

Comité Éducationnel
et de Pratique Clinique



ARTIFICIAL NUTRITION

GUIDE TO TRANSITIONS TO ADULTHOOD

La Vie par Un Fil

Association pour enfants et adultes en nutrition parentérale et entérale à domicile

in partnership with

PRESTATAIRE DE SANTÉ À DOMICILE
homeperf

NUTRICIA
Advanced Medical Nutrition

Asept InMed
Essentiellement simple...et tout simplement Essentiel

GUIDE TO TRANSITIONS
TO ADULthood

EDITO

The transition from "adolescent" to "adult" is marked by significant physical and psychological transformations. It is a stage during which young adults must acquire their personal identity by learning to impose their personality, to "cut the thread", and to integrate into an environment outside their family.

Just a few decades ago, this subject was not greatly developed in medical practice. Now, however, it is widely discussed as technical and medical progress allow young people with chronic illnesses to live the life of an adult. However, the burden of chronic illness adds to the normal traumas of adolescence or young adulthood, and risk trapping young people in this position in **a long corridor of isolation and anxiety**.

Many questions are raised and asked:

- ❖ How does one make the transition from the paediatric sector to the adult care sector?
- ❖ What obstacles and difficulties are encountered by the young people and their parents and relatives?
- ❖ How does the young person perceive his illness, treatment, body?
- ❖ How does he become independent and what are his capacities for adaptation?
- ❖ Does his independence only involve knowing how to connect and disconnect himself?
- ❖ What about his quality of life?
- ❖ How can a break in care be avoided at this sensitive age?
- ❖ How can his involvement in all areas of this transition be encouraged?
- ❖ What are the common reasons for not observing it? Be alert? Pull down the barriers to freedom? Distance oneself from the family and the medical environment?
- ❖ How will the care teams prepare for accompanying the young person through this difficult transition?





It is also **a stage synonymous with optimism, independence and new challenges**. It is not a dismal outlook... on the contrary, the young person will become progressively more independent and flourish. It is more reassuring than for "model" or "rebel" children.

There is no standard process for making the transition, but the onus is on all - medical teams, parents and young people - to adopt three key rules: **anticipation, preparation and collaboration** for a harmonious, "made to measure" transition, as each situation is unique and depends on the complexity of the care and the treatment project: enteral or parenteral feeding, type of illness (medical or medico-surgical), associated conditions, and also on the family context and potential for studies or professional integration of the young person &c.

The aim of this practical guide is to accompany everyone involved and help them success in the transfer from the medical world of children to that of adults under **optimum conditions of continuity and provision of care**.

It also aims to help the young patients on artificial nutrition to **face the new reality of life as young adults**: administrative processes, studies, work, friendships, love life, sex, self-esteem &c.



INTRODUCTION

Created in 1987, La Vie par un Fil (Life through a thread) acts for both children and adults in matters of home enteral and parenteral nutrition.

We are in the service of each and every person who requires artificial nutrition. The needs and expectations of these children and adults are changing at the same time as knowledge is progressing and techniques and equipment are being improved.

Initially dedicated to children on parenteral nutrition and concentrating mainly on assistance to families and combating isolation, the association has now widened its area of involvement to enteral nutrition and adults. The association now sees itself as a point of contact and a privileged partner to health professionals specialising in clinical nutrition.

This new stage is marked by a deeper involvement on the part of the association in the content, technique and practices of home artificial nutrition (HAN).

In future, it is hoped that our orientations will help us to influence and assist the world of research. Well, why not?

With the aim of sharing the experience of our families in assisting and informing patients just coming on to artificial nutrition, La Vie par un Fil created and published **the first volume of the White Book on Artificial Nutrition** at the Bordeaux congress of SFNEP in December 2013. It **concerns the daily aspects of home enteral and parenteral nutrition**, in the form of practical files.

The second volume of this White Book concerns the transition from the world of teenagers to the world of adults, in this specific case patients with chronic conditions and already on enteral and/or parenteral nutrition from paediatrics. This transition is a difficult one, unsettling for all involved - the young patient, the family and all the paediatric and adult carers. During the Nutrition Congresses held in 2014, this theme was one of the principal subjects of the presentations and debates. This critical transition has been carefully studied by the parties concerned in order to avoid errors in the treatment and social and professional guidance of teenagers becoming adults.



Given the complexity of the subject, this guide will be less practical and more psychological and social than the first. Like that guide, it has been compiled by Leatitia Bercovitz from the SBMA Communication Agency, with the support of testimonies from young patients and adults, their families and partners, and carers (coordinating nurses, stoma specialists, doctors and psychiatrists from both the paediatric and the adult sector). Each has made a contribution to developing the subject in their own field and the proofreaders, especially the doctors, have checked the text from a medical and ethical point of view. **It is therefore in a spirit of general and complete consensus of all persons involved that the subject of this transition from adolescence to adulthood has been treated.**

This year, we have widened our range of partners: Homeperf, as last year (provider of home health services), Nutricia Nutrition Clinique (laboratory specialising in medical nutrition) and Asept InMed (distributor of single-use medical devices).

In future, we wish to increase our partnership to include all HAN professionals in the world.

We are now being approached by the medical profession to testify to them concerning HAN. This new and visible solidarity is clearly a force that will help us all within the framework of our current and future projects. Doctors have told us that we are taking the

time to write what they do not have time to write, aimed at patients and carers within all aspects of daily home care and at all stages of life. This, clearly, is our mission as an association of HAN patients.

This step of producing a White Book for HAN is an essential feature of the long-term work between all parties and of course in the service of patients and the protection of their interests.

In addition, the methodology used has been followed rigorously according to the following phases:

Phase 1: Definition of objectives of Guide

(La Vie par un Fil Strategic Committee meeting)

Phase 2: Definition of schedule of conditions

Phase 3: Selection of partners to accompany us

Phase 4: Interviews of patients, families, carers and doctors

Phase 5: Compilation of original version of Teen-Adult Guide

Phase 6: Proofreading cycles (doctors, carers, partner sponsors, patients, spouses, families)

Phase 7: Choice of model (internal and cover)

Phase 8: Page layout with definitive text

Phase 9: Final correction of misprints

Phase 10: Editing, printing, on-line publishing on websites of La Vie par un Fil and of different partners

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The patients and their families

Violaine,

mother of Pierre, and **Pierre**, on parenteral nutrition, 14 years 6 months, and Violaine's father **Bertrand**

Hélène,

mother of Nicolas, aged 15, on parenteral nutrition

Catherine,

mother of Thomas, **Stéphane**, father of Thomas,

and **Thomas**, on parenteral nutrition, with ostomy, aged 15

Nathalie,

mother of Nicolas, aged 16, on enteral nutrition

Eliane,

mother of Guillaume, and **Jacky**, father of Guillaume,

and **Guillaume**, on parenteral nutrition, aged 17

Eléonore,

mother of Jules, and **Jean-Daniel**, father of Jules,

and **Jules** on enteral nutrition, aged 19

Adeline,

on parenteral and enteral nutrition, aged 27

and her partner **Alexandre**

Jacqueline,

mother of Florent, and **Florent**, on parenteral nutrition,

with ostomy, aged 28

Morgane,

on parenteral and enteral nutrition, with ostomy, aged 37

and her partner **Stéphane**

Yasmine,

on parenteral nutrition, aged 39, and her husband

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For Sacha.

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- ▶ Becoming an adult, a process full of commitments
- ▶ Becoming and being an adult with a chronic condition

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- ▶ Do I have to warn someone if coming with medical equipment during a test?
- ▶ Is it possible to get extra school time? What is the procedure to follow?
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- ▶ Attitudes of parents and others
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- ▶ Learning how to know and like yourself better

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- ▶ How can I get a copy of a summary of my paediatrician's files? How can I obtain hospital examination reports?
- ▶ Where do I find a list of what to do when going through the three stages, 16, 18 and 20 years?
- ▶ Where do I get assistance for properly managing and understanding the procedure?
- ▶ How can I manage the administrative problems when changing CAF?
- ▶ How can I manage the administrative problems when changing social security (SS) status?
- ▶ How can I manage the administrative problems when changing MDPH?
- ▶ How do I choose a suitable mutual fund?
- ▶ How can I obtain a complete file for making MDPH applications?
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01

BECOMING AN ADULT,
A STAGE OF LIFE
EVERYONE GOES
THROUGHUpsetting the timetable
of becoming an adult

The term **adolescence**, from the Latin "*adultum-esse*", means becoming an adult and also growing up. It is a pivotal point in human life, during which social and sexual maturity is reached.

The term "**adult**", meanwhile, is defined as a state of maturity: "One who has completed the growth process, is fully developed", "who provides proof of being balanced". The synonyms speak for themselves: "of age", "accomplished", "responsible", "balanced", "reasoned", "reasonable", "reliable" and so on.

This passage is a stage in life that is longer and less clearly defined in our time than in that of our elders. Although the age of becoming an adolescent is set at around 13-14, the age of ceasing to be one is steadily less clearly defined.



Persons deemed mature, whose age is fixed by law 15 is the age of sexual maturity, 18 is the age of civil maturity.

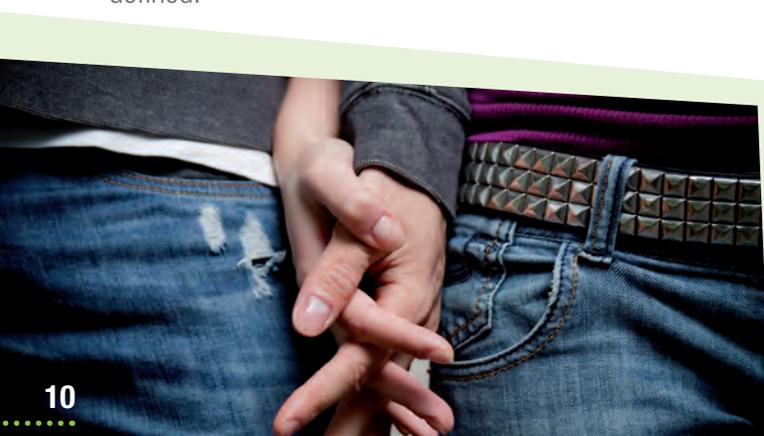
Sexual maturity sees an individual as capable of maintaining a sexual relationship with a partner of their choice without placing the partner in danger of breaking the law.

Civil maturity is the age at which an individual is legally considered civilly capable and responsible, that is, capable of being bound by the terms of a contract or another legal document.

However, does being able to court, be courted, have sexual relations, sign a contract or vote make a person an adult?

Less than 50 years ago, **rites of passage** were based on three stages in clear chronological order: military service, first job and marriage. Since then, we have developed five milestones that mark the onset of adulthood: completing education, leaving the family home, financial independence, living as a couple, and birth of first child.

However, the very idea of these milestones is now out of date, **as it implies the existence of a well-trodden path to adulthood at a time when young people do not all follow the road to maturity at the same rate.** Each marches at their own pace. Some pass through the five stages quickly, some do not live as a couple, some have no children, and some pass through these phases in a different order.



Some American psychologist refer to age twenty as "the age of emerging adulthood". Others in Europe, talk of "late adolescence" as the idea of becoming an adult at 18 makes no sense; the transition does not occur from one minute to the next. They explain that this new age bracket is born of the current socio-economic context: longer full-time education, the reduction in job opportunities for those fresh out of school, the introduction of living together and contraception into ideas of public morals with a delay in getting married, the wider choice of job opportunities for women, and assisted procreation, can delay pregnancy beyond an age when a woman is at her most fertile.

Another reason is "helicopter parents", always hovering around their children, always ready to solve their problems then and there. Young people do not wish to grow up as they are helped too much. Parents can infantilise their children.

And then, although **young people feel freer in their actions that older people**, (ease of access to information, increased choice of educational courses, professional career, emotional development, sex life &c), **they are also more restricted by social pressure, image pressure and limited scope for error.**

Underlining this muddle of boundaries to redefine pivotal ages, the media and the sociologists have adopted the new term "**adulescent**", a portmanteau word referring to the section of the population "stuck" between adolescence and adulthood. It is a state of mind devoid of desire to grow up, grow old or die.



Becoming an adult, a process full of commitments

It is a demanding time of life, a time for making choices to commit to an uncertain future, an uncertain world. It is a delicate stage but one that shapes the personality. Childhood is left behind and life faced head-on.

This turning point indicates maturity. To be mature is to know with perceptiveness what to do, to accept that the principle of reality prevails over the principle of pleasure, to bear the frustration of not everything being possible, and to adapt.

THE 3 PILLARS OF ADULTHOOD ACCORDING TO YOUNG PEOPLE

FINANCIAL INDEPENDENCE

RESPONSIBILITY

AUTONOMY

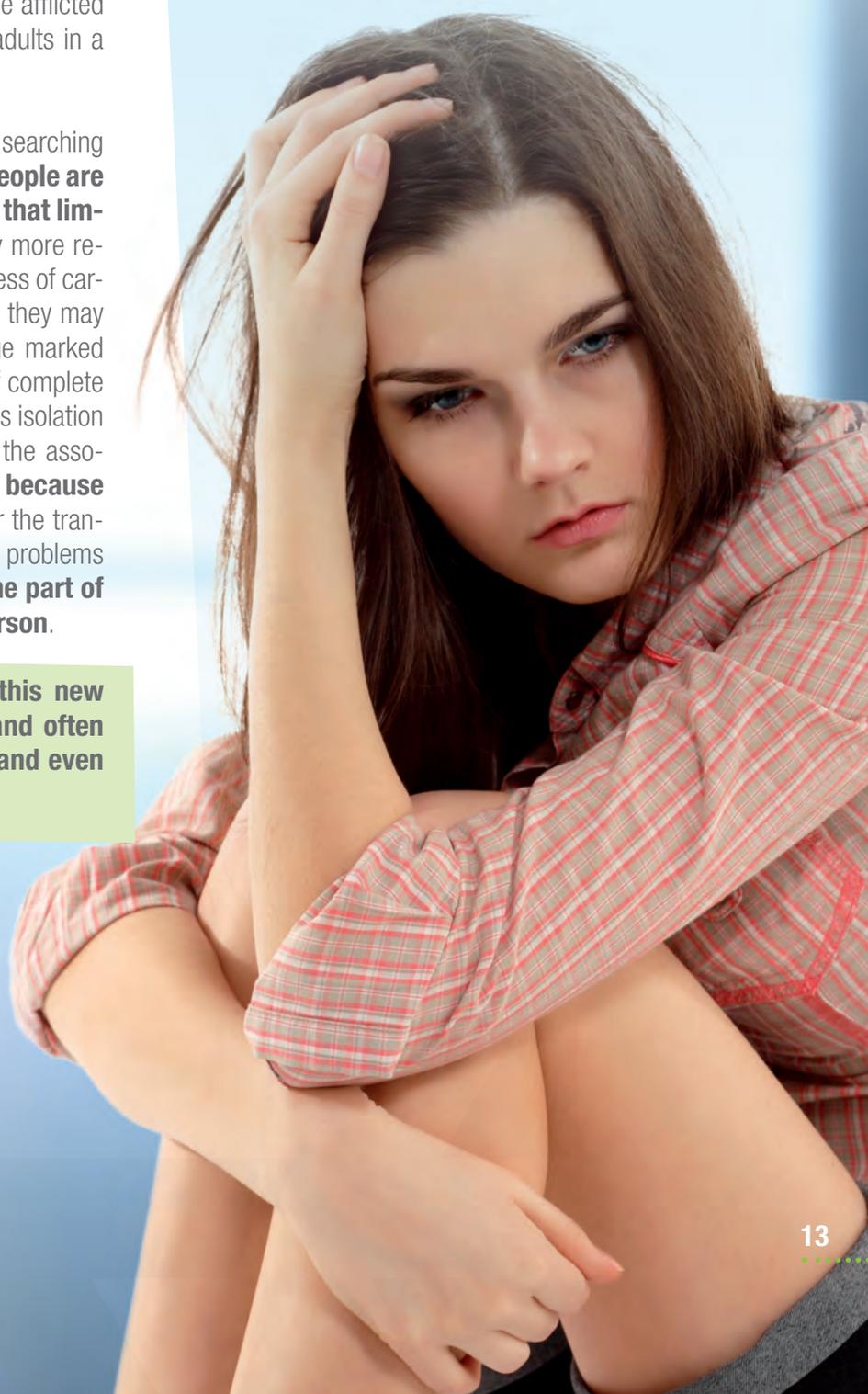


Becoming and being an adult with a chronic condition

The transition to adulthood is marked by profound physical and psychological changes, which lead to independence. It is a time at which sexual impulses, spiritual questions and intellectual crises can all come at once; **upheavals both large and small that can upset the world of not just young people but all those around them.** This is true for healthy young people as well as those afflicted with illness. Those with illnesses will become adults in a very different and sometimes very delicate way.

At a time when young people are legitimately searching for independence and autonomy, **sick young people are confronted with the demands of treatment that limits their freedom.** Although they are generally more responsible and mature than their peers, the process of caring for them can isolate them from their peers; they may feel excluded from their social group at an age marked by a whole series of experiences and a claim of complete freedom and a constant need to be affirmed. This isolation from daily academic and social activities, and the associated feeling of being forced out, sometimes **because of parents' over-protectiveness,** may hinder the transition to adult social life. These medico-social problems require much **thought and preparation on the part of carers and of those chose to the young person.**

Some adolescents cannot wait to enter this new stage; for others it is a forced passage and often synonymous with anxiety, inconvenience and even breaking.



02

TRANSITION TO ADULT SERVICES: A PASSAGE THAT HAS TO BE PREPARED

What is this transition?

This is **the period of planned passage from paediatric care to adult care for young patients suffering from chronic conditions, in order to ensure proper continuity of care.** This passage must correspond to a **period that is both medically and psychologically stable**, ensuring that puberty and most often growth are properly completed.

It may be a very critical and unsettling phase for a young person, as an adolescent will be attached to his "paediatrician" and "care team". He will be attached to the privileged atmosphere of the department, and will have habits and reflexes, and will not necessarily want to change systems.

It is true that the culture and organisation of paediatric care is noticeably different from that found in an adult department. **In paediatrics, child-orientated care will demand high levels of parent participation. In adult medicine, patients must be autonomous and independent, and family participation is limited.**

Although this passage is very positive in some ways because it drives the young person, it may be upset by areas of anxiety. The transition must be individually adapted. A specific approach based on the specific needs of each young person is essential for raising the emotional and practical obstacles that may alter the conditions of the transition.



What are the discloser signs of this transition?

Place yourself awhile in "patient mode". The paediatrician will report that this tall teenager, by his or her words and behaviour, is already in a more adult stage.

It is the doctor who will make this analysis, as it is rare for a young person to express a clear desire to become an adult.

The age at which these signs become apparent is highly variable, but the phase usually occurs between ages 16 and 21.

When the signs are not clear, it is the paediatrician who will touch on the question of transition and will gradually ease out the desire to transfer to adult medicine.

If the doctor reports that the young person is not anxious to move on, does not wish to be the "baby" in an adult department, he will temporise and tailor or adjust the transition. However, it is important to know how to bring forward the reluctant ones, who are not always the least mature!

Some examples of typical signs of an imminent change:

- ❖ When a young person wishes to be seen without parents, he is in a state of autonomy that allows him to face care without the support of his parents.
- ❖ He starts to be irritated by the babies and toddlers in the department. The structure therefore becomes less suited to his needs and expectations.
- ❖ He expresses a need to voice his own opinion and speaks in the somewhat harsh "teen" language. He wants to be in control of his illness, and decides to manage his treatment. He wants direct dialogue with his doctor.



These signs will help prepare for the transfer. They do not mean that from one day to the next, the adolescent switches to an adult doctor and the break is total.



Towards a gentle transition

When these manifestations occur, the doctor will condition the young person and prepare him very carefully for the transition to the adult world.

This transition will be made at the young person's pace, so that he will be ready to continue with his medical treatment. It is in fact a real accompaniment through the transition to the world of adults. It is highly significant for the patient as well as his parents and the medical teams, and must **be made in stages as harmoniously as possible.**

The relation between the young person and the paediatrician and care team must be simple and free of taboos. Above all, everything must be explained, and reassurance provided. **Two or three preparation consultations will be necessary.** Ideally, the last consultation should be conducted with the doctor assigned to take over the care present. During these consultations, the parents must always be present unless both child and parents expressly request otherwise. The doctor will explain to whom he is referring the patient, how the patient will be monitored, the hospital location, how the first adult consultation will go &c. The doctor will also reassure them, highlighting the mutual confidence of the paediatric and adult teams and their close cooperation before, during and after passage. In brief, all **human, technical and practical modes for ensuring an effective transition** to the adult medical world.

The doctor will also specify that **"there is no going back" from this transition.** This may appear abrupt, but it is a reality that the young person and his family must take on board. The transition is an obligatory stage, if only because of age issues. In that regard, it must be advised that because of age and physical characteristics, the paediatric organisations can no longer provide hospital admissions for more than 24 hours and/or specific investigations, and more specifically in an emergency context. As a rule, young people understand this reasoning and sometimes handle matters more easily than their parents.

At each consultation, the paediatrician must assess the psychological process of the young person and determine that he is properly on the way. **He will be asked what he thinks of it, what information he needs, what fears he has.** Some young people can be very anxious and hold tight to the reassuring environment of the department to slow down the passage to the adult world.



Possible fears in the transition

Transition to adulthood is a size-related stage, it puts a number of interrelated fears into perspective.



- ❖ The young person may fear losing a privileged, long-term relationship with his doctor and have feelings of abandonment, **sensing the end of a strong emotional and affective link** at a very sensitive time.
- ❖ The young person will have to change his world of care: "the transition from a world of Care Bears to a service that can come across as a very large, very cold and very sad machine". It can come across as dull when one is used to pale blue or pink, or metallic blue.
- ❖ Arriving in an adult department is also the **fear of being helpless**, clueless, out of place, being a mere number in a long list of patients, and living together with much older people whose condition looks awful or whose physical appearance is difficult to handle.

- ❖ Young people may fear that the adult doctor will not understand their illness or the more complex aspects of their particular condition, and may consider that the paediatrician is better placed to support them and give them suitably adapted medical and psycho-social advice.
- ❖ The young person can feel alone in assessing the quality of information on his illness, and feel that there is not enough on his medical file to properly trace his case and its specific features. Also, **the labour of memory can be a painful one**.
- ❖ Another anxiety is the sometimes strict time limits imposed on consultations in adult departments. The young person expects his doctor to develop relations of confidence with him beyond his medical needs, and to grant him **the time and flexibility needed for a global perception of who he is**. The young person will naturally expect his doctor to understand "that he is not just his illness", and to be interested in his ways of thinking, areas of interest, needs and plans.
- ❖ The "fear" of the future can create such a feeling of heaviness and "what's the use" that the young person **ceases to take care of himself and puts himself in danger**.



Educational work and therapeutic accompaniment

Educating a patient about treatment is to take his future in hand by **becoming actively involved in the treatment** when for a long period the young person has adopted a passive approach during the treatment process. Education about treatment will of course be very different depending on whether the treatment involves parenteral nutrition with catheter or implantable chamber, or enteral nutrition, usually with a gastrostomy. Add to that enterostomy care, and even bladder catheterization or other types of care for some patients.

As and when possible, **the young person will come to understand his illness or understand it in a new light**. He will acquire skills to help him understand the medical decisions concerning his health. Adolescents must understand the possibilities of treatment offered to them, and be encouraged to participate in the decision-making process.

Young people become decision-makers; they must develop knowledge of taking care of themselves, know their medical history and the risks and complications. They will learn to play an active and independent part in their care. By accepting instructions, **the young person will be truly informed and encouraged, and thus more prepared to follow the treatment plan**.



The life of an adult carries numerous and varied responsibilities, which assume the adult will behave with maturity, autonomy and perseverance. Moving to an adult department means you must act like an adult... scary! **If the young person does not fully understand the change, it may be useful to offer him an appointment with a psychologist, psychiatrist, psychotherapist or psychiatric practitioner to address questions of independence and explore his anxieties.**

The paediatrician allows about 18 months to prepare for this transition and ensure that the young person is "accompanied" as much as possible. It is desirable for the adult doctor to follow this progress through consultation reports. The reports will be sent to the parents, but the young person may read them. This will assure the young person that the important information and current data are well known to the future doctor.

Although this transition is always a challenge, as changing doctor can be trying after knowing him for 15 years, **there are measures designed to lessen the difficulties, one of the most important being education in treatment.**



“ He’s learning how to connect himself, he is the one who decided. He’s known how to disconnect himself since 16. About connecting, yes it is more complex, he’s starting to cope with it, but still with me or his Dad beside him. He knows what to do when his catheter is cracked or blocked. ”

Eliane, mother of Guillaume, aged 17.



❖ He must take the floor: whether in a paediatric or an adult department, **he will become master of his method of communication.** This means that he should not hesitate to ask questions, express anxieties and discuss things openly with the teams.

❖ The leaning of personal treatment measures is an **important means of increasing self-esteem and independence and allowing a young person to become a responsible adult.** If he manages his care better and better, his self-esteem will increase and the "separation-independence" transfer will be made easier.



“ Nicolas must pay close attention to his regime. He has known his regime for a year, and all the foods that he may or may not eat. When shopping with the educators, he explains things to them. He even went off on a week's skiing trip, without us. ”

Hélène, mother of Nicolas, aged 15.



“ Next year, in April, I'm going for training to get myself independent. That'll be in Paris. I can't wait to learn how to connect! ”

Pierre, 14 years 6 months.

“ ” Nicolas knows how to connect and disconnect. However he still makes mistakes when asked his weight, and I would like him to be able to talk more easily about his condition, which is flaminopathy A. This is a rare genetic disorder that gives Nicolas gastric, cardiac, respiratory, renal, orthopaedic and endocrine problems. ”

Nathalie, mother of Nicolas, aged 16

“ I don't want to depend on anyone any more. I want to be actively involved with my health. I think things will be good, I'll be able to travel. My mother's always nervous when I go away... One day, my sister invited me to go to Eurodisney, that was cool. It was my sister who took care of me, she's amazing. We went without our parents. ”

Guillaume, aged 17.



The acquisition and integration of treatment, and questions of observation, are a good scale that helps position the adolescent in terms of progress. He remembers all his medical history, the reports, certain danger signals, risks, emergency situations and details, although he could not quote the name of his treatment or the reaction of his body during the last three years consultations. **This is proof that he has progressed and that the educative work is doing its job; the young person is taking on the independence that adult treatment entails.**

The training and coordination nurse plays an essential role in this education work. Catherine Poisson, who does this job at the Necker Hospital, explains the training programme for young people on parenteral nutrition. The programme lasts for a year. It includes theoretical aspects: central catheter, mechanical risks, risks of infection, hygiene, hygiene of surrounding area, nutrition bag, pump &c. There are also practical aspects: methods of connection, dressings, action to take in cases of risk and emergencies, &c.

“ The basis followed is case-by-case. The young person must be followed according to his personal experience. For a young person particularly anxious to handle, start first of all with the practical aspects and then move onto the theory. Training may be personalised or in twos. ”

As the sessions progress, **the nurse meets with the parents to discuss the knowledge acquired.** The training sessions can take place during or outside school holidays; everything depends on the availability of the nurse and the young person.

“ ” It’s a new listening and the young person will doubtless learn in a different way from his parents, who were trained 15 years ago or longer. ”

On returning home, if the young person requires assistance it can be a good idea to call on a carer from outside the family circle, such as the **nurse trained by the home health service provider (PSAD).** This provider can also offer excellent support in steering young person towards close and involved accompaniment in the treatment. In this case, leave the teen in direct contact with the nurse.

“ The teen can stay for each session, 3 consecutive days and sleep in the family accommodation if he comes from the provinces. ”



How can parents help their child and the paediatric team?

Given that parents have devoted a lot of time to taking care of their child (in some cases, the sickness has taken them out of professional careers), they can sometimes find it difficult to let go, consider the child incapable of managing on his own, and even discourage his efforts to become independent.



“These children are assisted and sometimes left to go by themselves. Separation is not therefore easy.”

Jean-Daniel, father of Jules, aged 19.

The role of the parents is however essential for helping cut the thread and help the child take on his new areas of responsibility. **With their important role in the acquisition of independents, parents are also key allies of the medical team.**

“Pierre knows a lot more than he actually does. It is much easier when Mum takes care of everything, as she's been doing it for 14 years. On the other hand, it's true that when I hand everything over to him, things will be complicated for me!”

Violaine, mother of Pierre, 14 years 6 months.



“Thomas is currently learning how to connect; he's getting there, but he still needs to learn the order of the tubes. He can inject himself alone and manage his ostomy bags (ileostomy). I prepare the equipment for him, but that's just him being lazy; he knows what to do.

I have to remind him about his pills and the rules of hygiene linked to the care. We've always wanted him to be independent.

It's true that it's worrying at times, as we can no longer give him instructions in things medical.

But of course that's true in all things for all children.

I hope that he will not be adversely influenced by others, that he will know his limits and not go beyond them... but it's the experiences of life that will show him his limits.”

Catherine, mother of Thomas, aged 15.



Doctors are called on to help parents find a balance between their supervision and the independence that young people have to acquire regarding their care.

This is because parents are the ones who know their teens best, and do the same work as we do in preparing them for the transition to an adult world with all that this means in terms of academic and professional directions, administrative processes, finding somewhere to live &c. Parents also help them to grow up, their work is invaluable. During the previous transition, as the child reaches age 12-13, the paediatrician is already working with the mothers. He explains to the mothers that they are "too much on their child", that the child needs a "window" or an "opening" to grasp their illness by the reins, otherwise there will be problems in the years ahead. The mothers have too much quality, they are great at providing the care but their children remain very passive. Although they are a great support for the care teams, they must also be helped to make the transition. To do that, it is wise to choose together what the young person will manage, and the parents become controllers of what the child does to ensure his well-being.

From 12 to 13 onwards, when connecting, the child can prepare the equipment under parental supervision. The process is introduced very gradually, and it can take different lengths of time depending on whether the patient is a girl or a boy.

The parents must show their teen that they have every confidence in the paediatric team to prepare for the transition, and that they can pass on as much of this confidence as possible to the adult team.



Within the context of the transition, does the nutrition bag system change?

For **parenteral nutrition** in children, as they grow, the supports are regularly adapted. More than 90% of nutrition bags are "made to measure" by a designed, while for adults it's standard bags for more than 50% of patients. Adaptation is done according to level of dependency on parenteral supports and the presence of significant digestive loss (enterostomy). The drip equipment does not differ greatly between paediatric and adult disciplines.

For **enteral nutrition**, in order to cater better for nutritional requirements which change with age, there are products adapted for each age range: 0-1 years, 1-7 years, 7-16 years and over 16 years. It is important to use the right product, and therefore not keep using a child product for too long or move over too quickly to an adult product.

The adult range is generally very similar to the paediatric range with a formula adapted to the nutritional needs of adults. The bag system is unchanged. The few differences are found in the labels: the packages for paediatric products are more colourful and sometimes use pictograms to create a more appealing and children-friendly appearance.

Regarding the medical devices, the equipment is also identical, but there may be probes of different lengths and diameters. For very small children, very fine probes are used and the diameter often increases with age.

The industrial concerns have therefore designed their products to create a minimum of technical difficulties and facilitate the transition by avoiding changes of pattern for patients and their carers.



Arrival in adult services, an adaptation for everyone both above and below

Although the paediatric team and the child and his parents must adapt to this pivotal passage, the adult service teams are also mobilised. These teams may be very wary of getting it wrong, of being ill-equipped to welcome young adults, as they are better used to "mature" adults. **This transfer is, in truth, everybody's business. It can be eased by providing a human dimension and through mutual understanding of each person actively involved.**

Can the young person choose the most suitable moment for moving over to the adult world?

The moment for making the definitive translation can be a symbolic stage: obtaining a degree, starting an apprenticeship, another stage in active life. This can ease acceptance of the transaction and see it as part of a positive move forward. It must be ensured that none of the young person's priorities at that time compete with the management of his care.



Do I have the right to choose my future doctor and future hospital?

Yes. **This is a fundamental right, it is the free choice of the doctor and the hospital structure within the limit of availability of structures and respect for the regulatory framework.** Quite clearly one cannot choose a hospital for children after becoming an adult.

That said, young people who have been on therapeutic nutrition since childhood are patients with relatively rare conditions. Not everybody is capable of caring for them effectively and with a full knowledge of the case. As these rare conditions are often very complex, the paediatrician will be anxious to confide the young person in a doctor with an excellent knowledge of the subject.

Therefore, **the choice is made by a panel of doctors and specialist services.** The patients know the panel well, are very attached to the structure that they know and will not be taken care of by "just anyone". The paediatrician recommends them to doctors who treat adults within his network and will ensure proper transfer of the full medical file, not just an administrative transfer but a transfer of the whole of that young person's history.

The first consultation in an adult department

If not preceded by a joint consultation with the paediatrician and the adults' doctor, this is a consultation of the utmost importance. It is held with the parents present. The following are taken into consideration: the medical file (transferred upwards) and the state of mind of the young person and his parents. All the necessary explanations are given regarding the hospital structure in terms of infrastructure, organisation and function.



“ I trust my doctor to send me to the right place. ”

Guillaume, aged 17.



How do I deal with an emergency?

As already mentioned, an emergency situation must be properly anticipated, organised and explained. Certain communication "facilities" (telephone, which may be mobile, fax, e-mail &c) and organisational measures known in children's hospitals are not exactly the same in an adult environment. Things must be arranged so that the young person can be welcomed in a specialist environment and not in an emergency situation, which is often highly charged.

The young person must receive all information and know the means of communication for managing emergencies. The onus is on the adults' doctors to give them to him. The direct hospital telephone numbers for the doctor,

or for his secretary who will contact the doctor immediately, their e-mail addresses, and the details of the coordinating nurses, must be supplied. In case of admission, a decision to take or an advice to give, computer technology now allows easy access to the file by the whole of the multidisciplinary team.

The medical file

It brings together information formalised on a support, especially results of examinations, reports on consultations or interventions, prescriptions for treatment, and correspondence between health professionals.

Who can consult a medical file?

Several people may consult a patient's medical file. These include:

- the patient himself,
- the patient's legal representative if the patient is a minor or is of age and under tutorship (a person under guardianship can consult their own file),
- the patient's doctor if the patient or legal representative has chosen the doctor as intermediary,
- the patient's heirs after death, provided the reason for the request is given, and unless the patient expressed a wish to the contrary before death

How is the request made?

Request for access to the patient's file must be sent:

to the freelance health professional, or to the manager of the health establishment (such as the hospital), or to the person appointed by the manager for that purpose, or to the holder of the health data when they are not stored on site.

The recipient of the request shall verify the capacity of the applicant, establishing his identify and capacity of beneficiary of right of access to the file.

The period from communication to receipt of request is limited to:

- 8 days for a recent file,
- 2 months for a file on which the latest document is 5 years old.

What is the cost?

Consultation on site is free of charge.

When the applicant asks for copies to be sent, the costs arising to him may not exceed the cost of reproducing and where applicable sending the documents.

TO FIND OUT
MORE



03

BECOMING AN ADULT: DEVELOPMENT OF RISKY BEHAVIOUR AND FAILURE TO FOLLOW THE CARE

Getting into danger, a phenomenon that rises up during the transition

It is difficult, within the context of a chronic illness, to affirm that: "To grow is to accept the illness and also the limits that it imposes.", however, this is true. The corollary is the danger to which the young person in denial or non-compliance can expose himself. It is therefore during this period that young adult patients can put themselves in danger. **Why?**

To exist, to add spice to life? To harden themselves? To express an inner conflict? To test his limits and reliability and those of his family and society? To express his deep sense of suffering? Because nobody can understand him and everything seems unfair? To exercise his new critical spirit? To call parental authority into question? To express a defeatist view of the future? Because he feels crushed between the need to look after his health and his new responsibilities as an adult? Because he is depressed? To inflict suffering on a body that makes him suffer? To test a faulty body even more? Because of a feeling of all-powerfulness over the risk-taking? Through ignorance of the consequences of the risk run? To feel excited by playing a danger game? Because the daily treatment is seen as a burden? To hide up what makes him different from others?

Many different causes and origins can be envisaged; the situations listed in the following lines are possible variables that are useful as examples and possible areas for exploration.

It is essential to understand each situation, each environment separately and as a whole.



Unsuitable or counter-productive attitudes of parents

A painful preventive discussion, an excessively controlling attitude, and over protection, can give the young person a desire to ruin all the efforts that his parents have made in caring for him until now. Here, parents are hyper-controlling, almost intrusive, and shut the young person in... They can give him an unfair sense of guilt.

A parent who is too laid back, or lax, or absent while allowing the young person to do everything, does not address the real concerns of the young person or lead him into true freedom.

Failure to differentiate between generations which prevents the young person from distancing himself and bring considered in his own temporality.

All these behaviours can lead to loss of sense of responsibility in a person who will become an adolescent and then a young adult



A conflicted separation of the parents

If parents are in a constant state of tension and make their child a subject of rivalry, the situation can become explosive. The young person can decide to put himself at risk purely as a reaction to escape the conflict.

“Don't you see there are more important things than your war of nerves, your ups and downs, your "history of protection"?”

Risk-taking then becomes a way of pulling down the family edifice and asking questions that touch on the meaning of life.

Restrictions imposed by the illness

When becoming an adult, most young people both well and ill will look for a sense of belonging to groups outside the family. This means that they will transfer much of their attention from their family to their friends.

Patients with chronic illnesses can experience difficulty in creating or keeping friendships because of stays in hospital, frequent doctors' appointments and restrictions imposed by the illness. This "absenteeism" can cause social isolation, and as a reaction to that, anything that interferes with times of sharing or going out with friends.



Physical appearance

Adolescents can be very anxious about their physical appearance, pubertal development and level of sexual maturity. Adolescents with a chronic illness can be more afraid of suffering delayed pubertal development or physical abnormalities. **Physical changes linked with the treatment** (such as body odour, hirsutism or acne) **may occur**. Young people may also be greatly inconvenienced because of their apparatus: gastrostomy, probe, catheter, fistula, exit stoma &c. All these are factors that can increase anxiety caused by body image and undermine self-esteem, and can lead to withdrawal and rejection of treatment needed.



“ An adolescent has a new representation of his body. Aesthetic, sensual and sexual perception may be undermined by medicine. It can be very difficult to bear a prosthesis, which he sees as an intrusion into his body. ”

Dr Pierre Canoui.

The double betrayal of the body

When one becomes an adult, the transformation can be seen as an initial betrayal. More than that, however, the illness, the care and the equipment can also pose difficulties, like a double betrayal.





First woes and sorrows

“She left me because I’m not well, there’s no doubt!”

The illness can become the cause of every woe, sorrow and trouble.

The young person can decide to let everything go as though he is not, and never has been, ill.

The death of a friend

Young people with a chronic illness may be confronted with mourning a friend suffering from the same condition or another condition that has brought them together for several years within the paediatric department.

The loss of this friend, and **the negation of the possibility of their own death, can also lead to risky behaviour.**

Academic "disappointment"

A young person who had planned on long-term further education and now sees his dreams evaporate, either because he realises that he does not have the required aptitude or because the illness holds him back, may decide to stop taking his treatment.

The fact that the illness imposes restrictions can become unbearable and lead to withdrawal from treatment.

“If I wasn’t ill, I wouldn’t be rejected therefore I wouldn’t fail again!”
This is the childish effect of the magic thought, the equation of avoiding the illness
“I don’t care for myself because I don’t see myself as ill any more, and therefore all my troubles will disappear!”



The realities of adult life, period of disillusionment

When we become adults, we can discover that we've been lied to for years! Yes, I thought that as an adult I could do what I wanted, when I wanted, the way I wanted, with whom I wanted and anywhere... the horizons were limitless and boundless.

But at this moment in life, reality catches up and we can no longer do what we want, only what we can.

Life is not that simple, it is made up of duties and constraints. In order to realise ambitions, a certain number of criteria must be fulfilled, and sometimes this is not possible.

We therefore have to ditch the dreams and lose a certain level of naivety; and that is very painful!



“ I therefore have to lead a life that is ultimately less interesting than I thought it would be, the life offered to me is not as exciting as that one, therefore I'm going to stop my treatment! ”



To do like the others

As though risky behaviour allows better integration, adoption of rituals and membership of a group of contemporaries (a band) that looks to oppose the established order, cross forbidden boundaries and trigger aggression...

Priorities difficult to define

Dealing with the illness and its treatment can interfere more and more with other priorities such as leaving home, entering university or starting a first job.

Faced with all these priorities, young people can feel completely overwhelmed and incapable of managing their illness and their new responsibilities as an adult at the same time. Finding the right balance can sometimes be very painful and certain crucial aspects of care may be missed.



Budgetary pressures

When leaving the family home, one is confronted with a whole range of needs that hitherto have been satisfied by parents: rent, food, clothing, insurance costs, transport, administration and banking. This new financial responsibility can be very unsettling and frightening. Young people can feel incapable of taking on these new obligations, and under the pressure they may fail to care for themselves, an additional pressure that has to be faced.



“When you're between 16 and 21, a lot happens in life: school, first apartment, love, friends. Strict compliance with the restrictions of treatment is not necessarily on the list of priorities. Then, if you stop going to your appointments, nobody will come running after you like they did in the children's hospital. You can feel lost.”



What is risky behaviour?

- ❖ stopping care
- ❖ lack of respect for ways of preventing sepsis
- ❖ not observing protocols or duration of treatment
- ❖ deviant or unprotected sex
- ❖ excessive sports
- ❖ dangerous conduct in motor vehicles
- ❖ consumption of drugs, toxic substances or alcohol
- ❖ "binge drinking" (drinking oneself insensible)
- ❖ attacks on one's body: wild piercings, self-harm
- ❖ abandonment of plans
- ❖ social marginalisation
- ❖ ...

“ I’ve taken risks, not with connecting but with the medicines. Nobody ever really knew. Then I knew that I had to stop, because when I missed a connection, I paid the price and afterwards I was tired and dehydrated... ”

Morgane, aged 37



“ I was a rebel at age 15. I didn’t want to care for myself any longer as it stopped me from going out... and I was fed up with the treatments. Sometimes I wouldn’t take the medicines, I was very devious and an expert at hiding things. . I didn’t play with my life but sometimes I didn’t connect in the evening, I didn’t want to; I always told myself ” I’ve had one year off the treatment” , so I imagined it was actually possible. ”

Adeline, aged 27

With artificial nutrition, it is realised that risk-taking is relative. Children need to experiment to test their limits, but to be very sensible about it.



“ I’ve already had drinks at Christmas time, I know my limits. I’ll be sensible, I won’t put myself in danger, I don’t want to be on the sidelines. I must be able to work. ”

Thomas, aged 15.



“ I can’t do paint balling. I won’t put myself in danger. I’ll do everything I can to live my life to the full without running risks. ”

Guillaume, aged 17.

When in a state of anguish and fear, several valuable support points can be helpful

What can be done to reduce the periods that mix fear and endangerment, withdrawal and severance of treatment, daring and "threatening oneself"?

Parents

Listen to the child and his emotional states. Be there, not all the time but often enough. So that when destructive thoughts or behaviours rear their ugly heads, one can talk about them before acting on them.

So that the child knows someone is there for him. Continue to surround and not let go, while taking care not to become invasive.

This does not mean stifling, but continuing with the dialogue, it means not making him feel guilty and not dramatising, as risk-taking is his initiative and will help forge his personality. Even if the young person has a reputation as a trouble maker, calls everything into question, and seeks confrontation instead of compliance, parents must accept that a degree of tension will be sent their way.

They must provide reassurance, comfort and security on the way to independence.

Without that security and the sincerely expressed affection, children can feel abandoned. They must respond to the call and confirm their presence and support.

To stop the risk-taking, it is essential to relaunch motivation, help the child to find an interest in which to engage, and actively join in with it.

To exist in society is to be able to be there alone, face it and get on without anyone holding our hand. This is the only definitive proof that we have reached the shores of the adult world. One therefore has to fear, draw back. Parents have a key role, they must be capable of encouraging their child to go forward without fearing what might be seen as hardness. **Encourage the abandonment of certain dreams and facing up to reality is an indicator of confidence between parents and child.**





A few good friends

During this time, groups of contemporaries are powerful agents in both socialisation and support, and their function complements that of the family unit.

During the illness and its treatment, "buddies" can play a very important role in keeping the young person in the best possible condition.

This group may be best friends or the group that the young person hangs around with. Of these, some who are more "group leaders" than the others can act as interpreters and ensure that proper attention is paid to their sick friend and that he enjoys activities and trips out in keeping with his patterns and possibilities. To sum up, **these are reliable people with a responsible attitude, who ensure that collective times are arranged so that their friend can take part in them.**

This is the **way of giving them a taste for tomorrow:** make choices for the future and draw satisfaction from them.

From an academic viewpoint, this may involve steering and supporting them along alternative routes that they had not thought of. This could also involve helping draw up new professional plans just as satisfying as those being "mourned".

Parents can also prove reliable friends and provide strong support and thus help the child be a positive influence and empathise, as well as forming part of the process of encouraging the young person and reactivating their desires. They can also ask any tenant with whom the child lives to check to see that all is well.



The doctor

As a rule, the doctor will understand things quickly.

“ We feel these difficult moments in life, it's part of the human dimension needed to practise a certain level of medicine. We find out about them through alarm signals that have to be picked up: a lad who turns his head, who does not answer questions, who thinks about other things. This level of empathy is essential. This is the job of a doctor. ”

Dr Robert Janer.

The doctor will compare the consultation times to determine whether his feelings are confirmed. If this is the case, **he will monitor his patient closely to determine whether the signs are transient or if the young person is "sinking"**. When the signs persist, admission to hospital and the assistance of a social worker or psychological help will be suggested.

“ When I was troubled, I told my best friend Shéhérazade about it, she was my confidante. ”

Morgane, aged 37.

“ I have a protective friend who's close to me, he knows my illness and makes sure I take my pills properly, he has been with me for three years now. He's got medical history, he's in remission for leukaemia. ”

Thomas, aged 15.

“ Quentin's always been with me since year six, I tell him everything, he's super-kind. He's there, he protects me. ”

Guillaume, aged 17.



A therapist, psychologist or psychiatrist

Excess shyness, isolation, feeling of rejection, self-absorption, recurrent somatic symptoms, behavioural problems and risky behaviour are all symptoms that express a malaise and a need to be accompanied.

It is essential for those close to a young adult to ensure that he is heard, as if well-being is lost a specialist should be consulted.

“ Look at yourself and your surroundings, things don't seem to be going too well. ”

Thus, the young person, either because he feels it or because he is encouraged by those close to him, can be monitored. These consultations are first and foremost protected times during which the young person's suffering and sense of unease can be expressed and listened to without being judged. By stating what he is feeling, he can understand his behaviour and become aware of and make sense of his problems. He can also discover the kind of adult he wants to become. Understanding the difficulties is the first step towards finding possible solutions. **The therapist is there to guide him and help him find his own way; he will try to understand it in all its complexity with kindness and neutrality, the personal commitment of a psychotherapist, and an empathy that is at the heart of the relationship of psychological assistance.**

Professional secrecy is an essential part of the relationship forged by a psychotherapist; he is the one who can unlock the words and access the young person's innermost thoughts.

A "relay" adult

There is a movement of distance in relation to the family unit; it is a time when identification with one's parents becomes less clearly defined. **The young person can therefore look to lean on an adult "friend" who becomes his "reference point" at that time.**

“ I believe strongly in meetings between teenagers and adults; it could be a nurse, a sports teacher, a music teacher, a friend's father, or an uncle or aunt, somebody who is present during this "no-man's land" period. To sum up, any adult with whom the teenager can identify. ”

Dr Nolven Rouvière.



The social networks

Do social networks create isolation? Is this not a bit too glib? Or something of a cliché?

On the contrary; thanks to the Internet, young people can find the testimonies of other patients, feel reassured by reading about their experience, exchange with them, &c.



The feeling of discouragement in the face of the illness can be reduced by **belonging to a community**, a safe place in which patients can express themselves and feel understood. When pain is very much apparent, these exchanges are highly beneficial for the patients; they help them express what they are feeling, especially when they don't complain. They can even feel highly valued and very active when they are seen as **"expert patients"**, providing information regularly within their community. There are networks dedicated to chronic conditions in France.



According to Michael Stora, psychologist, psychoanalyst and co-founder of the Digital World Observatory of Human Science, **there are advantages in these systems, which have now become unavoidable for the new generations born into a world of social networks.** They provide a kind of great mirror which can neutralise doubts, fears and more or less self-centred wounds &c. It's also a test of truth when their post flops... makes you grow up!

“ They can look in the virtual for sources of feeling valued that reality does not offer them. Obviously there is still a risk that nobody will react when they open a link that looks good. The thing of interest is that a shy or inhibited person can make use of this space to lose their inhibitions and find more success with Facebook or their blog, or on Twitter, than the one who is leader. ”



Patients' associations

They are there to bring patients out of their isolation, inform them, protect their rights and give them practical help. Their meetings and discussion groups are special exchange places in which people can meet, understand each other, offload fears, find solutions for adapting and develop solidarity. **Thanks to these associations, you can make a circle of friends who've been through the same trials and similar treatments, and share things more easily and without a sense of taboo.** It is a valuable space to be and feel your peers lifting you up. There are numerous associations according to the patient's condition. **On the subject of therapeutic nutrition, the association La Vie Par un Fil, created in 1987**, brings together young people and adults on the subject of enteral and parenteral nutrition. The patients and their families come together at a holiday camp once a year, in May, to share experiences and initiatives and offer advice, and also meet several times a year in regional groups to develop relations and assistance.

Houses for Teenagers (MDA)

There are "Houses for Teenagers" (MDA in French) designed for people aged 11-25 years and their close relatives. One can be found in every Department.

It is a place where one can feel welcome, express themselves and find advice on everything to do with young people in matters of health, relations (family, friends), sexuality, school, ill-feeling &c.

The MDA provides rapid responses suited to teenagers and their families. Their activity complements that of the health establishments. In the MDA, health is considered in physical, psychological, relational, social and educative terms. Each MDA is a small system that mobilises professionals from various practices: doctors, nurses, psychologists, educators, social workers and others.

Consultations are without appointment and free of charge, and may be anonymous if the young person wishes. Parental authorisation is not obligatory.

<http://www.social-sante.gouv.fr/espaces,770/famille,774/dossiers,725/protection-de-l-enfant-et-de-l,1112/la-sante-des-adolescents-et-des,1266/les-maisons-des-adolescents,1798/les-maisons-des-adolescents,5537.html>



<http://www.lavieparunfil.com/1/la-vie-par-un-fil/>

A National 1901 Law Association recognised as being of general interest to children and adults in matters of enteral and parenteral nutrition at home.

The association "**La Vie par un Fil**" has the following aims:

- Overcome isolation of families
- Provide information on artificial nutrition, the infrastructures in place and administrative issues
- Bring in mutual aid and facilitate links with the medical profession
- Energise and relieve families
- Favour academic and social integration.

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04



THE TRANSFER: EXPERIENCES, PREDICTIONS & SUGGESTIONS

Through a few testimonies from patients and carers, we have been given a better insight into how the transition is lived through from the inside, how it is perceived and understood. Each conversation proves that there is no clear-cut route, no rigid recipe; the reaction can be completely pessimistic or completely optimistic. However, in the light of these differing experiences, certain areas for improvement and common suggestions are worth sharing in order to shed light on forthcoming transitions.

.....> Testimonies of patients

Morgane,
on parenteral and enteral nutrition, aged 37

“ ... In the paediatric department, the nurses are very kind, they mother us and we feel really pampered. Apart from that all-enveloping feeling, there’s an activity area where you can meet with young people from different departments and take part in all sorts of activities: ping-pong, card games, photography and plastic art workshops, billiards, table football, a music room, and a computer area. There were evenings organised as well - karaoke, theatre and concerts. When I arrived in the adult department, there was nothing.

My paediatrician got in touch with the adults’ doctor and I went to the adult department with the departmental head and a friend. **I was nervous and didn’t say much.** However, unlike many other 18-year-olds, I enjoyed my transition. There are lots of old people but that doesn’t bother me. They tell me their stories and I meet their children... But it’s true that **when you’re 18, and see a person who’s even 40, that looks terribly old...**

What I really missed was the leisure area, one like we had in the paediatric department. All the adults had only a cafeteria.

What was actually difficult **was losing touch with friends two or three years younger** than us, whom we’ve never seen again... ”



Adeline,
on parenteral and enteral nutrition, aged 27.

“

... **Teenagers must be accompanied and not allowed to go it alone, as a feeling of isolation can set in very quickly.** For my part, things did not go very well. I was 21. **I didn't feel properly oriented and I even looked for another adult doctor.** In my opinion, the way my case was handled was too lax. My paediatrician simply wrote a letter of recommendation and I had to re-explain everything that happened since I was born. It was me who called to arrange the appointment, and I wasn't accompanied. **I discovered a whole new world all by myself.**

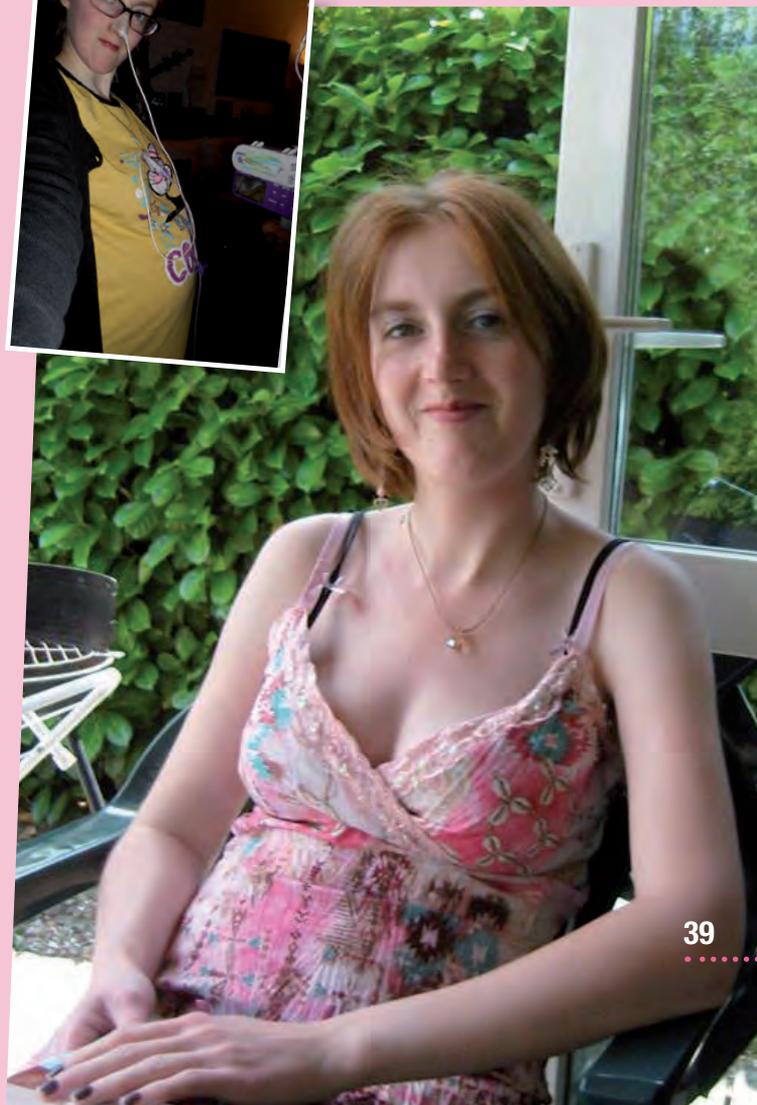
I had the feeling that the doctor I met with was only renewing my prescription, nothing more. **The appointment lasted 5-10 minutes: a blood sample, no particular problems, renewal of prescription, that was it! I felt that the care was neither human nor specific nor indeed comprehensive...** I was very disappointed at the start. After 18 months I asked to change doctors, I took the initiative that time. I looked around me, I'm a friend of some patients. By chance I signed up for a forum and got in touch with a boy of my age. He talked about a doctor who cared and paid a lot of attention. I managed to find the "right doctor", that is, the one who really listened to me and asked me all sorts of questions. To start with, it's a lady doctor, and I feel more at ease. Her care covers everything: she asks me how I'm feeling, which is very important because that can affect the treatment, my love life, news from my husband, our quality of life &c.

Whether the transition was from teenager to adult or child to teenager, it's not been easy. In fact, when I was even younger, for example, there was no real education on treatment available. **They explained to my parents but never to me direct,** so that from age eleven onwards I started taking care of myself all alone. The paediatrician saw my mother to ask questions about how I was handling the transition, but I couldn't understand what he was saying, his words weren't suitable.

Now, when I'm faced with a problem, I can easily talk to my doctor's secretary and also to my home health service provider when he's on call. Also, **the nurses and dieticians working with my service provider have been a huge help when I've asked them technical questions over the telephone.** I could be anxious about my flows, or my Port-a-Cath... they listened to me really well and their answers were really useful. I can really count on them.

About administrative procedures, it's my Mum who deals with those - they don't help at the adult hospital.

”



Florent

on parenteral nutrition, aged 28.

“ In the paediatric department, I had all the best, top-class equipment. Pumps that worked, perfect tubings.

Michèle Lamor taught me everything in 3 weeks, and she was tough, but amazing.

My parents were assistants and I was the surgeon.

When I arrived at the adult hospital there were hundred-year-old pumps, no automatic stages. I had to pass 3.5 litres in a minimum of 12 hours. I had to redo all my stages calculations. It was very hard going, everything had to start again from zero



I would have like to be listened to more. They knew everything in that adult department. 10 years on and their methods are totally antiquated.

Sometimes I get worn down, even though I don't usually; but when the whole thing stinks, I tell them what's on my heart.

The two hospitals should be in contact with each other, call each other, ask each other questions on whether all's well.

It was a complete break... ”





→ Testimonies of carers

“ ... You get the call one to three years before the final transfer. In practice, **everyone finds things difficult**: the young person, the family, the doctors, the whole team. There's a level of nervousness as the young person coming in is very used to his paediatric department. In Necker, for example, there's the Plein Ciel activity area; then they arrive at Beaujon and there's nothing. Everyone dresses and speaks formally... **It can be pretty harsh**. You can feel really lost when you first stay in hospital as an adult. And there are **moments of anger that burst out as well**. You need a lot of time to get confident with the new team.

But arriving in the adult section is **also a positive step**. It's a time for **opening up to others**. You have to open up to other patients with other diseases, other disabilities... People help each **other**. This transition, it's **like a door that you open up to life**. Most often, the transition means getting independence and a new type of freedom. We talk about therapeutic education, complete independence in terms of care, which is possible for young adults who can now connect and disconnect all by themselves if they wish. Sometimes I'm amazed to see a young person, completely independent, continuing to have one of his parents do some of the technical care. It's probably part of the transition you have to make from teenage years, wanting to be free but still to be fussed over by parents sometimes. You probably have to respect this transition time, but the independence is a real step towards the future as an adult. How can you envisage leaving home, starting a family, finding a job, studying or training, or simply going out with friends, if Mum or Dad are always there to prepare things, help you, even do the care? This can be a difficult period for parents, who when they lose the role as their child's "carer", can feel a bit lost and redundant, but it's a compulsory passage for every parent who watches their child grow up.

With adults, it's true there are fewer means, fewer resources. Overall patient numbers are more important than in paediatrics. **But we are not uncontrolled**. We respect the protocols started in the paediatric department, and really make the effort to prepare in advance for the arrival of a new patient. I've had husbands, wives, parents or a trusted friend on some consultations. It's important to welcome them, but I always request some consultation time alone with the patient. You have to touch on many subjects that are more or less delicate, which can't be discussed with parents in tow, such as sexuality, contraception or addiction, but there are also issues connected with the administrative change. An adult looking for an apartment, or a job, that's not always obvious... You don't always know how to help them, you keep resorting to social workers. You also have to be vigilant; people can feel abandoned if they're very anxious, you really have to avoid these feelings. Another area of caution is when the young person has siblings. **The transition to and arrival in adulthood can really upset families**, with breakdown or separation... -You must be able to talk about it.

I also see cases of people refusing to become independent. Sometimes the parent of a 25-year-old will stay in the room while the care is provided, saying "I'm there just in case, I won't do anything". No doubt it's just to reassure them, but we have to envisage young people alone at home. One of the big problems during transition is how to keep doctors and everyone else involved in touch? This means **setting up a network** as there are no multidisciplinary appointments. However, there may be collaboration between teams: such as a surgeon coming into the adult department because he knows the young person very well, having operated on him several times. Joint consultations can provide room for systematic reflection as when the young person sees us all together, we speak with the same voice even if we don't do everything in the same way. ”

Francisca Joly,
Professor of Nutrition, Gastroenterologist at CHU Beaujon in Clichy,
Manager of Approved Centre for Parenteral Nutrition at Home.

“

...In my generation of doctors, we worked only in the field of paediatrics. When I reached 24 I knew only paediatrics, not the world of adults. We immersed ourselves in the world of children. We always spoke to them as children. We don't realise what a shock the transition can be.

There are no guide or instructions, it's not taught in the universities. It's a theme to work on and develop with the families.

Our duty as paediatricians is to "help children growing well". To help teenagers in all the things that confront them, such as contraception. To help them manage their care, which is only possible if the parents accept the delegation and the young person wants to do it. Do they always want their hands free?

Another problem linked with the transition is financial issues. Parents worry about "How will things go when my child reaches 18, who gets the benefits and how can we help them get them? ... ”

Cécile Lambe,
Paediatrician, Approved PNAH Centre
Necker Hospital for Sick Children, Paris



“

... A teenager can be a complicated person, who may reject, deviate or test... There are problems of self-image, of independence from parents... For us, they are our babies, we don't want to let them go, **we cocoon them**. It's difficult when you don't think they're responsible enough, and also difficult to ask parents to let go of the reins. ”

Virginie Duval,
Coordinating Nursery Nurse, CHRU de Lille.

“

...The transition can appear easier when you're on enteral... but this view is too simplistic, as the illness is sometimes complicated especially when there are multiple disabilities. Transition is a sensitive stage whether you're on enteral or parenteral nutrition.

You need associations, especially for these rare conditions... They are an invaluable source of mutual aid. And they can wield considerable power with public authorities. ”

Dominique Guimber,
Paediatric Gastroenterologist at CHRU Lille
Approved PNAH Centre



Suggestions of any kind

- ❖ Young people develop a long-term emotional bond with their paediatrician, one not limited to a simple presentation of medical facts and treatment guidelines. A consultation may touch on development of skills to help the young person address a wide range of daily problems directly or indirectly linked to his or her illness: prevention, friends, school, choosing a job, contraception &c. This kind of support seems to get less when you enter the adult care world. Interactions concentrate more on medical aspects than on psychosocial aspects. Taking the time to get an **overall view of one's situation**. We are not talking to an individual in general, but a unique person. You need to know who they are, how they act, what worries them, what life plans they have...
- ❖ The care teams and those close to the young person must ask him questions on his **surroundings and relations with friends**, in order to ensure that he is making and retaining friendships that are invaluable at that time of life.
- ❖ Both parents and medical teams must encourage young people to become as independent as possible while taking account of an **objective assessment of their capacities and limitations**...
- ❖ The care teams **may help the teachers to understand the patient's state** and facilitate his or her integration and the monitoring of his school programme. They must also help parents foster realistic **expectations with regard to the academic achievements** of their teenage with a chronic illness.
- ❖ Touching **on the question of the young person's sexuality**, with respect for their level of maturity, is fundamental. Parents must help the young person discuss it with a third party, who may be the doctor, a therapist, a gynaecologist or the general practitioner. This will help the young person ask questions about his sexuality (whether or not sexually active), sexual orientation and activities, and about what constitutes physical or sexual abuse. This is also the moment to answer questions on what kinds of contraception are compatible with his illness and treatment, sexually transmitted diseases, the hereditary aspects of his condition, pregnancy, the effects of the condition on pregnancy &c. These questions must be discussed with the doctor without the parents present.
- ❖ Why not suggest visiting **the adult department building accompanied by somebody who transferred from the paediatric department** one or two years ago and can guide and reassure the young person?. Individual and group sessions aimed at helping young adults to get to know and help each other.
- ❖ The adult departments can have a space dedicated to young people; this may be a sheltered meeting area, or a coffee machine where they can all meet and come together. These moments of relaxation are essential as they provide young people with an opportunity to express their fears and anxieties and share their experiences freely.
- ❖ The care teams and the parents must **find out about organisations, help groups and patients' associations** who could support the young person.
- ❖ For young people with altered physical appearance, why not seek professional advice on hairdressing, make-up, clothes &c?
- ❖ To **make the administrative processes easier**, the parents must lock their child's files and prepare for the transfer with papers complete and up to date.
- ❖ The La Vie Par un Fil association proposes **organising and leading groups of teenagers in the hospitals** with adult participants who have already crossed the threshold.



05

COUPLES,
INTIMACY
AND SEXUALITY

The time at which the transition from teenager to adult occurs is also that of the first feelings of love, of becoming one of a couple, of breakups with varying levels of pain. It is also the time of questions about love, the meaning of love, communication between two people in love, seduction, intimacy, libido, complicity, sexual flourishing, whether or not the feelings will last.

During the discovery, initiation or development phase, one's **love life is a great concern for the vast majority of young people:** they are, have been, or dream of being, in love. A love relationship usually produces pleasure, can lead to disappointment and sadness, and is most of-

ten **a very important and special form or training.** In particular, it helps the process of **socialisation through discovery of another and methods of appropriate interaction with another.** In addition, young people learn how to select a partner progressively by assessing the positive or negative aspects of their experiences. The relationship is **also a source of self-esteem,** showing that one is able to reach a partner and thus confirm that you are desirable. It also encourages commitment to emotional and physical intimacy, clarification followed by affirmation of **one's sexual identity.**

At present, and without prejudging anyone socially, the generation aged 16-21 acts very much on impulse, with easy changes of accommodation, place of study, job &c. Against this moving background, a couple can become a sesame, a place of refuge and feeling valued, especially as young people are often confronted with divorce in their families.

Their wish is therefore for stable and durable relationships. This wish is often very difficult to satisfy. What happens when you're young and have to carry a gastrotomy, a catheter, a stoma or any other item of equipment? **What can be done at connection time, or when you have to rest? What of the fear of having an emergency?** How does one talk about it, how can the spontaneity of impulse be maintained? **How can a mutual and balanced relationship be maintained** without turning it into a patient-carer relationship?





“ I’m scared of getting intimate with a girl, scared of her reactions, scared that she’ll react badly, or be frightened or surprised, that she’ll reject me. ”

Guillaume, aged 17.

The commonest challenges involve communication and intimacy.

Communication and romantic encounters

When is it best to discuss nutrition methods with a new partner?

This is a sensitive question as there is no ready advice to offer, no stock response. We can leave out short-lived adventures in which there is no point in going further in matters of confidence.

Some people talk about it early, directly and frankly, in order to elicit a reaction, even the worst possible one. Others decide to talk about it progressively and gently. Some mention it indirectly by referring to a person close to them, in order to "test the terrain" and protect themselves against a rejection that may be taken badly. Finally, others take a long time over it.

When the subject is broached quickly, it can be problematic as the couple do not yet know each other well enough. Time is needed to learn to discover each other, open up and attach to each other. On the other hand, if the special person is told late, they may feel cheated or betrayed and become suspicious.

The question is undoubtedly one of the right measure, and this will vary from couple to couple according to each person's history, personality and communication skills.

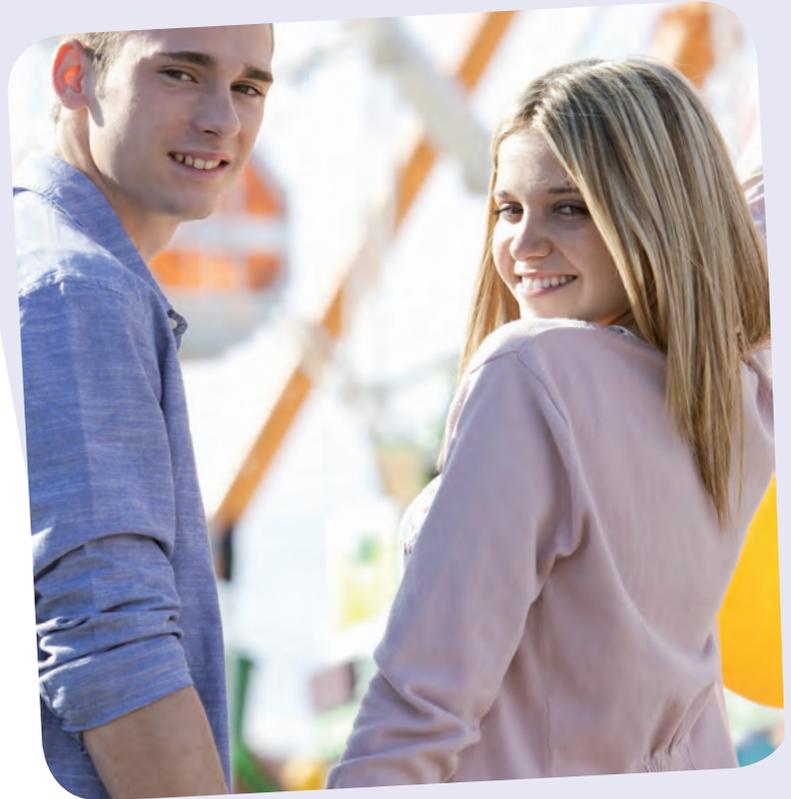
“ Before going out with a guy, I talk to him several times. At the start you don't explain everything, don't frighten him, don't go into too much detail. If he agrees to meet you, and he doesn't run for it, you explain a little more to him. It doesn't happen from one day to the next. ”

Morgane, aged 37.



Initiating open communication

At the start of a relationship, **it is true that declaring one's illness and method of nutrition can be an enormous challenge, simply because it appears to "spoil the atmosphere"**. One's history of illness and daily contingencies are unwanted guests. So how to mention it? It's not very romantic! Being different can frighten people and send them running. After doing everything to achieve a balanced social life and strong confidence, you don't want to ruin the chances of a beautiful encounter. **However, although declaring it can be risky, it also helps determine whether the other person is close or remote.** A couple, even in the earliest stages, must agree to discuss their respective life plans in order to better define their priorities and shared objectives. **A couple must manage the realities of life and be aware of them to survive.** Husbands and wives must share everyday things and face the tests rather than be crushed under fears and obstacles.



Open communication is therefore a great way of finding out what is really important and less important to the couple.

Dialogue on this matter is a normal stage. Self-revelation consists of speaking to the other person, telling them what happens in their inner world or their secret garden. **Self-revelation involves, in one way or another, opening up to another. It is a good indicator of the level of intimacy expected when a relationship starts.** It is not because talking about the way one feeds oneself requires any depth of exchange, or adds weight to the lightness of the first months or dulls the magic of romance or the sparkle in the eyes.



From coming together to choosing...

When two people meet, it is a shock of love, they are in a state of idealisation, of coming together. You tend to look at the one you love through rose-tinted spectacles, live only for the moments of intensity and exaltation in love... and then comes the time to choose. It does not mean that everything was great and wonderful and then all becomes dullness and disillusionment. It means that the love relationship is established if the couple decide to confront their differences and move forward together. A couple's love is a matter of decision and willingness, way beyond the vagaries of moods and emotion, of image, of appearance. You choose to build within reality. It suggests that one has developed sufficient skill to accept a partner as they really are. **The couple decide to create a space common to them without losing their vital personal spaces.**

What is the best way to discuss nutrition methods with a new partner?

The way to say it

Finding the right words without frightening the other person is hard. There is no universal response. Here are a few formulations worked out from testimonies obtained within the context of writing on this subject.



“ I eat normally but I digest very little of what I eat. When I was a child, I had an operation at age 9 and most of my large intestine was taken out... I have problems with digestion and to compensate for that, I take perfusion. I show him my fistula... ”

Yasmine, aged 39.

“ I explain that it's a problem with my intestines and I've had to have several operations. As I've had several operations, I don't have much intestine left and I can't digest food like everyone else. I have to have infusions in the night. I don't talk about connecting but about having a perfusion, because the word "connection" suggests that I'm connecting to the mains like one of those electric cars! I explain that I have an implantable chamber and that it can't be seen, I invite him to touch it if he wishes. I also tell him that I'm fed through bags that contain vitamins, trace elements and so on... everything I need to live normally like he does. ”

Morgane, aged 37.



Truth brings couples closer

Genuine communication at the start of the relationship suggests that the tense feelings experienced when the declaration is made will be considered.

The person who is not ill can:

- feel the fear of seeing the other person shrink and die
- feel insecure and destabilised
- feel guilty about being healthy
- not want to take on the responsibilities of a carer
- fear being no longer able to have a good time, laugh or relax if the other person cannot join in
- fear excessive emotional demands
- not feel up to it
- be in denial

The illness can reject, block, disarm a person and give them a certain feeling of powerlessness.

Talking about one's illness and treatments to a person you have just met makes you vulnerable. You legitimately fear being rejected and left. Talking about therefore provides reassurance against that fear. And if there are reactions of fear, pain, discomfort, anger, shame or guilt, **the partner can provide evidence of understanding, sensitivity and kindness.**

In a certain way, **it also helps sort those who "are" from those who merely "appear".**

This helps make a better choice of potential partner and determine whether you can open up more.

Discovering openness and genuineness helps truly create a foundation of confidence and can lead to a whole wealth of feeling.

Learning to express yourself well encourages further revelation and progression of one person towards the other.

The person who is ill can:

- prefer to break up rather than spoil the other person's life or tie them down
- want to separate in order not to make the other person suffer or feel their pity or be cared for out of a sense of duty
- feel that they are a burden

- ❖ Don't be afraid that the relationship won't be strong enough to bear being frank
- ❖ Don't be afraid that a frank discussion will affect the person's state of health
- ❖ Silence is not a good strategy



When illness draws near...

It must be realised that illness, at whatever age, can draw a couple closer, unite them. Facing things together, being open about them, can be a first experience that helps the couple and their love grow by reinforcing the links that are forged over time. It is also because each person will express their needs, expectations and fears that the couple can talk about the future and plans both big and small.

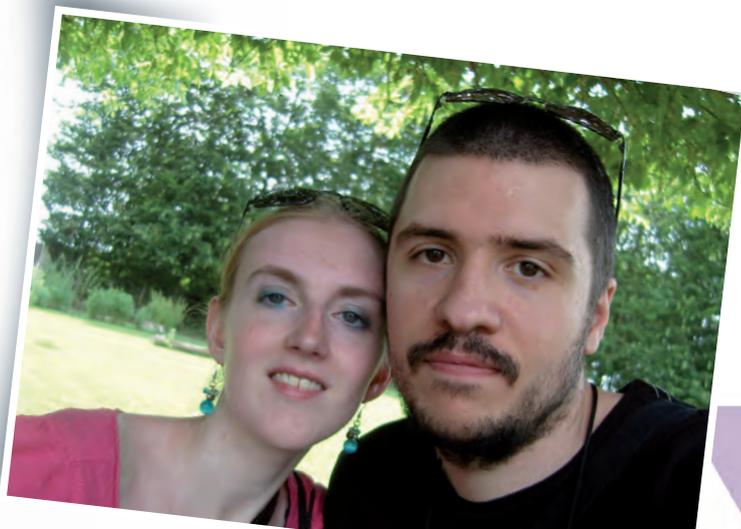
Sexuality is also a releaser of words

Sexuality can be involved in the decision to talk about things. Many questions may arise: how will my partner view my body? My scars? Will things happen naturally? Will my partner be afraid of hurting me? Of touching me? If he wants a tender moment and I'm tired, how will he react?

However, it can also be a great source of togetherness, tenderness and kindness that encourages openness.

“Before, I used to ask myself how I would find someone to accept me the way I am, with the perfusions... it's not easy to admit... but finally everything happened naturally.”

Adeline, aged 27.



“We laugh a lot. I tell him that if you touch me and I don't cry out, that's because it doesn't hurt. We take the drama out of the situation. Nutrition is not in itself a hindrance.”

Morgane, aged 37.

“I don't like being touched on the scars very much, I don't like being caressed in those areas, I tell him that's enough, that's all.”

Adeline, aged 27.

The role of parents

- Every teenager, sick or otherwise, ask themselves questions about relationships, regardless of sexual orientation, and about intimacy. Parents can play very different roles:
- A child learns by observing his parents' behaviour. If parents or adults switch off the television or interrupt a film show as soon as a couple approaches, a message that this is "forbidden" or "unnatural" will be inculcated. It is therefore important to face and address questions about intimacy, without however pre-empting the child's thought processes by providing answers to questions that he has not yet asked.
- Establish an atmosphere of confidence and relaxation around this type of subject, so that the young person can progress on his journey without problems or complications. He will therefore know that when he wants to talk sexuality, it will be possible and at his own pace.
- The young person will not necessarily go to members of his family to raise these questions. The parent must therefore suggest that the child find the information out from persons or places where he can easily find responses: a doctor in whom he trusts, a specific public information service, family planning &c.
- The illness and its treatment are additional points that both parents and young people must take into consideration in searches for information, orientations and exchanges.



Will a new partner becoming a carer?

In a couple, each person is the other's companion and fellow traveller. A partner must therefore become not a carer, but a helper. In addition, this is reciprocal. Each gives the other moral support and affection, while taking care to preserve the other's personal resourcing space and respect their personal limitations. **The partner who is not ill is neither a doctor nor a nurse, the onus is on the care and medical professions to fulfil that role.**

“ I reassure him straight away by explaining that I can manage everything by myself and I have no need of a nurse. I'm completely independent. ”

Morgane, aged 37.

If you and your wife or husband want that partner to acquire a basic minimum of therapeutic education, your home health service provider (PSAD) (if you are monitored by a provider) can be called to provide the accompaniment. The coordinating nurse in the PSAD or in the Approved Centre, or an independent nurse, can visit the home and give essential instructions on the techniques for your treatment or possible malfunctions, point out signs of dehydration, hypoglycaemia or skin problems, and teach simple methods of overcoming these problems.



Intimacy and daily life

The word "intimacy" comes from the Latin word "intimus", which means the innermost or deepest place. Sexual intimacy refers to a quality of relationship and reflects the way in which two partners jointly handle the opening of their inner world to each other, as well as being close on a daily basis. Intimacy has many aspects, including physical, intellectual and emotional, between two people. This, however, is not the point to explore in depth. The aim here is to talk about what can upset intimate and daily life when one is on artificial nutrition and starts a life with another person.

The expression "living together" clearly indicates the implications of a couple setting up under the same roof. It is in fact a question of "sharing" life. Although the idealised image of the other person can initially mask minor faults when love is new, **"living together" assumes an agreement to live together with understanding and respect, knowing how to give the other person space.**

Very often, as will be read in the testimonies, **inconveniences can affect the sick partner**, who tends to be overcome and/or live in a world of excessive modesty and priorities. This partner will tend to magnify everything that they perceive as opposite to glamour and attractiveness.



The apparatus

“The feeding tube is not very glamorous, but I didn't wear it during the day and as he works nights, overall he didn't see very much.”

Adeline, aged 27.



“The sound of the pump was irritating to start with, but now I have a quieter one. My hanging frame is on casters and that makes a noise on the floor, I'm scared of waking him.”

Adeline, aged 27.

“When you're connected, you simply have to take care not to move your arms or legs inwards the threads during the tender moments. I use sufficient tubing and extensions to make us free in our movements.”

Morgane, aged 37.

“ I always wear a T-shirt when making love, for reasons of modesty. When you're connected, it's less creative, the positions are flatter and less fun. I can't let go, I keep watching and think about the positions. I'm looking at my catheter. I'm always frightened of it tearing out. ”

Florent, aged 28.



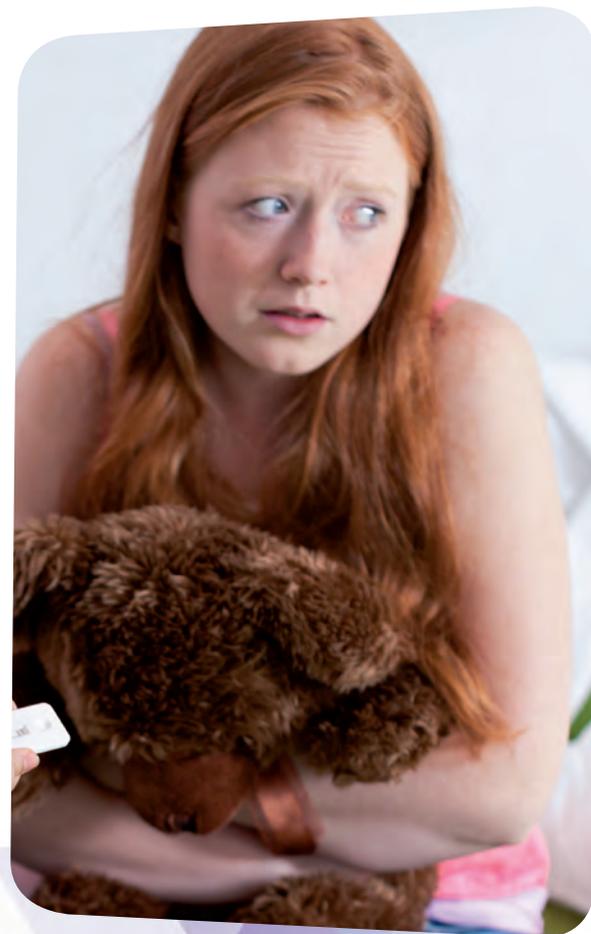
“ When I'm connected, we don't make love, it's a real inconvenience to us and I'm frightened of it tearing out. ”

Adeline, aged 27.

Problems of transit and other embarrassing problems

“ Transit, that's what's troublesome. I can have problems of transit, and that's not always easy to say or explain. I have diarrhoea, I often get up. When we go out, I have to look quickly for where the toilets are. And at the toilet, the smells are powerful. Sometimes I have a crisis and we have to pause a film several times while I'm watching it... That makes me feel uncomfortable. But he takes it all really well, he's very relaxed, and we laugh about it. ”

Adeline, aged 27.



with an ostomy

See DEDICATED FILE: LOVE LIFE WITH AN OSTOMY



Guilt feeling of patients in love-making

Patients can feel uncomfortable with their husbands or wives for several practical everyday reasons:

- Changes to use of time because of frequently feeling tired.
- Going out for shorter times of social or leisure activities.
- Difficulties in imagining the future on occasions.
- Being fed up of medical examinations, awaiting results, anticipating a recurrence of certain symptoms such as pain, &c.

These feelings can have a very debilitating effect on the couple's life and make the patient bitter and sick at heart and in body. The patient may feel a need to hide away or be quiet in order to find it in him to deal with matters. The patient may also tend to exacerbate the situations.



Practising humour

Humour can be one way of taking the drama out of a situation or touching on sensitive subjects without exaggerating or trivialising them, in a more relaxed atmosphere. It has undoubted virtues, which help build up a feeling of working together.

If you feel that your channels of communication are blocked, trust in your sharpness of mind by finding the right word, the little word that sparks laughter, the pretty play on words; this will help unravel the problem and release the tension. Humour can help both the patient and his partner step back. Humour helps address a sensitive issue from a different angle. Laughing at embarrassing subjects avoids closing them in and encourages openness with your partner and puts them at ease. Humour can protect against hurting and being hurt, offending and being offended. **It is an effective way of getting yourself understood and understanding each other better as a couple.**

“When I'm in pain, I'm irritable with my husband and I feel guilty. I feel guilty of slowing down or stopping activities; I cry, I don't feel good, and I'm angry with myself.”

Morgane, aged 37.

“I'm always seeking time between each care. And when I'm in hospital, he has to go to work, run the house and visit me. He's knackered and upset, it's hard for him.”

Adeline, aged 27.

Talking about it is one of the best ways of getting problems out. Continuous dialogue is better than lapsing into silence, or hiding away, which only creates a sense of distance.



06

LOVE LIFE
WITH AN OSTOMY

The ostomy is created during a surgical procedure. It is defined as an outlet on the skin, in the abdominal wall (the belly), where a section of intestine or urinary system comes out to evacuate stools or gas, or urine, when they cannot be expelled through the normal channels.

An ostomy may be temporary or permanent. It always requires the patient to wear a device known as a drainage bag or collection bag. Here, we are only talking about discharge ostomies and recent love-making.

How can I explain an ostomy without it sounding dirty?

Not only it is not easy to have a foreign body on yourself, talking about it is quite difficult and can sound dirty or even repulsive. It must however be explained, as this helps build a relationship of confidence with someone else.

The ostomy can be introduced with simple words.

“ I had my large intestine removed. I have a bag that feeds me artificially, I also have an ostomy bag, and therefore I often have to visit the toilet. ”

Florent, aged 28.

“ I say that I have a bag on my stomach that collects the stuff from my insides. ”

Morgane, aged 37.



Initially, one can explain the disease and its effects; the ostomy is one of the effects. Then show the bag as something that helps things go much better, keeps you in good health and allows you to enjoy a normal social life. To speak this way is to accept it fully and provide proof of self-esteem.

Using your own words and personality, you can make the description sound good: it's a "drainage bag" or a "mini-shunt system". Avoid medical jargon and technical explanations, they will not help your partner.

You can also suggest typing in keywords linked to an ostomy on the internet, and do the searches together. This way you can find definitions, pictures and testimonies from partners of stoma patients on blogs and forums. Some people are very reluctant to suggest exploring the web, as the search engine can sometimes reference photos and content that will frighten rather than help project yourself.

“ I told my girlfriend that I'd been ill since I was a child; I didn't tell her the name of the illness so that she wouldn't search and find awful photographs. I explained to her that it's a rare condition, that I'm fed by a perfusion and have an ostomy because my intestines aren't quite right, and therefore I can't use the toilet like everybody else. I didn't use the word "pouch" because it sounds like a kangaroo's pouch. I don't have any trouble talking about it. We slept together, it was no problem. I explained it to her properly. ”

Thomas, aged 15.



Having an image of an abnormal or disfigured body?

“When you look at yourself in the mirror, you ask yourself: how could a bloke accept that?”

Morgane, aged 37.

It is true that when an ostomy is created, one's self-image can be upset, and the first stage involves accepting the change. This is a hurdle that everyone has to clear, in a world where the body is the first victim of the quest for beauty. Perfection becomes a duty, and being dominated by appearance, a norm. A healthy appreciation of this change to the bodily image is essential. Initial perceptions of the body can be of a body that has been truncated, damaged or murdered, or creates feelings of shame, humiliation, regression, uncleanness or fear. By respecting an adaptation time particular to each person, and with the assistance of specialist such as stoma therapists, the ostomy can also be seen as a very positive necessity for enjoying life better when faced with a once debilitating illness.

The ostomy can help restore self-esteem and improve self-image and comfort with life: more freedom, enthusiasm and ease when participating in activities of all kinds.

Knowing how to adapt and accept the body the way it is, is essential as your perception of yourself will have a major influence on your partner's perception and on you.

“My body is like good wine, getting better with time.”

Florent, aged 28.



Don't ever think that the ostomy concerns only you; it must be an integral part of your life as a couple.

It is normal to be reticent when meeting a new partner. However, if the relationship grows, the subject must be addressed. It forms part of the discovery of each other. If you do not uncover yourself after a certain time, this can lead to questioning, distance and coldness, and the other person can end up not understanding. Communication and confidence are at the heart of the acceptance process, as are kindness and harmony.



How can I show myself and enjoy love-making with an ostomy?

“On the first few nights, nothing happened. It was more a discovery of each other's bodies.”

Morgane, aged 37.

It is perfectly normal to be very nervous for the first time with a new partner, **but do not think entirely about the pouch, or your perception of it as a passion killer. Don't put yourself in the other person's shoes...**

Preserve your energy so you forget about the ostomy during the tender moments. You are the master of your body and your intimate reflexes.

If your partner asks to see the ostomy, and if there is no risk of hurting yourself while love-making, it is up to you to reassure and explain that intimate relations are no problem with an ostomy.

It is quite possible to show your bag without stripping. However this may be, if your partner expresses a wish to see it or even touch it, don't put up obstacles. This will create a pre-conceived and false idea and possibly a taboo which could lead to awkwardness or even rejection.



How can intimacy be improved with an ostomy?

- Empty your bag before love-making.
- You can wear a mini-bag: smaller, opaque, very practical and discreet bags exist. Some brands even provide small bags that adapt to individual body shape and body movements to obtain and maintain perfect adhesion between the device and the stomach.
- If you have a colostomy, you can perform colonic irrigation before love-making. This is a washing process that evacuates the entire contents of the colon, that is, relieves the intestine by producing stools. Irrigation can be done every two or three days. It is done using about 800 ml of tepid tap water and a small, simple irrigation kit designed for the purpose.

How can I keep all my sensuality with an ostomy?

Although in everyday life it is easy to conceal a stoma under clothing, it is not so easily hidden in intimate relations.

It's up to you to decide whether or not to show your ostomy to your partner during love-making.

You can cover your bag with underclothes (T-shirt, shortie, boxers, nightdress, slip &c), with a strip or scarf around the waist, with underwear specially designed for stoma patients, or with an ostomy cover. This has the advantage of preventing contact between skin and plastic.

“ I have a nightie, a top or a shortie to cover the ostomy. ”

Morgane, aged 37.

The ostomy cover is an envelope made of cotton or non-woven material into which the bag is slipped. There are standard models, as well as models covered with lace or decorated with fantastic designs. Not only do they bring comfort, they also prevent irritation that can sometimes be caused by sweating.

Now there are even e-commerce sites that market lines of underclothes for male and female patients; these lines make the pretty general-public brands pale into insignificance. The sets come with attractive and even sexy appearances: satin boxers, lace camisoles, embroidered slips and corsets, and so on.



<http://www.fsk.fr/64-1843-sous-vetement-adaptés.html>

<http://www.micipourlavie.com/fr/merch>

<http://www.vblush.com/>

<https://www.ostomysecrets.com/life-style/from-our-founder.aspx>

<http://www.couvre-poche.fr>



These underclothes and accessories also have the advantage of bringing you support - the bag fits nice and close to the abdominal wall - and comfort while you make love, and do away with the fear of leaking.

Sensuality can also be favoured by producing a suitable background before making love:

- a choice of silky bedclothes.
- a choice of surrounding scent and music. candlelight;
- intimate preparation: soft skin, fragrance, hair removal, shaving &c.

The ostomy removes very little spontaneity from the act of making love. It requires a little preparation, but ultimately it is the same for any stoma-free person who takes a quick shower and dresses up to arouse desire and indulge the art of seduction. The only drawback is: avoid lying on your belly.



“When I make love, I wear a tank top. I put on small bags as that's more discreet. I'm not at all afraid of the bag leaking, I don't even think about it. I can do every position.”

Thomas, aged 15.



And can ostomy be synonymous with sexy?

Have a look at the blog by Jessica, a young Canadian girl full of energy, also interested in new technology, graphic design, fashion and modelling, and who maintains her femininity and her ostomy with no trouble at all.

<http://uncoverostomy.org/2011/10/30/who-said-an-ostomy-cant-be-sexy/>

<http://uncoverostomy.org/2011/10/30/ostomy-up-close/>

<http://uncoverostomy.org/>

<http://about.me/jessgrossman>



How do I manage the problems of smells and stool gases caused by the ostomy or by digestive problems?

“ Sometimes the bag can produce smells. I don't feel very good about that. I put Fébrèze® in the toilet pans. That said, a "normal" person feels it too! ”

Morgane, aged 37.

Most ostomies are equipped with a filter that helps evacuate gases and filter smells. Local solutions can also be used to neutralise leaks of smells:

- A lubricating deodorant solution to pour into the bag, which takes stools down to the bag bottom.
- Deodorants and air fresheners.
- Light a match (always carry some) when emptying the bag.



For gases, you can also place your hand over the bag to reduce them a little, but don't be inconvenienced by it all the time. The gas has to be given off, it's quite normal. We all have a level of gas, of flatulence; it doesn't stop us living as couples and as a society.

A few tips for reducing gases and stool odours. Consume in moderation:



- fatty foods, spicy foods, dried vegetables (lentils, split peas, flageolet beans &c), cabbage, turnip, artichoke, salsify, mushrooms, cucumbers, maize, Brussels sprouts, garlic, asparagus, eggs, fizzy drinks, beer,
- fermented cheeses, game meats, barbecued meats, black pudding.



TO FIND OUT
MORE

Stomatherapy

Stomatherapy (a very recent specialism, which has existed for only about thirty years) relates to digestive and urinary stomas, fistulas, urinary and faecal incontinence, wounds and scars.

A **stomatherapist** is a nurse with several years' experience of working in a digestive or urinary surgery department or in a department of gastroenterology. He or she has undergone additional training in a number of modules to obtain a clinical stomatherapy certificate.

The stomatherapist is involved in the choice of apparatus and in the education of patients.

- He or she knows all about the various makes of apparatus on the market. This helps provide a "technical" response to problems relating to the apparatus and to skin irritation.
- The therapist assists patients on a psychological level, getting them used to caring for themselves, helping them acquire knowledge, and facilitating their return to a personal, familial, professional and social life that is as normal as possible.

The stomatherapist works closely with multidisciplinary teams:

- Surgeons, gastroenterologists, dieticians, care teams in the broad sense, outside care networks.
- Manufacturers of the equipment (product evaluation, meetings &c).
- The patients and those close to them.

The stomatherapist can provide valuable help in addressing sensitive subjects linked to sexuality and to the stoma both for young adults and for more experienced people.

There is no age limit for having a new encounter!

The patient can contact the stomatherapist for a solo or joint visit.

The stoma patient's partner can also request an appointment with the stomatherapist to discuss points of, doubts, things unsaid, and fears.



Many thanks to Mesdames Paule Moisan, Cynthia Tonellato and Delphine Paradis for their experiences and information concerning stomas and stomatherapist during the work on this theme.

Paule Moisan

Paediatric Stomatherapy Nurse
Necker Teaching Hospital Centre for Sick Children

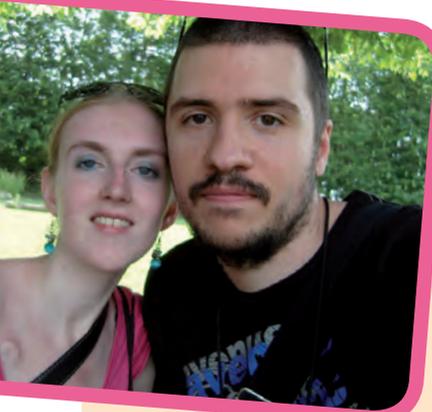
Cynthia Tonelatto

Paediatric Stomatherapy Nurse
Necker Teaching Hospital Centre for Sick Children

Delphine Paradis

Stomatherapy Nurse
Adult Department, Hôpital Beaujon

07

ATTITUDES
OF PARTNERS

.....➔ Alexandre, partner of Adeline.

“

... We met on the Internet before we saw each other properly. We talked about all sorts of things, she didn't talk about her diet straight away, just said that she had health problems, but I knew there was something there. After a few months, we decided to meet. She came to my place in Colmar. My first reaction was that she was petite, she didn't seem to have any cares. We talked but not about her condition, just like a normal couple discovering each other. I'm very free and had no feelings of rejection in me. She then told me she had a thing called "apple peel syndrome", and had to connect so many times and so many days per week, and had to watch what she ate. I'm not a complicated person, I understood and simply said "okay".

When I saw the first connections, the hanging frame and the pump, I was impressed but it didn't shock me. **I was in love, I love her more each day, I just accept her as she is.**

As for love-making, no problems. Initially she connected by placing the thread directly in her nose, then with the catheter and the implantable chamber. You just had to make sure you didn't touch it or lean on it during love-making, otherwise no problem, full steam ahead!

On the contrary, when she connects, nothing for me to do as sex. Concerning the precautions to take before love-making - none, all's good. She's not on sugar, no need to go through an elaborate ritual beforehand!

Concerning Adeline's scars, no particular problems. I wasn't really surprised, it was more like a game. She was showing me: "Yes, I've found one here and another over there." And I said to her: "Yes, I've got them too, here and here and here!" We had a competition to see who had the most, and I won it!



For an emergency, as for any person who's ill, I call the nurse or the emergency services, and I know you have to clamp the catheter if tearings occurs.

We don't have any problems with being jealous. I do everything to ensure she's not. Whatever she can't eat, I don't eat in front of her, and everything she can't do, I do instead of her. **I do everything I can to help her feel like everyone else.**

All this means is that when you love someone, whether they're sick, disabled or dying, in my eyes they're someone like everyone else, and I see Adeline as my equal - that's all. ”

.....> Stéphane, partner of Morgane.

“

... I knew when I met her that she had health problems, and as we talked, she took the time to explain how the perfusion bags provided a supplement to her diet, as well as the methods of sterile connection and disconnection.

There's no risk in having sexual relations, you have to be a bit careful but the bags are pretty sturdy and provided you're a bit careful, everything goes really well. Sometimes we don't even think about it. As a precaution, Morgane always wears an ostomy belt which helps hold the bag up, you would really have to push it to produce a problem. It's the same for the implantable chamber - it doesn't move, and the needle is protected by the dressing so it's "no problem", or pretty well. However, Morgane does worry about it a bit more, and I don't think she feels as much as ease as I do about things.

It's the evening connection that's the real passion killer. She has to have a shower, make sure there's no dust in the room, and then connect; about an hour overall, and that's tiring.

The dressings, there aren't that many; just when she connects to protect the needle and chamber, otherwise you can't see anything.

You hear nothing, or at least very little, in the intestine.

For going into hospital, it's a bit tough when she has to, like it is for everyone (whether an emergency or not), but in any case we don't have the choice.



"My wife is beautiful" is all I can find to say... the implantable chamber can't be seen. And the ostomy? No need to say any more about that than anything else... it's not much different from another person, as I said before. I asked to see it, to find out more. It's just a different method. And as I'm always telling the children (because I do environmental education, especially in schools) : "All that goes in must come out!"...For example, Morgane doesn't deride me for my "broken nose" and **she talks a lot about her cellulite or the box of tricks she has down there and doesn't like either... So finally, I say if again, it's no worse than anything else.**

And what about the smells and gases? It's like everyone else... I tell you, when I use the toilet it's not pretty either!

Morgane does feel slightly guilty when our use of time gets disrupted, but it's especially difficult for her. **So I keep telling her, she needn't feel guilty. And when we have to cancel it's not serious, we just plan for another time.**

Regarding problems of envy between the sick one and the well one, there's no evidence of that, especially because in reality it's not just the couple who's involved, it's everyone.

We just try to do lots of different stuff, because as she says quite rightly herself: she's not "disabled". It just means we have the means of doing all sorts of things. For example, we're going to the thermal baths at Amnéville soon! We've been hang-gliding and we're going skiing in the winter! ”





.....> Jérôme, husband of Yasmine.



“ ... Yasmine explained her method of feeding the simplest way possible. She told me that she had almost no intestine left, that her digestion was accelerated and therefore she needed another method of nutrition.

When I got to know Yasmine, I was a bit scared about how her condition would affect our future life. However I quickly saw that she was completely independent, excessively so I'd say. That reassured me. **She's always done everything to stop her condition affecting our relationship and family life - it's almost invisible.** She's always worked full time, and she's very independent and full of life. I would say that she does a bit too much (especially this year), but things will be better in a year's time, when she's finished her training and the house is built.

Yasmine takes a lot on. I keep telling her that the timetable is not a priority and we'll always get by. **She has priority in everything else. And this would be the case illness or no illness.**

I tend to be a little more protective over her, but this year is a difficult one and both of us are tired. That, however, has not stopped us talking about a possible trip to Australia!

There is no risk in having sexual relations, and no particular precautions. We know that it's a thread we walk along, we can step off if we have to.

The fistula is part of her, I knew right from the beginning and I don't ask about it any more, even though she covered it with a scarf at the beginning.

If there's an emergency, Yasmine knows exactly what to do and guides me. We have the family doctor's telephone number, he knows her well. ”

08

TEACHING

How can I continue studying if I'm in hospital for a long time?

In a 1991 circular (no. 91-303), the Ministry of Education states that it was necessary *"to ensure provision of schooling during periods of hospitalisation, either by favouring the constitution of groups of children or teenagers in the care establishment, or by providing personalised education to the patient"*.

In practice, this system is generally aimed at children in hospital for longer than two weeks. When a return home occurs and the child cannot return to

school, the Home Education Assistance Service (SAPAD) can intervene and work together with the child's school. Some insurance contracts provide for education with a particular teacher in hospital and/or at home. The Ministry of Education has provided parents of children in disability situations, and the children themselves, with a contact number. It provides aid and support in relations with the education authorities:

**0810 55 55 00 or by e-mail:
aidehandicapecole@education.gouv.fr**

For university students, the Regional Council for University and Academic Structures (CROUS) can be useful for obtaining advice and provision of aid.

It is also sometimes possible to work in partnership with a school and/or higher education establishment and a correspondence study organisation, such as the National Distance Learning Centre (CNED).

“ I had great teachers who provided me with work in the hospital when I sat my BTS and were available by phone if there were problems. ”

Adeline, aged 27.





Do I have to warn someone if coming with medical equipment during a test?

If the medical equipment does not hinder the student taking the test, or does not require the assistance of a trained professional, there are no specific instructions; otherwise, the procedure described above will apply. As a courtesy measure, one may decide to advise...

Is it possible to get extra school time? What is the procedure to follow?

In order to benefit from extra school time or an adaptation for examinations, tests, continuous assessment &c., the candidate must present a recognised disability, namely: **"Any limitation on activity or restriction of participation in life in society, suffered within their environment by a person because of a substantial, durable or definitive alteration of one or more physical, sensory, mental, cognitive or psychological functions, or because a multiple disability or disabling health problem"**.

The application for support must be sent to a doctor nominated by the **Commission for Rights and Independence of Disabled Persons (CDAPH)**.

It is advisable, if the pupil or student has a recognised disability at the time of registration, to send the application for support at the same time as the registration. For the others, it is advisable to send the application two months before the examination dates. In all cases, a copy of the application (without the medical elements) must be sent to the department organising the test. The doctor will issue what is termed an advice, which will set out the specific conditions under which the examination will be held. It shall also set out the authorisations, such as those providing exemption from part or all of the test, staggering of exam timetable &c.

The advice will be received by the candidate and by the administrative authority organising the examinations.

It is possible to get medical care during a test and be able to finish it later?

This specific case forms part of the support given during examinations in situations of pupil or student disability. The procedure is therefore the same as that described above and will be covered by the advice of the doctor appointed by the CDAPH.

How can I manage stress as exams approach?

A good idea is the lucky charm!

A "lucky charm" is a small talisman sent by a father, grandmother, cousin or best friend. Why does this work?

Because we know that it will help us, not to know things that we have not learnt before, but to bring to mind knowledge that we have acquired.

When you arrive in the examination hall, the lucky charm will give you the confidence that you have in it to help you succeed.

Rather than being troubled by fear of failure, you will think of all your chances of success and your inner conviction that you can meet the challenge.

The lucky charm is a way of bringing in good fortune and the power of belief to counter stress, panic and emotion.

Once again, of course, if you don't study it won't work and its hyper-operational power will be lost. Other advice for avoiding panic.

Other advice for avoiding panic

Organise your revision throughout the year. Master your subjects. Although luck is real, miracles are rare!

Avoid the adrenalin of preparing the previous evening: the expenditure on stress is very high!



A few techniques for managing stress.

Abdominal breathing

This relaxation technique is used to bring rapid relief to states of stress and anxiety, and to counter unpleasant emotions such as anger, sadness and fear. One of the main benefits of this technique is that it can be used almost anywhere and only takes a few minutes to apply.

It can be explained by some nurses, the psychologist or the somadoctor in the department. Do not hesitate to ask them about the method.

Sophrology

Created in the 1960s by a specialist in neuropsychology to improve the quality of life of his patients, sophrology is a combination of oriental techniques, meditation, yoga and western relaxation. **Sophrology helps bring body and spirit into harmony and banishes fear and stress.** It combines muscle relaxation, respiration, visualisation and promotion of positive thoughts.

It can be a means of achieving independence in management of stress and adapting permanently.

There are other types of relaxation that can help patients (such as the Schultz or Jacobson methods).



Full consciousness meditation?

Initially used to reduce stress caused by illness, chronic pain or difficult treatment, this method has made a major contribution to improvement of life quality for many patients.

This meditation does not involve hours of sitting on a yoga mat. It is not a practice of hippies or idle people. **It involves focusing one's attention entirely on the present moment and analysing the sensations felt. The duration is of little importance, only regular practice counts.** The same applies to the place of medication; it can be done while walking, running, brushing the teeth, preparing for sleep &c.



Recommended bibliography

Mindfulness: full consciousness for teenagers

Manage stress and emotions better - improve concentration and self-confidence

Author: David Dewulf

Description

For some years now, full consciousness has become one of the most important methods of learning how to manage stress.

It is based on meditation, a method of capturing the attention that can help teenagers overcome the highs and lows of this stressful and difficult period of life. Instead of reassessing the past or always straining towards goals far in the future, full consciousness learns how to be present with what is there, in the present moment, with gentle and open attention.

This book, which follows a programme of eight stages, shows how full consciousness can provide a way to better concentration, better self-confidence, less mental rumination and greater respect for oneself. In this guide, teenagers and their families and teachers will find situations, illustrations and testimonies as well as suggestions for activities and exercises to practice every day.

Dr **David Dewulf** is an authority in the field of full consciousness. He directs the Institute of Attention and Mindfulness and manages numerous training courses throughout the year for both adults and young people. He also works with various universities in order to study the effects of full consciousness

Everything there, just there - Full consciousness meditation for children and teenagers, with 1 audio CD.

Author: Jeanne Siaud-Facchin

Description

Full conscious meditation is all about learning to be really present. Being present in the place where you live. At the moment in which you live. Right now. This is what changes everything. For each of us, and for children and teenagers too! This book has been written to help children grow, flourish, live better, resist distraction and be less stressed and more concentrated. Everything is there to prevent you from being swallowed by this world. It means that they can become adults with well-being in their head, in their heart and in their life, fully content with what they are.

Jeanne Siaud-Facchin is a clinical psychologist and psychotherapist, the founder of the Cogito'Z Centres. She practices and teaches full consciousness meditation in Paris and Marseille. A recognised specialist with gifted children, she is the author of "L'Enfant Surdoué", "Helping Children with Academic Difficulties", "Too Bright to Be Happy?" and "How Has Meditation Changed My Life?", all of which have enjoyed great success.

09



ORIENTATION AND PROFESSIONAL LIFE

Does being connected provide disabled worker status?

The term "disabled worker" applies to any person whose possibilities of obtaining or retaining a job are reduced through alteration of one or more physical, sensory, mental or psychological functions.
Being on artificial nutrition can lead to problems in everyday work environments (extreme tiredness, associated illness &c). Artificial nutrition is within the scope of **disabled worker capacity recognition**.

If yes, what is the procedure for getting it?

An application file must be sent to the **MDPH (Departmental Disabled Persons Unit)** for your department (it can also be downloaded on service-public.fr CERFA document 13788*01). Once the file is completed, the **CDAPH (Commission for Disabled Persons' Rights and Independence)** will accept or reject the disabled worker status after examining the file and hearing the person concerned.



What advantages and disadvantages could this status bring?

If the CDAPH issues a recognition, the worker can benefit from certain aid to facilitate his integration and retention within professional work.

When job seeking, he may benefit from the services of the CAP Emploi Network (created by the Ministry of Employment) and specific actions provided for by departmental programmes for professional integration of disabled workers (PDITH).

Various forms of financial aid from the State and possibly from the regions are provided to facilitate recruitment, job development, accompaniment or support within a job, and possibly to compensate for the burden of disability. AGEFIPH (Association of Fund Management for Professional Integration of Disabled Persons) also offers financial assistance and services to employers and disabled workers.

It is up to each person to decide whether or not to disclose their recognised disabled worker status to a current or future employer. The decision is on a case-by-case basis. If you have a job, recognised disabled worker status can bring:

- Ease of access to certain training courses for professional development.
- Ease of access to the skills and professional orientation register.
- Possibility of benefiting from specific recognition by an employer for support in a job, purchase of special equipment &c.

Disabled workers also benefit from a reclassification obligation when a change in their state of health makes it impossible to continue in their current job. They are also protected against unfair dismissal.

If you experience problems at a given time when you are absent or especially tired, and if your employer knows that you have recognised disabled worker status, he can perhaps better understand your difficulties. In this specific case, recognised disabled worker status is an official recognition of your health problem, which must be taken into account by your employer, your immediate superior, and your colleagues.

In addition, difficult moments forge character. Depending on which job interests you, your experience may be a very significant eligibility criterion and you may have developed more determination, capacity for thought, talent, special awareness, fighting spirit and increased attention to others, as well as a definite sense of humour and enthusiasm. Some employers are fully aware of this, and know that your energy is completely consistent with their desire for profitability.

“ I asked if I needed to talk about it when I applied. This is the great question: do I talk about it or not? I have disabled worker status. I talked about it anyway. He put me at ease during the interview and I was scared that I would be criticised for not mentioning it. During the interview I suggested staggered hours, I had to mention it because of circumstances as I'm still connected at six in the morning. He told me that provided you're there on time and do your work, no problems. ”

Adeline, aged 27.

“ I went to a subsidiary of Orange on a work-study basis and declared my illness. When I applied to the parent company, I didn't say anything straight away, but after that I explained it to my manager. ”

Yasmine, aged 39.



Can you apply for any kind of job?

Can one be a doctor with artificial nutrition?
It is compatible with being a guard?
Could I be a rugby player? Could I be a lieutenant?
Here also, there is no clear-cut distinction, no generalised restrictions for all.

Here follows a ranges of testimonies from people on professional orientation courses, in training or in work.



“ I want to be a dietician and I had to go through training in the hospital and did not have the right to be vaccinated. However, I have a friend who's an international photographer, and another who's a nurse. Almost every job is a possibility as I see it. ”

Morgane, aged 37.



“ I wanted to be in the army, but they told me that would be difficult, because of rhythm, intensity... I have a friend in the Navy. They go off for a week on the ship, that would be too difficult to manage in terms of logistics and care. I wanted to be a paramedic and they told me not to do it, as I can't carry loads that are too heavy. Otherwise, I trained as a shop worker in a DIY store. That was very physical work, I was loading 25-kg cement sacks onto shelves. I was working very fast. I simply said that I needed regular access to the toilets. I'm really happy, I loved that training. The boss even suggested I should be recommended for the next stages... But the training lasted three days and I wasn't sure that was really suited to my condition. After doing all the training, I was gutted. I want to be a sales person. ”

Thomas, aged 15.



“ I work full time. I'm a manager and I can adjust my working hours... ”

Yasmine, aged 38.



In some hospitals, like Cochin, there are professional orientation interviews. The transition passes through this reflection stage. Please feel free to find out.



10

SELF-ESTEEM
AND ATTITUDES OF OTHERS

Both a sickness and a visible or invisible disability will bring us hurt, physical and emotional suffering and a sense of injustice. The attitudes of others can increase this suffering and provoke differing reactions: self-absorption, isolation, solitude, failure to rise to responsibility or taking of excessive risks, aggression, exhibitionism &c.

Many young people are very sensitive to the attitudes of others to whom they feel constantly exposed, and this sensitivity can increase together with all the changes involved in becoming an adult.

There is, first of all, the very significant influence of the media.

They send codes about how people should be, think, dress, succeed in society and so on. These codes can regiment and close in whenever a young person feels that they do not conform with these rigid formulae.

Then there is the image that others project in social life. The words and attitudes of parents, family members, friends and others who refer to a self-image that can reveal, awaken, build up, question or destabilise.

Attitudes of parents and others

In adolescence, as our bodies and minds change, we need to be confirmed by our parents' attitudes. We enter the body of a man or woman, our personality forms with its tastes, and we look in our parents' attitudes for confirmation that we can be loved, even if this is sometimes in an atmosphere of confrontation or conflict. We then gain in self-confidence because of this positive attitude, which creates a feeling of security but also makes room for freedom and recognition of identity.

There are also other positive attitudes: those of teachers, friends, colleagues or trainers who encourage us and help us face difficulties.

However, many young people are paralysed by the attitudes of others. If we heed the attitudes of others, it is because their judgement is feared; the fear is that the other person will project an unfavourable image of us. This fear is clearly born of a fragility of self-esteem, a lack of self-confidence and a threat to one's identity.

The importance given to others' attitudes is simply the consequence of a lack of self-esteem.





Getting free from others' attitudes

You can't get ahead in life without others. But how can you make their judgements and attitudes productive instead of destructive? How can the impact of others' attitudes towards you be minimised and your own self-esteem maintained?

Agree not to know what others are thinking

You can't know this, and you cannot control the thoughts of others.

That's the way it is, accept it and you will lose much less time upsetting yourself and seeking to please everybody, which incidentally is impossible!

Accept that what others think concerns them only

Everyone has the right to their own secret garden. A world in which all thoughts are accessible to all would probably not be viable.

Everyone has self-centred thoughts, pre-conceived ideas or criticisms that are to varying extents bad.

They are not necessarily logical or even explicable.

A person can think unpleasant thoughts, and that's their problem and not yours.

In reality, others are much more concerned about themselves than about you

Others will not judge you as much as you think, because they don't have that much time for you.

They are much more preoccupied with judging themselves and asking themselves what others think of them. It's a kind of pantomime in which each person endlessly mimics another. Increase your peace and serenity, and keep your energy for more positive thoughts.

Respecting and cultivating one's singularity

Wanting to belong to a group and be accepted by all its members is natural.

For this reason, many people imitate so-called "popular" people, in order to be liked and recognised by the greatest possible number.

This, however, can lead to the real "me" being lost, in terms of one's own referential but also in terms of other people's ideas.

Acting according to one's own beliefs and convictions leads to self-respect, confidence and acceptance of all the differences that make us what we are, and the knowledge that we are "original".

Recognising what is seen as a failing or fault will make us more realistic and help us grow: accepting imperfection and fallibility the evidence of which is quite normal.

Other people wish us well, or at least don't wish us ill

As a rule, people whom we meet wish us well, at the worst they do not wish us ill, or are simply indifferent.

Saying and doing evil are actually less prevalent than we tend to think.

“ I'm asked questions: Why have you had that, how did it happen? But I find that quite normal. ”

Jules, aged 19.



The importance that we assign to others will confer too much power on them.

The more importance we attach to the judgement of others, the more our own judgement will lose value. This will ultimately give others the power to determine our own value!

What they think belongs to them only, insofar as their opinions and judgements are based on their system of values, tastes and perceptions, which is not universal. Their thoughts and attitudes concern only them! Frequently, our thought processes are distorted and exaggerated. We dislike ourselves mostly because of what we feel others think. Once again, it a wicked waste of time and energy to have these **abusive and denigrating views**.

Learning how to know and like yourself better

We must take time to learn to know ourselves so that we can then “filter” and interpret the remarks and reactions of others.

What should we do to learn to know ourselves?

This is something that is done progressively with time. Talk about things with somebody close to you, somebody you trust: a friend, a family member, a doctor. Determine together with this person what makes us rich, our strong points, our assets, our originality. You can also recall times in life when you were acknowledged, thanked, or congratulated for your skills, tenacity, braveness, "good actions", collectedness &c.

If there is nobody with which you can discuss these points, you can talk it over with a psychologist who will help. Also, at the end of each day, think over little gratifying moments in order to develop confidence and personal esteem.

How can we develop a proper self-image?

In order not to be dependent on the opinions and considerations of others (and not to become self-centred and self-analytical at the same time), there are numerous keys for developing self-esteem and keeping it for a lifetime.

- **Having confidence in our personal values**
- **Cultivating positive attitudes**
- **Making the most of our body's assets as well as its defects: theatre, adapted sports, dance &c.**
- **Being satisfied with oneself as often as possible**
- **Being optimistic**
- **Taking on and assuming new responsibilities**
- **Taking care of ourselves**
- **Accepting one's emotions**
- **Not comparing ourselves with others**
- **Setting ourselves realistic objectives**
- **Finding our own tactics for resolving our problems**
- **Understanding that doing our best is more important than "winning".**



“ I think my body is good but since I’ve started body building, I’ve grown to enjoy being me, people say that I’ve changed, that I’ve grown, everybody’s complimenting me. In the necker I was completely warned against it, I should never carry more than 10 kg, I’m now up to 65 kg. I go there three times a week, an hour to an hour and a half per session. Before that, I was weak and puny. I’ve become much more assured. I feel much more at ease with people. It’s helped me a lot, with girls as well :-). ”

Thomas, aged 15.



“ I’ve passed my BAFA and even camped out in the wild. The conditions were tough, but I did it! ”

Jules, aged 19.



What are the possible effects of poor self-esteem?

Poor self-esteem is comparable to being in chains or leg irons, or inside an inner prison of doubt, fear of failure and paralysing nervousness.

The consequences are variable and all prevent us from moving forward and realising our potential:

- Lack of socialisation / always being suspicious of people
- Little feeling of control over our life
- Problems of learning and orientation
- Negative feelings about the future, a sense of immobility
- Inability to take decisions
- Being easily influenced
- Shyness, inhibition, discomfort, stress
- Risk of self-destructive behaviour.

Self-esteem is based on self-acceptance, with an accurate appreciation of our strengths and values and a feeling that we can face up to life’s inevitable challenges. Forging a strong and healthy perception of ourselves is the basis for our inner harmony and well-being.

11

COORDINATION
& ADMINISTRATIVE MATTERS

Here follows a wealth of information on the very practical and formal aspects of the transition to adulthood. Administrative and organisational aspects are dealt with on a serial basis with very practical questions and answers. Everyone can quickly find answers to their needs here.

How can I get a copy of a summary of my paediatrician's files? How can I obtain my hospital examination reports?

For patients not yet of age, a copy of the medical file can be requested by the representative(s) of parental authority. With the consent of the representative(s), the treating doctor and/or specialist monitoring the patient can also send a request.

In most cases, the request must be sent to the director of the hospital. Supporting documents may be requested, such as a copy of the family booklet, to prove the relationship, or written proof that the representative(s) of parental authority authorise the doctor to obtain the file in question. All these requests shall be made by registered letter with advice of receipt.





Where do I find a list of what to do for the three stages, 16, 18 and 20 years?

16 years:

Personal Social Security card inclusion on town hall roll

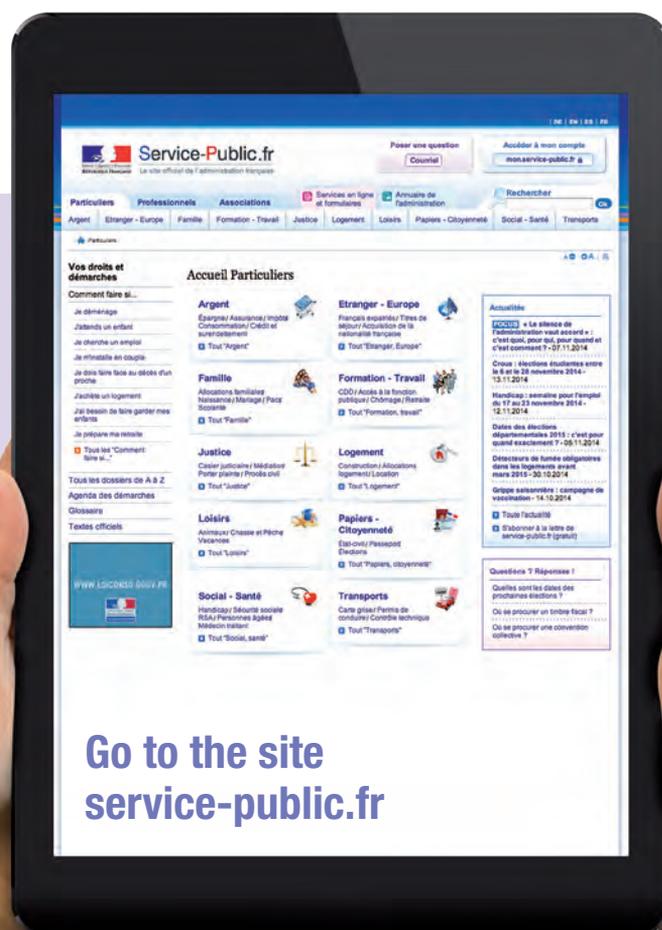
18 years:

Legally of age - right to vote, right to drive, choice of career, open personal bank account

20 years:

One year before, send a file to the MDPH (Departmental Disabled Persons Unit) for transition to the adult sector. On receipt of notification, close the child file at the CAF (Social Security Office) and open a proper adult file, request recognition of disabled person status.

The official social security website, ameli.fr, can provide details of the steps to take. All that is needed is to go to “rights and procedures” and choose the personal or professional situation that concerns you. For example: “you are under 20”, “you are in high school”, “you are a student” &c. You can also visit the offices of your sickness insurance fund.



Where do I get assistance for properly managing and understanding the procedure?

If you are admitted to hospital or have hospital appointments on a regular basis, the social services in the care establishment are there to assist you.

You can also find assistance and advice on the unique number set up by the sickness insurance: **36 46**

Finally, each sickness insurance fund has a permanent presence of advisers or social workers with whom you can make appointments.

It's also worth asking the social workers at the CCAS (District Social Action Centre) at your town hall.



How can I manage the administrative problems when changing CAF?

A simple change of address can be reported on line using the “on-line change” service on the site caf.fr or making an appointment direct with an adviser.

If this change of address leads to a change of sector, the CAF will automatically transfer the file to your new fund. The transfer will be made as soon as your new address is registered. Before a change of CAF, if you are in receipt of AAH (Disabled Adults' Allowance), try and lay aside a little money in advance of the time when the transfer takes effect.

How can I manage the administrative problems when changing social security (SS) status?

Change of SS status occurs when you transfer from the status of your parents to your own status. Your file must be transferred together with your acknowledgement of ALD (long-term condition) and your care files. Similarly, if you pass through student status, which is a particular status: the student social security is a mutual fund. Transferring to worker status is more straightforward. All these changes take a little time, but less than those made with the CAF.

When you change address, it is less complicated: the same principle as changing address with the CAF.





How can I manage the administrative problems when changing MDPH?

You must ask the MDPH (District Disabled Persons Unit) in the Department of origin to transfer the file to the MDPH in the new Department. This must be done as quickly as possible so that the benefits granted are not interrupted. It is important to advise the new MDPH of your complete new address and provide it with supporting residence documentation. Keep a little money aside and a copy of all your papers and files.

How do I choose a suitable mutual fund?

Students from 16 onwards must register with the Social Security students regime. Note that scholarship holders are exempt from paying charges (about €195 for an academic year). Certain specific student mutual funds have a public service delegation for managing student social security, and also fulfil the function of an additional mutual fund.

Starting a job means that you can no longer access this kind of organisation.

For people on low incomes, it is possible to make an additional application to the CMU (Universal Sickness Cover), which will reimburse the price charge for all forms of care recognised by social security. It is granted for one year (renewable on demand) and depending on resources. The AAH (Disabled Adults' Allowance) is above the threshold for allocation of the CMU and additional CMU.

For other situations, membership of a private mutual fund is not obligatory but is highly recommended. The tariff will vary according to cover chosen. For this reason, several estimates will be necessary in order to make a choice. It is advisable to choose initially a mutual fund that reimburses the fixed daily hospital charge as priority without limitation of days, and also covers pharmacy, technical equipment and appliance costs.



How can I obtain a complete file for marking MDPH applications?

The MDPH (Departmental Disabled Persons' Unit) applications forms are accessible and can be downloaded on the official public service site service.public.fr under the heading "on-line services and forms".

You can also find these forms on the MDPH welcome sites in each department or in their local branches. The hospital social services also have these forms.

Ask the hospital and its treating doctor for all the hospital admission forms, laboratory results, X-ray examinations and surgical reports. Also ask the works doctor to produce a certificate.

Will I have to pay more for my insurance?

Insurance companies have no right to demand higher payment for an insurance contract because of sickness or disability, except in cases of loans. In this case, please refer to the AERAS agreement. The AERAS agreement (insure yourself and borrow with an increased health risk) allows people who have or have had a serious health problem to obtain property loans or consumer credit more easily. <http://www.aeras-infos.fr/site/aeras/lang/fr/Accueil>

<http://www.aeras-infos.fr/site/aeras/lang/fr/Accueil>



To find out more,
go to the dedicated link of the "La Vie par un Fil" association on
<http://www.lavieparunfil.com/>



Many thanks to Catherine Kajpr for sending information, and to the social coordinators of the home health service provider Homeperf, who gave a wealth of information in response to the administrative questions above.

Itinéraire Santé Homeperf :

Itinéraire Santé Homeperf is a social information and accompaniment service that improves the care of sick people, led by the Homeperf social coordination team. Some patients cannot, or have nobody who can help them, carry out the social formalities or procedures (social security, social assistance, accommodation &c). The consequences can be drastic both on a social level and in terms of continuity of care.

The social coordinators are there to listen and provide social accompaniment, as well as providing responses to administrative demands (compilation of finance files or searches) or daily management (home helps, carers, associations).



And then...? ...

Once you become an adult? As for other adults, there is a whole range of possibilities for development with the precautions linked to artificial nutrition.

This will be the following theme in the White Book for artificial nutrition at home, for those who have risen to the challenges of these transitions and those requiring artificial nutrition at a later stage.

Within the context of long-term parenteral nutrition, with or without entrance or exit ostomies, we can report a happy reality in France in the form of 17 pregnancies in 13 young women who produced beautiful babies with no particular problems although some of them were premature. The mothers were closely watched before, during and after pregnancy. The medical and obstetric teams learned a great deal and progressed in this field. This is a hope for any person embarking on the "connected" life.

A short conclusion to be read by parents

Parents are there to accompany their children through to adulthood. Some find this marvellous and are impelled to help, while others are scared and live through it with fear and desolation. There is no judgement, no comparison, no attitude more exemplary than that of another person. Being a carer-parent is very unusual and fears and misgivings are completely normal.

However, children must fly the nest; it's a law of life! Every parent must support their child and accompany them through the departure and increase their all-important confidence.

Parents can be reassured by the fact that in reality, there exists a kind of invisible elastic. Children make outward and return journeys: initially to find their own laundry services and things that help equip them, and later for holidays. Top leave home is not to turn your back on your family!