and care of children vascular pathologies.

Toward a possible autonomy

A self-help guide for families experiencing disability

Edited by Maria Langellotti in collaboration with Raffaella Restiano and Marica Quaglietta

Support from…

About us

Alessandra Bisceglia “W Ale” Foundation is a Charity Organization for the study and care of children vascular pathologies (Government Recognition n. 683/09, Prefettura di Roma). It operates in Italy through promotional, projectual and learning activities. In detail:

Promotional activities:

- Distribution of educational material for the general public and for Medical Doctors,
- Events organization for awareness and fund raising,
- Distribution of the book *“W Ale, la forza di un sorriso” (Hooray of Ale, the strength of a smile)*, a useful tool to understand the Foundation’s aims, including a collection of Ale’s life experiences together with memories from the persons she met.

Learning activities:

- Training of Medical Doctors specialized in vascular diseases,
- Support to the families asking for those specialized Medical Doctors’ help,
- Organization of conferences about vascular pathologies directed to Primary Care Physicians and Paediatricians.

Projectual activities:

- Collaboration with private and public organization aimed at realising several projects. Among the many we did, *Familiarizziamo* and *Le stanze di Ale* are our main goals.

---

[1] W Ale (or Viva Ale) is the Italian Equivalent for “Hooray for Ale!”, where Ale is the Italian short form for Alessandra

Familiarizziamo[2] is a project aimed at supporting the families both through paper publications, on-line information and psychological counselling, and through life easing practises in presence of a long-term project improving the patient’s autonomy (for example, by promoting a direct call taxi service with car dedicated to disabled people, as happened in Rome).

Le stanze di Ale[3] is project aimed at the training of specialized Medical Doctors, the enhancement of Care Centres relationships, the promotion of human and technical network for vascular anomalies patients and families, the opening a series of welcome centres (the rooms) all around Italy for both patients and families.

Our first goal will be strengthened and other will be put into action in the future, by means of further training of specialized Medical Doctors and awareness campaigns, in particular those promoting architectural and cultural barriers overcoming.

Our mission

As part of its mission, the Alessandra Bisceglia Foundation supports the families of those afflicted with an invalidating pathology who struggle to live a fully realized life, without getting hammered not only by the disease but by its everyday social and organizational implication.

This guide is a little contribution, a food for through for all parents experiencing the difficulty of facing both their new role’s great responsibilities and the presence of malformations and disabilities of their children. It is a tool and it is part of a wider project through which we also offer experts’ on-line counselling[4] about the steps to undertake to develop an autonomy suitable to our children’s potentialities. Moreover, our guide gives a “you-are-not-alone” message to those busy in overcoming everyday difficulties, so that they could realize that **striving** is paid back by the goals they score.

We have to focus on the fact that autonomy is possible only if its targets cope with our children’s potentialities, not with our desires or, even worse, with the anxieties and **selfishness** that urge us to prevent them from experiencing their skills, in order to spare them frustration and to avoid us more stress! In addition, we have to give them a “**YOU CAN**” message, instead of a list of forbidden things.

In our guide we explain both the meanings of “autonomy” and “possible autonomy” highlighting the positive and negative familiar behaviours with regard to autonomy gain. We also offer some problem-solving hints. An apparently theoretical work that actually comes from successful stories!

A possible autonomy

Before explaining the concept of autonomy, it’s easier to define another idea. A possible autonomy is the ability to identify and accept the disability’s objective limits, a condition that doesn’t allow a person to be fully independent in everyday life. The disability limits have not to hamper the person’s

---

[2] “Familiarizziamo” is the Italian translation for Let’s got to know each other

[3] “Le stanze di Ale” is Italian translation for Ale’s rooms

[4] “L’esperto risponde” (Ask our expert) is a service provided by Psychologists and Psychotherapists through which a user receives an e-mail personalized answer to his request of psychological support

skills and desires, it’s only needed a fine tuning of his target. A failure’s risk is lessened if expectations are not high and after considering that even able-bodies persons could miss their set target.

In a few words, a possible autonomy is the skills a disabled person shows in taking his own decisions and responsibilities and in facing difficulties.

With a new idea of a possible autonomy, a disable child grows up doing his best to develop his resources, but a peaceful and stimulating environment is a must since his birth.

…every man has his own set of values to accomplish with. The ultimate goal is to gain a better quality of life and to do it as independently as possible…

Why a self-help guide?

When a son is diagnosed with a chronic disease, the whole family is involved both from an organizational point of view (the child is unable to accomplish with everyday tasks) and a psychological point of view (causing a disruption in common familiar relationships that may inhibit or hamper the child’s possible autonomy development).

A child’s physical disabilities puts the whole family to the test, especially when the diagnosis arrives at an early age, forcing a rearrangement of a complete set of home rules.

The aim of this guide is to give the often-unequipped families experiencing a chronic disease adequate tools to cope with emerging difficulties. From the starting point of sharing sufferance together, this guide aims to promoting autonomy when more effort is needed in everyday life.

What is autonomy?

It is…feeling safe and sound in order to be able to face the world…

It is…developing an own consciousness…

According to a more traditional point of view, autonomy means not depending from the others in any way. What if we have a disable person? According to this view, he won’t be completely free because he will always experience practical difficulties in his life. Independence of everything or everyone has the fault of not considering the man as a social being: a man has to be put in his context, a social environment where he may operate in everyday life both on a practical side (for example, doing his person care by himself) and on a psychological point of view (for example, deciding on his life choices by his own). With this broadened concept, a man may reach a possible autonomy on condition that people around him shouldn’t consider him as a passive subject and that he had developed healthy **attachment** relationships in his early life. For more info about attachment relationship, go on reading…

…attachment

Attachment, that has a key role in human beings' relationships, it is the kind of bond originating in the first year of life between the child and a reference figure (usually, his mother). According to some scientists, a healthy personality's development depends on an adequate attachment the person had with the reference figure. For example, if the child is stimulated to explore the surrounding world, he will develop and improve the knowledge process, a basic and natural process for every human being.

A child-parent relationship articulated on mutual confidence, emotional helpfulness and interactive skills gives the result of a person with self-esteem, who is able to recognize difficulties and ask (and offer) help, because he knows he may count on someone. On the contrary, if child-parent relationship is marked with confusion and incoherence, it will result in the so-called "dual attachment", a condition that as a negative influence on the development of an independent personality. Dual attachment, in fact, causes incoherence and a lack in adult autonomy.

Dual attachment may also be figured out in those families experiencing difficulties (a child's disease, for example), preventing a mutual confidence environment to be settled, a key element in autonomy development.

Family experiencing disability

As a general rule, a child's birth always causes a change in parent's lifestyle and a certain confusion arises. As a result, parents answer to the new-born need by reorganizing everyday life.

Having this in mind, the birth of a physically disabled child is an even more complex event to cope with, considering the emotional turmoil and practical upset involved, together with the often-present sacrifice of hopes and dreams about a healthy child with a physiological development. In a word, it is a highly stressful situation that originates more efforts to face both child's disability and parent's frustrated expectations.

Which emotions?...

When a child is diagnosed with a rare pathology or a chronic disease, parents experience pain and emotional turmoil, a situation that may turn even more harmful if it impacts the child's development. Confusion grips mind and action.

Rage, shame, fear, guilt and inadequacy feeling are a first response to the diagnosis. Only after (but not in any case) acceptance of the problem and a project's elaboration arise.

Sometimes emotions are so inflated that don't allow the take on responsibility of the problem, on the contrary they cause conflict and mutual accusation between the parents or towards the doctors. These behaviours delay every attempt to positively solve the problem and foster a more secluded attitude of the family.

Many factors are at stake. The extreme seriousness of the disease, for example, accounts for a harder conflicts' resolution and makes more demanding the subsequent familiar crisis' overcoming. As a general rule, the more psychological and physical burdens the family bears, the more difficult is to successfully manage the deriving stress.

What hampers autonomy development?

In the autonomy's development a disabled child experiences difficulty linked both to his condition and the environment's attitude, namely fear and dual behaviours that interferes with his possible autonomy. Parent or people's overprotective attitude, in fact, is often an obstacle to the child in terms of independence gain. In addition, contradictory behaviours from parents causes shame and relationship's difficulties in their son, even ending in the child's isolate from his social context.

Many factors are at stake in influencing the parent-child relationship and a possible autonomy's development of a disabled son, among which familiar dynamics, stress levels, the presence of other disease, etc. in particular, a prolonged and poorly managed stress may have negative emotional and behavioural fallout on the whole family.

What if the family doesn't accept a disability condition?

When an acceptance or an adjustment of the disability situation doesn't occur, there is a risk of attitude like…

- Over-protection;
- Refusal and denial of the problem, with requests for an admission in a (private) hospitals or with several specialists' consultation, for example;
- Vulnerability and identity problems;…

…a bunch of factors hampering autonomy development.

Risk factors for autonomy development

Overprotection

This attitude arises when a child experiences an excess of protection from his parents so that his autonomy development is limited. Overprotection is a frequent feature in many families, not necessarily experiencing disability; nevertheless, the latter is the case when it becomes more and more meaningful because it raises to the top the fears of difficulties for parents and disabled child.

Why are many parents overprotective when this attitude hampers the surrounding's exploration, that is to say knowledge and, at the end, autonomy development?

Overprotective attitude may arise from parent's feat that something negative could occur to their son: as a consequence of this, the whole world is depicted as a threat from which one has to be always protected.

Moreover, this attitude may derive from the kind of education parents had when they were children (parents often reproduce the same educational models they experimented as children).

As a result of the fact they are constantly worried, overprotective parents always warm their children against every possible danger, teaching them to feel unsafe everywhere. Those parents decide for their son, taking the burden of every responsibility.

Of course, a child need protection and has to count on his parents, but at the same time he must have the possibility to explore the world outside on his own, to grant himself a better growth.

Refusal and denial the problem

Attitudes like problem minimization or denial, or aggression and claims towards the surrounding world may prove extremely dangerous because they prevent any possible form of help to be settled.

Refusal of a disabled child is not necessarily embodied by a physical abandon, but often by a confused and so unintelligible situation. Refusal is expressed towards estrangement and requests for admission in hospitals or, more frequently, with several specialists' consultation and even acting like the problem doesn't exist (denial of the problem).

Learn more about that

Scientific evidence shows that young people suffering from a chronicle disease and whose parents perceive them as vulnerable, declare high stress level that even increase when they face new social relationship.

Remember

Fear is just an emotional that gives us information to adjust our behaviour. Even if fear is not negative in itself (it is a powerful tool experiencing fear in front a situation harmful to our safety), it may result in overstate reaction with regards to the originating context. Considering the world primarily as a source of fear may result in a stiff attitude towards it, causing parents' increase in anxiousness and preventing the child's surrounding exploration, the latter being fundamental in knowledge broadening and autonomy development.

Vulnerability and identity problems

The above-mentioned elements may also result in confusion dealing with growth and identity building.

The difficulties a parent experiences in recognizing his son as "able to…" hampers the child's autonomy and identity development. Usually, a child with disability is considered as extremely vulnerable, and this consideration is emphasized by an extremely serious disability.

In other worlds, parents' fear and anxiety regarding their son's physically conditions result in an increase in the perception of vulnerability, dysfunctional familiar relationship and often problematic behaviours of the child.

Promoting autonomy development…

Family as a series of tasks to accomplish with in the child's development on the fields of relationships, behaviours, knowledges and feelings.

Parents are their child's first and major watchers and one of their primary tasks is relating to their son as main actors and perceiving themselves as active subjects in his growth, especially when he has to face difficulties.

In the case of an only parent, the child's growth and autonomy development is more difficult. In such a situation the single parent is burned with a higher load of stress and a parent-child relationship is harder to set the point that the child's cares may prove ineffective and problematic social attitudes may arise.

A disabled child implies more difficult and defatigating tasks to accomplish with: how can a parent do his best in coping with such a threat?

Coping appropriately with a critical event depends of a several factors, among which we may list the importance the family tributes to the event itself and the ability to recognize and organize familiar and social allowed resources.

The first main step is teaching the disabled child to have confidence in himself and in the environment around him. On the contrary, stressing the child's inabilities will only result in feeding the child and his parents' rage, together with the child's self-perception ad "unable" or "loser", a factor hampering his healthy growth.

As a general rule, considering the child as an individual gaining a raising level of autonomy will help his parents in coping at their best with the most critical events in the so-called separation period (the one starting with school or working world entry and going on with a widening of the social network the disabled child/teen/adult is part of).

Protective factors

Protective factors are those allowing a family to find inner strategies and resources to face and successfully manage difficult situations.

What is self-confidence?

A self-confident child has a good perception of himself and of his capacities, he trusts in himself and in the goals he may score so that he is willing to try anyway.

A list of protective factors is here included. Remember (as just said) that self-confidence is the key tools in a disabled child growth and autonomy gaining.

According self-confidence means:

- Making the child feels welcomed and loved;
- Allowing the child or teen to experience new things and encouraging him in case of failure. Ha has realized he is just learning and that the road to success is paved with practice;
- Helping the child in expressing his feelings and emotions, in order to better understand and manage them;
- Stimulating the child in making his choices, without necessarily imposing and deciding in his place but having respects of his preferences. This attitude helps his growth and motivates him in taking future decisions;
- Nurture his skills and inner resources.

The above listed factors allow a personality development assuring the future disabled adult an appropriate self-management when he will experience unfamiliar contexts.

Allowing family unit, DIALOGUE AND COLLABORATIVE ATTITUDE is a competitive advantage and a primary resource in both the chronic disease's comprehension of the problem and step-by-step acceptance.

RULES SHARING among family members to cope with everyday needs is a way to ease everyone's tasks, allowing a better management of physical and emotional burdens.

FRIENDSHIP, SOCIAL INTERESTS AND ACTIVITIES are resources in the way the, assuring parents to be supported by someone else, help them in the safeguard of their wellness as of their son's.

PARENT'S CONFIDENT ATTITUDE towards the child helps in strengthen his potentialities and in defining his limits.

INFORMATION is the key factor opening the way to the previously listed factors, because it broadens the problem's knowledge and keeps a useful-to-solve-problems social network alive. By means of knowledge, for instance, the family may better understand the disease's medical implications, in order to improve their son's physical condition and social integration.

Let's take stock of the situation

Scientific evidence shows that, shortly after the diagnosis communication, the child's family needs not to perceive itself as abandoned and that 1 of 4 couples of parents declared themselves unsatisfied because of poor information and unintelligible clinical case. Bad information or misinformation may often lead parents to search for more information on not-specialised sources, like internet or not-scientific magazines, bolstering their confusion and sense of impotence.

That is the reason why…

Broadening the disease's knowledge in the correct way helps in recognizing difficulties and in getting the right tools to cope with them.

Moreover…

Considering the current situation and rethink the future expectation allows the parents to face reality and to set a plane based on the acceptance of the new familiar identity.

Summary of risk factors and protective factors with regard to autonomy development

RISK FACTOR ← AUTONOMY → PROTECTIVE
FACTORS

- Overprotection
- Refusal and denial the problem
- Vulnerability and identity problems

- Confident attitude
- Dialogue
- Rules sharing
- Friendship and social interests
- Collaborative attitude
- Information

How can a family cope with difficulties?

The amount of difficulties a family with a disabled child faces may result in additional disadvantages causing distress to one or both parents. The great number of specialised medical visits, the possible pharmacological therapies, the countless rehabilitation surgeries, for instance, increase familiar stress and physical and mental weariness. There is a concrete risk to lock up in one's grief, getting involved in situations that don't allow an adequate answer to everyday needs, boosting the psychological distress.

What can a family do? Don't be ashamed to ask for help

For a family, asking for help means having a problem and revealing a sort of incapacity in coping with it. That is the reason why sometimes parents experience a strong difficulty in asking for help: the request is full of personal consequences, especially when it is addressed to relatives, friends and other person anyway important for the family.

Being ashamed in asking for help often hides a sometimes not recognized judgement problem. Actually, expression like “I can’t talk to anyone because no one could understand me…” or “No one can even guess what I’m experiencing” are a way to hide oneself behind other emotions like discomfort, shame or fear in admitting to oneself of not being enough strong to coping autonomously with the problem. In such a situation, asking for help acquires a distorted and dysfunctional meaning because it is considered like showing weakness, not strength.

Asking for help

It is not delegating but asking for a bit of support used as a stimulus to go ahead.

Sometimes it is necessary to admit our limits to make it through the night. A thought like “I can’t cope with it only be myself” could be a nice starting point to an intervention plane to manage emerging difficulties.

Social network and support

In the long-term, a family with a chronic disease child may run out of their own resources, risking social isolation. Thus, there is a need to restore the depleted resources to cope with the always emerging difficulties, maybe searching for an appropriated support network outside the family.

A social network is a key factor. It means having the possibility to…

- Talking with friends and other anyway important person to live a full social life;
- Developing a support network among families experiencing the same problem;
- Using available service to get specific therapy or individual support.

The lack of consideration of the above-mentioned factors often results in both parents and child isolation, closing down and limited participation to any activity, making a social integration more difficult. Social support represents an efficient kind of help for a family facing the difficulties linked to a chronic disease.

Social support: practical and emotional help

- Practical help

It is made by information and material resources like transportation services, home assistance and volunteerism.

- Emotional help

It is made by the expression of worries and the identification of emotions like rage, fear, discouragement and shame, that accompany the parents' and disabled child's experienced.

Social emotional help is a kind of support needed when the disabled child and his parents learn to know their emotional world by recognizing and accepting their negative feelings in order to manage them appropriately. It is quite common that an individual couldn't define his feelings, not to mention the capacity to express them aloud. These difficulties are stressed in families with a disabled child, where attention is focused on the disease, leaving a few room to parents to understand their emotional status and even less their son's. In such a situation, the entire familiar system is built around the disease, causing a probable isolation and an excessive burden of stress.

What kind of intervention?

Family is the first resource, therefore organizing a set of interventions on it, it is useful and appropriate. They are intended to:

- Returning the experience of the parents with a disabled child to normal;
- Boosting parents' competence. Parents often have difficulties in perceiving themselves positively, like persons able to manage a highly stressful situation and that hampers the crisis overcoming;
- Valuing parents' capacity of adaptation to difficult situations;
- Helping parents in mutual support, an element often declining when difficulties increase;
- Helping parents in gaining both support and dialogues from relatives, friends and other persons anyway important for the family.

Tip… Parents must count on fixed reference figures, especially with regard to psychological support, to be driven and helped appropriately in managing difficulties.

Sometimes…an intervention plan aiming and engaging parents in a group or individual work. Only during group therapy, for example, many express aloud their emotions, fears, incomprehension, sufferings and doubts with regard to their capacity to cope with the critical event they live. Thus, a group work, like a parent training programme, is a way to confront oneself with people experiencing similar situations.

Parent training

Driven group experiences where it is possible to create a space to share emotions and express recurring mood with regard to difficulties in managing problems.

The above-mentioned intervention programmes aim at improving parents-child relationship, teaching educational methods and giving parents the possibility to learn more on their son's psychological development. Such interventions shift attention from the son's pathology to the entire familiar group.

Attention is focused on the family as a whole, home being the starting point to better understand relational and adaptive dynamics to the problems.

Food for thought

A child diagnosed with a chronic disease implies more consequences for the family than an adult. Parents have to face not only problems and disadvantages linked to the illness, but also the critical phases related to an individual's development.

Passage from childhood to adolescence is an important moment of changes for everyone and it has been supported especially in those families experiencing a chronic illness condition. In the latter case, the process involves both the typical physical and psychological changes of the growth phase and an eventual worsening of the child's chronic condition, namely an often-unbearable threat for the whole family.

Adaptation to the most important life changes is the key factor to brainstorm on, because it is the starting point to cope with difficulties when we have to face a critical event.

Familiar stress may be linked to several factors like parents' characteristics, child's age and seriousness of his disease, available resource to cope with distress. Parents' stress (and its implication on the child's disease) may be influenced primarily by the emotional status they live.

Parents having difficulties in perceiving themselves positively and able to sustain a problematic situation represent an obstacle to the crisis overcoming, making more demanding the way to a possible improvement.

In such a situation, parents support it is important both emotionally and practically, so that parent's emotions may drive the child's cognitive and emotional development (it is the child experiencing disease on his back!). A child's healthy and functional development is a useful tool in a project to gain them efficient self-management and as much autonomy as they can.

Remember…

If children live with criticism, they learn to condemn.

If children live with hostility, they learn to fight.

If children live with fear, they learn to be apprehensive.

If children live with pity, they learn to feel sorry for themselves.

If children live with ridicule, they learn to feel shy.

If children live with jealousy, they learn to feel envy.

If children live with shame, they learn to feel guilty.

If children live with encouragement, they learn confidence.

If children live with tolerance, they learn patience.

If children live with praise, they learn appreciation.

If children live with acceptance, they learn to love.

If children live with approval, they learn to like themselves.

If children live with recognition, they learn it is good to have a goal.

If children live with sharing, they learn generosity.

If children live with honesty, they learn truthfulness.

If children live with fairness, they learn justice.

If children live with kindness and consideration, they learn respect.

If children live with security, they learn to have faith in themselves and in those about them.

If children live with friendliness, they learn the world is a nice place in which to live.

Dorothy Law Nolte, *Children Learn What They Live*, 1972

Bibliography

Index

W ALE The strength of a smile

Make it, in spite of everything

Alessandra Bisceglia “W Ale” Foundation is a Charity Organization for the study and care of children vascular pathologies.

Alessandra Bisceglia’s model of life was both simple and great. She was a journalist, a TV author, a young woman with excellent human abilities and professional skills, together with an absolutely out of common inner talent and strength.

Alessandra made us live a wonderful experience and taught us that **we may overcome every difficulty**.

She showed us that **we can make it, in spite of everything**, working hard with resolution and perseverance.

Alessandra left us a precious legacy!

Suffering from her birth of an extremely rare vascular malformation that obliged her to the wheel chair since her teen years, her disease didn’t prevent her from planning ahead her life.

She always considered life with joy and passion, refusing the traditional way disabled people used to live their lives. She fought against prejudices and overcame every obstacle, reaching goals that seemed prevent to her.

She successfully managed in going beyond every physical and cultural barrier that were placed in her way.

She reached her possible autonomy!

Acknowledgments

On behalf of Alessandra Bisceglia “W Ale” Foundation, I sincerely thank everyone how supported this project, allowing this guide to be realized.

“W Ale” Foundation President - Raffaella Restaino (Ale’s mom)

This publication was realized by Alessandra Bisceglia “W Ale” Foundation

Support us: …

Contributions are tax deductible in Italy

Printed on xxxx