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Practice guidelines

Transition from pediatric to adult care in adolescents with hereditary metabolic diseases: Specific guidelines from the French network for rare inherited metabolic diseases (G2M)

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ABSTRACT

Inherited metabolic diseases (IMD) form a heterogeneous group of genetic disorders that surface primarily during childhood and result in significant morbidity and mortality. A prevalence of 1 in 2500–5000 live births is often reported. The transfer of adolescents from pediatric care to adult health facilities is often difficult for patients and their families and can lead to a breakdown in medical follow-up and therefore serious complications. Existing recommendations for the successful transition of patients with chronic disorders do not specifically address patients with IMDs associated with dietary treatment. Here, the French network for rare inherited metabolic diseases (G2M) presents its reflections and recommendations for a successful transition. Preparations for the transfer must be made well in advance. The transfer must aim for adolescents gaining autonomy by making them responsible and providing them with the knowledge that will enable them to manage their care themselves, know how to react appropriately if there is any change in their condition, and move comfortably within the adult healthcare system. This requires the active participation of the patient, his or her family, and pediatric and adult care teams. It involves multidisciplinary management plus the production and maintenance of an educational therapy program. Finally, the identification of physicians and dietitians trained in IMDs, relevant subspecialists, and even expert patients could improve the continuum of complete and appropriate care for these patients within adult medicine.

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1. Introduction

Inherited metabolic diseases (IMDs) form a heterogeneous group of genetic diseases that mainly begin during childhood. While these are individually rare, they are numerous when

considered as a whole and cause significant morbidity and a certain degree of mortality. A prevalence of 1 out of every 2500–5000 live births is often reported. A retrospective study that used data from the West Midlands regional diagnosis laboratory (Birmingham, UK) between 1999 and 2003 found a higher prevalence: 1 out of every 784 live births [1].

Over the past few decades, the survival of these patients has improved considerably due to progress in care. In general, it has

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been demonstrated that more than 90% of patients with chronic diseases will survive beyond the age of 20 years, which was not the case in the 1970s [2].

Consequently, during adolescence, these patients need to follow a program to transfer their medical care from pediatric centers to adult healthcare institutions.

The French network for rare inherited metabolic diseases (the G2M) was established by the Ministry of Health in 2014. Its goals are to organize and coordinate the actions between the different actors (reference centers, competence centers, patients' associations, basic and clinical research teams, etc.) involved in caring for IMDs. Existing recommendations for the successful child-adult transition of patients with chronic diseases did not specifically target patients with IMDs associated with dietary treatment. Here, the G2M presents its reflections and recommendations to improve this transition.

2. The child-adult transition

Hudsmith and Thorne define the transition as "a deliberate and planned process that meets the medical, psychosocial, educational and professional needs of adolescents or young adults suffering from chronic physical and medical diseases when they move on from paediatric medicine into the adult health care system" [3]. Blomquist presents the adult transition as a shift from pediatric care to adult care, from school to employment and from life within the family household to independent life [4].

Adolescence is the period of life during which difficulties in adherence appear most clearly. These are applicable to 20–70% of young people depending on the pathology and equivalent numbers are observed in adults [5,6]. Therefore, this is not a specificity of adolescence; rather it is the age at which this behavior becomes significantly apparent. It is essential to identify it and to attempt to understand its mechanisms [7].

The issues of adolescence and its physical and mental transformations are affected by chronic disease on all levels. Numerous aspects must be addressed, and namely subjectification, gaining autonomy, sexualization, restrictions, deprivation of freedom, dependence and threats. These different elements conflict with the adolescent's future plans: fears regarding the long term, shortening of the future, dreams and plans, etc. Refusal to submit to therapeutic requirements, "adjustments" to treatment, or rebelling against the disease appear and are naturally linked to adolescence. The role of caregiver teams is to recognize, beyond this "irresponsible" behavior, an attempt to experiment that must be accompanied in its transition toward the appropriation of the self and the disease. Poor adherence constitutes a major worry for caregiver teams, who see the success of treatment challenged [7].

The transition is therefore a long process aimed at producing a continuity of quality and coordinated care adapted to development before, during, and after the transfer of the adolescent into the adult healthcare system. In addition, it aims to encourage the empowerment of the patient in his or her family, social and professional life.

2.1. The transition remains inadequately prepared

The transition process remains difficult. This is because it still too often takes place through a brutal transfer for patients who are ill prepared for it and who are going through a period of life characterized by multiple physical, psychological, and social changes likely to result in problems in medical adherence.

Confronted with adult care mechanisms that adolescent patients and their families perceive as confusing, finding that

doctors are often unfamiliar with their disease due to the rarity of the pathology and/or having little experience in their care, certain patients return to pediatric units, whether sporadically or regularly, which raises numerous problems, both medical (consideration adapted to the healthcare needs of an adult) and legal (in particular during surgical intervention). In addition, the prolongation of their stay within pediatric medicine may act as an obstacle to patients' necessary gain in autonomy now that they have become adults [8].

Due to the lack of preparation, this transition in care carries the risk of resulting in a breakdown in medical follow-up, which at times extends over the long term and is the source of serious complications. Pacaud et al. report breakdown of medical follow-up rates of between 11 and 69% among children afflicted with type 1 diabetes and an increased risk of hospitalization related to acute complications [9].

The patient's gain in autonomy in his or her family, social and professional life, which constitutes one of the goals of a successful transition, must be improved [10].

2.2. Creation of the G2M's recommendations

To draw up these recommendations in a single document, the G2M's methodology was the following:

- the establishment of a work group composed of pediatricians, physicians in adult care, and adult and child dieticians. This group met three times to establish the state of affairs of the child-adult transition based on a literature review, and in particular international guidelines, as well as to determine the concrete actions to be carried out in France ([Annex 1](#));
- the execution of a survey of pediatric and/or adult dieticians at all IMD reference and competence centers as well as other French hospitals. This survey was used to establish a summary of the dietary care for IMD patients at the main nutrition units in France.

Following this undertaking, the prerequisites necessary for the proper execution of the transition were highlighted: the identification of specificities, the prevention of breakdowns in follow-up, educational therapy, and the need to establish recommendations regarding the transition: medical, dietary and feedback recommendations.

These recommendations established by the G2M regarding the child-adult transition were reviewed by a private pediatrician (external to the work group) as well as the members of an IMD patients' association ([Annex 2](#)).

3. Arguments

3.1. Obstacles to the transition's success

3.1.1. Obstacles related to the patient and/or his or her family

The lack of knowledge of the disease combined with limited aptitudes for the self-management of care constitute well-identified obstacles to the success of the transition. These deficits are explained, among others, by the way the pediatric system works, significantly involving parents in medical and care decisions, but still insufficiently involving the young patients themselves. The "paternalist" model of caring for young patients does not adequately prepare them for the transition to autonomy [8]. Under these conditions, patients approach their transfer to adult medicine with a great deal of apprehension and a feeling of being abandoned by the pediatric center, with the fear that they are not yet ready for the transfer [11]. Parents' emotions can also

hinder the transition's success, because they may make parents suspicious of adult medicine healthcare professionals, who, by encouraging the adolescent to develop autonomy, involve parents in care to a lesser extent [12]. In addition, adolescents and parents may see the transition to adult medicine as "one more step toward the complications of the disease and even death" [12]. Last, a certain number of children with IMDs present a mental handicap that will only allow them to obtain a very partial level of autonomy. Therefore, one of the goals of the treatment of a young adult presenting a moderate intellectual disability remains promoting self-management and autonomy as soon as possible in a way that makes sense for the person himself or herself [8,13].

3.1.2. Obstacles related to care

Pediatric care, which is centered around the family, requires a large degree of participation in decision-making on the part of parents and is offered by a multidisciplinary team. On the other hand, adult care focuses on the patient; it requires the patient to have a large degree of autonomy and makes less use of interdisciplinary and intra-family resources [14,15]. Furthermore, few teams (doctors and dieticians) within adult healthcare units are trained in IMDs and the specificities of their care, with the majority being reluctant to accept the responsibility of caring for adolescents, who are considered to be "difficult on the medical level and demanding on the emotional level." These observations explain a certain degree of hesitation among pediatricians with respect to the transition [12].

Dietary care for IMD patients is both complex and crucial. Patients 18 years of age and older cared for by adult medicine are often still not very independent on the dietary level. They may be upset by caregivers with inadequate knowledge of their specific needs, thus exposing them to a risk of serious decompensation.

A survey of pediatric and/or adult dieticians from all IMD reference and competence centers as well as other French hospital centers established a state of affairs of the dietary care of IMD patients. A total of 22 hospital units responded, representing 2000 pediatric patients and 860 adult patients. It indicated that:

- the training of dieticians in the specificities of dietary care for IMDs takes place through experience and mainly occurs via oral transmission between colleagues;
- while pediatric centers work consistently with dieticians who have acquired this necessary knowledge, this is much less frequent at adult centers;
- the small cohorts of patients afflicted by the same disease make it difficult to acquire this knowledge.

3.2. How to encourage a good transition

The success of the transition is based on considering the medical needs specific to the pathology as well as the psychosocial and educational needs of the patient entering adulthood. It is necessary to structure and plan the transition as well as to establish links between the pediatric and adult healthcare systems that will make it possible to coordinate the transition [16]. A key element and the driving force behind the success of the transition remain the motivation and involvement of the pediatrician and adult physician in charge of the adolescent. Even though the child-adult transition may result in a feeling of abandonment among patients or may expose them to medical risks, it is also an opportunity for important positive changes, including the development of autonomy and distance with respect to the family (at times with the establishment of a separate living space) and the possibility of addressing questions preoccupying the adolescent (emotional and sexual life, professional insertion, etc.).

3.2.1. Existing transition models and recommendations

Different scholarly organizations have issued recommendations on the transition to adult care of young patients requiring special care [4,13,17-21].

In general, recommendations for the transition to adulthood emphasize that it is a continuous process that may start as early as diagnosis and extend until after the transfer. The announcement of the transition must be early and must be carried out at a pace suitable to the young patient, who must acquire the knowledge and attitudes necessary for his or her care that will allow him or her to easily navigate the adult healthcare system. Intellectual disabilities must be taken into consideration in the creation and implementation of the transition process. Recommendations insist on the importance of the coordination and planning of care and the partnership between different pediatric and adult healthcare professionals and the young patient and his or her family in order to ensure continuous, complete, and accessible care during transitions. In 2001, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians [17] issued recommendations directed at resolving problems related to the transition to adulthood. Most notably, these scholarly organizations announced the following principles:

- to ensure that all patients with special healthcare needs that have become adults have an identified healthcare professional in charge of the transition and taking responsibility for current healthcare, the coordination of care and the planning of future healthcare. This responsibility is assumed in partnership with other pediatric and adult healthcare professionals, the patient, and his or her family. The goal is to ensure that all patients have continuous, complete, and accessible care during the transition period;
- to identify the fundamental knowledge and competencies required for providing appropriate healthcare based on the progress of patients with special healthcare needs during the transition. In practice, to integrate this knowledge and these competencies within the training and certification requirements for residents and primary care doctors;
- to prepare an up-to-date, usable, and accessible summary of the patient's medical history. This information is essential for the success of the transition and provides the basis of the shared knowledge necessary for collaboration among healthcare professionals;
- to create a written transition plan at the age of 14 years with the young patient and his or her family. At a minimum, this plan should include care that must be given and who will provide it. This plan must be reviewed and updated each year.

The Canadian Pediatric Society [13] issued the following recommendations in 2007:

- main principles:
 - to be aware that the transition is a continuous process that may start as early as diagnosis and end a time following the transfer,
 - to provide the adolescent with resources and relevant educational documentation throughout the transition process;
- elements related to the young patient and the family:
 - to centre the planning of the transition on the patient taking into account his or her family,
 - to provide relevant attention and support to family members,
 - to carry out the transition at the patient's pace;
- multidisciplinary teams and community resources:
 - to integrate the planning and preparation of the transition within specialized clinical establishments in place,

- to provide care adapted to development, including a plan consisting of stages of increasing responsibilities with regards to self-management of care. The family doctor is an integral part of the caregiver team. If the adolescent does not have a family doctor, encourage referral as quickly as possible,
- to provide adolescents with information regarding their disease and the resources available, including clinics offering sexual health screening for young adults,
- the provision of transition services may include individual counselling, psychoeducational groups, notices and verification lists for staff, patients and parents, joint transition clinics and online tools.

4. The recommendations of the G2M

4.1. *The transition of IMD patients presents specificities*

The medical and dietary transition of IMD patients raises problems common to all chronic diseases, including those of the transfer of medical records, the upstream preparation of the announcement of the transition, the age when the transfer is made, the implementation of active collaboration between pediatric and adult teams, and the difficulties raised by intellectual disabilities. However, this transition also raises specific issues:

- dietary care, which plays a central role in the treatment of IMD patients, is most often complex. Lack of adherence to the required discipline may have serious consequences over the very short term;
- the issue of patient orientation is key. Metabolic disorders are extremely varied and may be accompanied by injuries concerning multiple specialties simultaneously (for example, hepatology and neurology);
- multidisciplinarity in adult medicine is more difficult to organize and is often less understandable,
- the coordination of care is generally left to the treating physician, a situation that is not adapted to IMDs;
- the preparation and monitoring of pregnancies among IMD patients requires expertise and specific competencies.

4.2. *Recommendations for a successful transition of young IMD patients with dietary treatment*

The recommendations of the G2M for the transition of young IMD patients encompass elements of the above-mentioned recommendations and contain specificities imposed by the features of care for IMD patients with dietary treatment.

The child-adult transition can only take place under the proper conditions if the healthcare professionals for adult care (doctors, dieticians, etc.) are identified and solicited beforehand:

- prevent the child and his/her family from experiencing the transition as an abandonment by the pediatric system:
 - prepare the transition starting at the beginning of adolescence by helping them learn autonomy,
 - explain the mechanisms of the transition to children and parents as early as possible,
 - attempt to determine the optimal time for the transition with the young patient and his or her parents,
 - do not determine the age of the transition based on the age of the patient but rather on his or her maturity, autonomy (in particular with regards to self-care) and the stability of his or her condition,

- gather the adolescent, parents, pediatric and adult dieticians, pediatrician, and adult physician prior to the transfer to adult medicine during a joint transition consultation. This will initially be orchestrated by the pediatrician, who will progressively give control to the adult doctor. The joint transition consultation must be respectful of each child and must establish an environment of trust between the healthcare professional and the patient,
- continue the joint consultation for a time period exclusively dedicated to the transition of dietary care,
- provide adolescents with a specific approach, in particular regarding issues related to sexuality or maternity, and more specifically in the case of mental disabilities,
- develop an educational therapy program specifically adapted to IMDs and to the transition phase, which should be shared within the G2M,
- work with patients' associations during this transition, providing moral and psychological support to adolescents and accompanying them, by holding cooking workshops, patients/parents meetings, etc.,
- establish an annual future meeting calendar, if possible, with two reminders, through mechanisms to be defined with the patient (email, conventional mail, telephone, etc.) 1 month and 1 week prior to the meeting, for example;
- carry out the transfer during a period of clinical stability:
 - only carry out the transfer to adult medicine if the clinical and treatment situation is stable. No modification of treatment or diet should be made during the time periods immediately before, during, and after the transition;
- implement active and consistent collaboration between pediatric and adult teams during the entirety of the patient's care trajectory:
 - make a summary of the joint transition consultation bringing together adult and pediatric care teams,
 - recognize and ensure the training of adult doctors and dieticians in IMDs to guarantee the continuity of care (this training will necessarily include setting aside time dedicated to this training): establish devices for educating healthcare personnel regarding the specificities of nutrition for IMD patients in the form of an inter-university degree (DIU) overseen by a teaching committee within the Société française des erreurs innées du métabolisme (SFEIM),
 - organize communication between pediatric and adult healthcare units,
 - use a computerized medical file that is the same for the pediatrician and adult physician,
 - a nurse dedicated to this transition phase may play a major role in the coordination between these different times,
 - dedicate devices specific to adult care for the organization of multidisciplinarity and the training of the paramedical team. The adult doctor and dietician are unable to ensure a peaceful and successful transition without these paramedical foundations and a multidisciplinary team;
- anticipate emergency situations:
 - guarantee nutrition security: implement a logistics process adapted to ensure the security of the dietary care for these patients: availability of specific dietary products, possibility of making specific nutritional mixes for enteral nutrition, traceability of the calculation of portions, and a nutritional stipend for caregivers in hospitalization units, etc.,
 - make the management of emergency situations by doctors and dieticians possible at all times,
 - be provided with emergency protocols at each reference center, which are available for the different facilities admitting pediatric and adult emergencies as well as the resuscitation units caring for these patients;

- manage specificities related to pregnancy:
 - manage specific issues regarding the IMD patient and the fetus,
 - need for a maternity ward capable of caring for these high-risk pregnancies, which develops and maintains a close relationship with the original pediatric ward for the child to be born;
- organize feedback at each center:
 - provide medical and dietary feedback to pediatricians and child dieticians so that they are aware of the patient's progress (improvement, aggravation, appearance of complications, organ transplants, implementation of new treatments, etc.). This enables a more objective initial discussion at consultations during the pediatric age in response to questions asked on the transition to adulthood,
 - establish a registry of patients who have undergone the transition to carry out evaluations a posteriori within the goal of improving the conditions of this transition.

Fig. 1 presents a diagram of all conditions to be met for a successful transition according to the G2M.

5. Conclusions and perspectives

The child–adult transition is a long process aimed at achieving the continuity of care adapted to development before, during, and after the transfer of the adolescent to adult healthcare institutions.

This is a delicate period for the patient, because it coincides with physical, psychological, and social changes that may result in a rupture in medical follow-up.

The ideal age for the transition of an IMD patient to adult medicine is determined based on his or her maturity, autonomy and the stability of his or her condition. The preparation of the transition must be anticipated as early as possible. It requires the active participation of the patient, his or her family and the pediatric and adult care teams.

Sufficient knowledge of his or her own medical status will allow the adolescent to self-manage care optimally and to easily navigate the adult healthcare system. Most particularly, the young patient must understand the mechanisms and goals of his or her care, must be capable of detecting a potential change in his or her state of health, and must know how to react appropriately.

Beyond the patient and his or her family, the improvement of the transition involves the coordination of pediatric and adult teams to ensure the necessary care. It is worth noting the importance of multidisciplinary care for these patients and the creation and pursuit of an educational therapy program within adult healthcare units. The strengthening of the teams involved in caring for IMD patients is essential (dieticians, psychologists, doctors trained in IMDs).

Associations of parents with children with IMDs provide valuable accompaniment throughout the patient's healthcare pathway and in particular during the transition phase. The

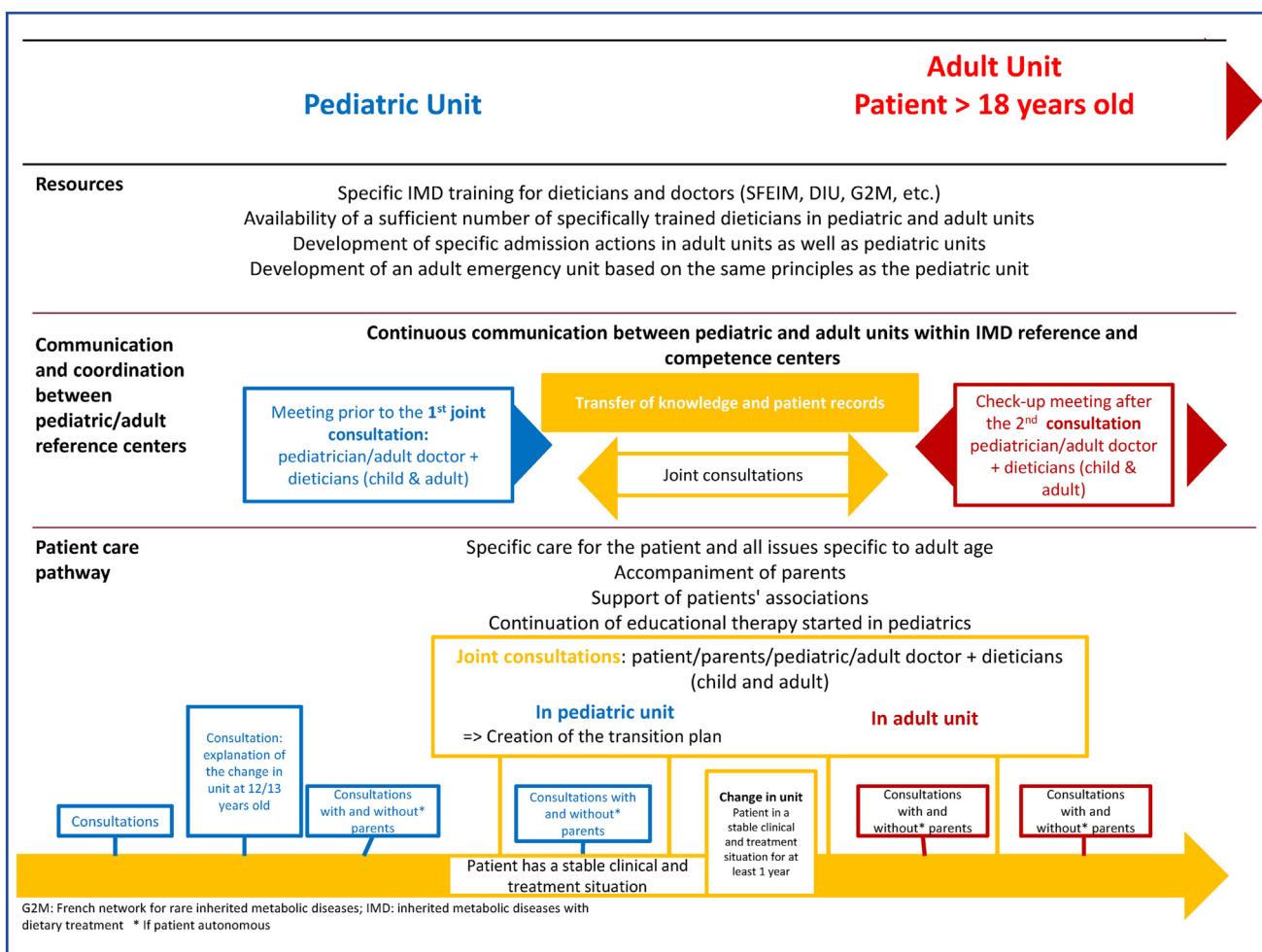


Fig. 1. Diagram of all conditions to be met for a successful transition according to the G2M. SFEIM: Société française des erreurs innées du métabolisme; DIU: inter-university degree; G2M: French network for rare inherited metabolic diseases; IMD: inherited metabolic diseases with dietary treatment. * If patient autonomous.

development of specific documents by the G2M for patients and healthcare professionals explaining the transition and how to manage it would be a helpful tool.

Disclosure of interest

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The authors declare that they have no competing interest.

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