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Department of Child and Adolescent Health and Development

# The Adolescent with a Chronic Condition

## Epidemiology, developmental issues and health care provision

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# Acronyms and abbreviations used in this report

| | |
|---|---|
| CNS | central nervous system |
| FEV1 | forced expiratory volume |
| HEADSSS | Home, Education, Activity, Drugs, Sexuality, Security, Suicide and self-harm |
| HIV | human immunodeficiency virus |
| IGF-1 | Insulin-like Growth Factor |
| IQ | intelligence quotient |
| NHIS | National Health Interview Survey |
| OC | oral contraceptives |
| STI | sexually transmitted infection |
| WHO | World Health Organization |

# Introduction

The incidence and prevalence of chronic conditions is rising in most developed and developing countries and will constitute the main cause of death by 2020[1,2]. Among children, and especially among adolescents, increased life expectancy due to improvements in nutrition, hygiene and control of infectious diseases are producing an epidemiological transition in which noncommunicable diseases including chronic diseases and disability are emerging as major health problems. This transition has already occurred in developed countries[3–8]. The management of any chronic condition during adolescence, a time of rapid growth and physiological changes accompanied by important individuation and socialization processes, constitutes a major challenge for the individual, his/her family and the health-care team. The purpose of this paper is to present data related to the epidemiology of chronic diseases during adolescence, to review their impact on the bio-psychosocial processes of adolescence and to provide evidence-based suggestions on how to manage young people with chronic conditions in a comprehensive and holistic way.

Although adolescence[a] has been defined by the World Health Organization (WHO) as the period between 10 and 19 years of age[6], most of the content of this review applies to individuals from 12 to 19 years of age, that is having entered puberty. A non-categorical approach has been used, as first defined by Stein and Jessop in 1982[9,10]. These authors suggest that there are commonalities that cross disease categories and that, while there are issues that are specific to each disease, the commonalities can be used to increase the experience of the practitioner. These cross-disease commonalties apply not only to children and adolescents, but also to their families[11]. Finally, although this paper focuses mainly on the issue of somatic diseases, its content applies to a large extent to any chronic condition, including mental illness and chronic disability.

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[a] To avoid too many repetitions, we have used interchangeably the word adolescent, teenager and young people all of whom should refer to individuals aged approximately 12 to 19 years. We have attempted to use both genders (e.g. he/she or his/her) whenever possible.

# 1.

# Epidemiology

The prevalence of chronic conditions among adolescents is difficult to assess due to the lack of quality data focusing specifically on this age group, as well as the diversity in methodology and definitions used[12,13]. There are many issues involved in the definition of chronic health conditions, including duration, age of onset, limitation of age-appropriate activity, visibility, expected survival, mobility, physiological functioning, cognition, emotional/social impairment, sensory functioning, communication impairment, clinical course, and uncertainty about the outcome[11]. For instance, for asthma, definitions used vary from "ever wheezing" to "ever diagnosed by a physician" with several other possibilities in between. If conditions such as mild asthma or correctable vision conditions are included, the prevalence of chronic conditions in adolescence can be as high as 15%. If the definition is narrowed, the prevalence is reduced by half[14].

Table 1 shows raw data regarding the prevalence of chronic conditions among in-school adolescents according to surveys carried out by self-administered questionnaires in a number of countries. Rates seem to be higher among males, rural residents, less privileged social classes, impoverished areas within countries and adolescents living in less educated families[12,15]. Note that the validity of these data is limited as school-based surveys may not include those with severe physical limitation who either stay at home or live in special institutions.

Tables 2 to 5 provide figures for specific conditions such as diabetes, asthma, cerebral palsy and obesity. The differences between studies quoted relate partly to differences in methodology (e.g. data from hospitals, insurance, population-based data, data from school surveys, etc.). However, even if similar methods of data-gathering are used, the prevalence of certain conditions can vary considerably between countries. For example, the incidence of type 1 diabetes in children under the age of 15 years varies worldwide, from 0.1/100 000 per year in China or Venezuela, to 36.5 in Finland or 36.8 in Sardinia, Italy[16]. These differences can also be seen between regions within the same country. In China, for example, the incidence rate varies between 0.1/100 000 per year in Zunyi to 4.6 in Wuhan, and in Italy incidence rate ranges from 7.2 in Lombardy to 36.8 in Sardinia[16]. The same variability also holds true for disability rates. For the 10–14 year age group, rates vary from 108/100 000 in Myanmar to 6726 in Canada, and for the 15–19 year age group, they range from 142.6/100 000 in Myanmar to 5099.5 in Austria[17].

Globally, the incidence of childhood cancer (under 15 years of age) is estimated to be between 100 and 150 per million. Different prevalence patterns can, however, be observed. In Europe and North America, leukaemias are the most common childhood cancers, followed by central nervous system (CNS) tumours and lymphomas, while in Latin America, leukaemias, then lymphomas and CNS tumours predominate. In Africa, lymphomas largely predominate. The incidence seems to be higher for males and to differ among races and socioeconomic status[18]. In Europe, 5-year survival rates for childhood cancers are increasing and reach up to 94% for Hodgkin's lymphoma and 65% for leukaemias[19].

# 2.

# The reciprocal effects of chronic condition and adolescent development

The development of the individual during this period of life can be divided into three main stages: early, middle and late adolescence, each characterized by specific biological, psychological and social steps (see Table 6). While any chronic condition can potentially affect these developmental processes, the reverse is true; that is, both physiological change and psychosocial adjustments can have an impact on chronic conditions. As a prerequisite to adequate health care for young people with chronic conditions, this section of the paper reviews these reciprocal effects of chronic conditions and adolescent maturation, as summarized in Table 7.

## 2.1 Effect of chronic disease on growth and puberty

Chronic illness may delay growth, puberty and the maturation of other biological systems through lack of nutrients (malabsorption in cystic fibrosis and other gastrointestinal disorders; competition for nutrients from chronic inflammation and infection; increased nutritional requirement from excess physiological work (e.g. asthma), toxin excess (e.g. renal or liver failure; hyperglycaemia in diabetes; interference with Insulin-like Growth Factor (IGF-1) generation); down-regulation of hypothalamic hormones (gonadotrophins, growth hormone) due to chronic inflammation, nutrient unavailability, low weight, hypothalamic damage (thalassemia), stress (reducing growth hormone production) and cytokine production (e.g. in juvenile chronic arthritis); stress reducing hypothalamic drive; and the side-effects of medications such as steroids*[20][a].

Delayed growth and puberty are common to most adolescents with chronic illnesses, although more common in those where malnutrition and chronic inflammation are also a factor (e.g. bowel disorders, cystic fibrosis). This delay may be transient, with later catch-up growth producing normal adult heights, however permanent growth loss may also occur. Large birth cohort studies, such as the British 1958 birth cohort[21] of 12 537 subjects, found that physical chronic illness of any type in childhood and adolescence made no difference to adult height, whereas children with psychosocial chronic illnesses (e.g. enuresis, mental health problems) were on average 1cm shorter as adolescents and adults, a finding which remained significant after controlling for confounders such as socioeconomic status***[22].

### *2.1.1 Asthma*

Both cross-sectional and longitudinal studies have shown minor reductions in growth with asthma during adolescence and also at final adult height, occurring predominantly in children with severe disease. A recent large Swedish study**[23] of over 20 000 young men at final height showed that asthma in childhood/adolescence was associated with a 0.7cm reduction in final height; however recent UK data suggests that only those using inhaled steroids at moderate to high dose (>400ug per day) had significantly reduced stature during adolescence**[24].

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[a] In an attempt to ascertain the strength of the evidence in the various areas covered by the paper, the main references are preceded by an asterisk: the strongest evidence (meta-analyses, systematic review or double-blind rct) is marked with four *; three * refer to cohort, case-control studies and longitudinal surveys; two * to qualitative research, case or observational study; and one * to unsystematized review or expert opinion

### 2.1.2 Diabetes

Longitudinal data on the effects of chronic illness on adolescent development are sparse. One longitudinal study of annual self-reported development in 86 adolescents with type 1 diabetes mellitus and 103 healthy comparison young people found that in the first year of the study, those with diabetes reported delays, compared with their healthy peers, in some developmental tasks, particularly physical maturity and an independent lifestyle[25]. However, these delays had resolved by the end of the five-year longitudinal study***[25,26]. Mild delay of around a year in pubertal timings is common in young people with poor control of type 1 diabetes**[27,28]. This is frequently accompanied by transient growth retardation in early adolescence[29]; however mean final height has been shown to be normal in a number of populations**[28,30].

### 2.1.3 Inflammatory bowel disease

Significant growth and pubertal delay are common in inflammatory bowel diseases, with over 50% showing reduced height velocity during adolescence and around a quarter with significant short stature through adolescence**[31]. Pubertal delay is common, even into the early twenties*[32], but little data are available on final height in these conditions.

### 2.1.4 Other illnesses

Children with HIV infection show growth suppression out of proportion to the severity of their primary illness, as a result of growth hormone resistance and enhanced cortisol secretion. In haematological conditions such as sickle cell anaemia, thalassemia, or bone marrow transplant, damage to the hypothalamus and/or pituitary may lead to growth hormone deficiency, gonadal insufficiency, and hypothyroidism**[33]. In girls with sickle-cell anaemia, recent data suggest that mean age at menarche is delayed by a mean of 2.4 years but that all patients eventually attain menarche, with weight the principal determinant of timing[34]. Growth and pubertal delay are also common among children with cystic fibrosis, along with diabetes mellitus caused by pancreatic fibrosis, whereas chronic renal disease is associated with growth and pubertal delay, as well as secondary hyperparathyroidism[33].

Many physicians dealing with young people, including paediatricians, may have few skills in assessing puberty. A recent study in adolescents and young adults with inflammatory bowel disease showed that only 20% of young people had ever had a pubertal assessment**[32], despite strong evidence that growth and pubertal delay are common in these conditions[35]. Recognition of potential endocrinopathies in children with chronic illness is an important aspect of the care of these children because the disturbances are frequently amenable to treatment, permitting full or partial restoration of normal growth and development *[33].

As noted previously, biological, psychological and social development are highly interrelated and the timing of one may affect development in other domains. The psychological and social effects of delayed puberty should not be ignored. Delayed puberty, for example, may result in low self-esteem in boys, and in difficulty separating from parents due to apparent immaturity. Adolescents affected by delayed puberty may be treated as less mature than real age by adults and peers and face difficulties in getting work due to apparent immaturity[36].

## 2.2 Effect of chronic disease on psychosocial development

### 2.2.1 Well-being and mental health

The well-being of chronically ill adolescents is determined largely by the severity of disease and the amount of treatment required, however it is also determined by the psychological and social complications that may accompany such conditions[37]. The variable nature of such complications is shown in the sometimes contradictory findings in different studies: In a meta-analysis review, Lavigne and Gaier-Routman****[38] found that the risk of psychological adjustment problems can vary across disease groups, with young people with chronic conditions more likely to display internalizing symptoms than healthy controls. Other studies[**39] found that chronically ill girls were more likely to have emotional problems than their healthy counterparts, but that the same was not true for boys. Ill youth may show a higher prevalence of at least one psychiatric diagnosis than healthy controls[40] and are more likely to experience depression or have low self-esteem[41]. In type 1 diabetes, young adults appear to be as psychologically well adjusted as their healthy peers, whereas young people with asthma appear to feel lonely, unhappy or depressed and suffer from somatic symptoms significantly more often than healthy controls[**42].

### 2.2.2 Cognitive capacities

It is unlikely that chronic illness affects the basic neuronal maturation mechanisms that underlie the development of abstract thinking capabilities in adolescence, however little data exists in this area. Certain chronic illnesses such as diabetes and sickle cell disease are known to have long-term neuropsychological effects in adolescence, although these are the result of the disease process (hypoglycaemia in diabetes[**43] and cerebrovascular accidents in sickle disease[**44]) rather than representing a generic chronic illness effect.

In contrast, there is evidence that identity, self-image and ego development are affected by chronic illnesses in a generic fashion[***45]. This is particularly true when illness is more severe and verbal intelligence quotient (IQ) is higher[****46]. Body image and the development of a sense of the sexual may also be impaired by chronic illnesses, which either distort the physical body (e.g. stomas or scars)[47] or require treatments that may be distancing to others[*48]. Population-based studies show that adolescents with chronic illness report higher body dissatisfaction than adolescents without chronic illness. These body image issues focus particularly on weight (but are not limited to those with nutrition-related conditions such as diabetes), and result in higher rates of high-risk weight-loss practices[***49]. Body image issues or dissatisfaction may theoretically impair later sexual function, although population-based studies suggest that adolescents with chronic illness have higher rates of sexual intercourse and unsafe sexual practices than healthy controls[**50]. It is possible that body image problems may act to increase risk in sexual behaviour.

### 2.2.3 Education and school

Recurrent illness and the demands of treatment regimens may significantly impact upon school attendance and educational achievement, which in turn may result in vocational impairments and loss of financial independence in adult life. Also, the developmental imperative for educational attainment may affect chronic illness through conflicts of priorities between chronic illness management and schooling requirements. Young people and their families may prioritize education over treatment during the key educational stages in later adolescence e.g. missed appointments; refusal to do lunchtime treatments; refusal of regular transfusions in sickle cell disease due to missed school[**51]. The way that health professionals deal with the educational system is key to reducing the impact of intensive educational requirements on chronic illness management[*52,53].

Teenagers with chronic conditions are more likely than their healthy peers to miss school due to their condition or to the treatment they need[**54]. School attendance may be affected by the severity of the illness, treatment adherence and psychological problems[**51], but ill young people miss more school days both due to their health problems and because they are more likely to skip school[**55]. In fact, adolescents with chronic conditions often miss more school days than can be attributed to their treatment needs[**56]. Lost school time ranges from 13% for patients with orthopaedic problems to 35% for those with cancer[**56]. Those with asthma are more likely to perceive their school performance as below average than others[**42]. Evidence from studies of adolescents with chronic arthritis also shows significantly higher school absence than the general population, and that school absence was associated with decreased compliance with physical treatments and with psychological disturbance[**51].

We must ask to what extent such educational difficulties have a long-term impact. Data from the longitudinal British 1958 birth cohort show that chronic illness in childhood/adolescence resulted in poorer educational qualifications and higher risk of unemployment, particularly in males[***57]. However, adolescents with chronic illness followed up into middle age showed no diminution of financial outcomes, except in those from lower socioeconomic classes who had significantly lower life chances and income***[58]. This suggests that the deleterious effects of chronic illness on educational and vocational outcomes may be overcome by higher family and professional support. In the clinical arena, the importance of actively helping young people with chronic illness or disability develop independent adult living and vocational skills has been shown in longitudinal follow-up studies**[59].

### *2.2.4 Family and peer relations*

The presence of an adolescent with a chronic condition imposes an increased burden on the parents[60]. The demands of managing a chronic illness and the restrictions on life-style inherent in many disabling conditions increase dependence on the family, and carers, at a time when this should be decreasing**[61]. At the same time, young people may also become dissociated from their peer group, particularly in those with taxing medical conditions and those that mark them out as very different e.g. ileostomy**[47]. Given the large range of severity of chronic conditions, as well as differences in measuring family functioning, it is once again not surprising that research findings can be conflicting: Some families cope adequately with this situation while others are overwhelmed by the problems generated by the condition. Most young people with chronic conditions describe the relationship within their family as good, although their parents tend to overprotect them*[62]. Adolescents with cystic fibrosis reveal that family members provide tangible support**[63]. While some studies found no differences in family functioning**[60], others indicate that family interaction may be lower in chronically ill young people than among healthy controls**[64]. Mothers of chronically ill children and adolescents may show higher levels of psychopathological symptoms, whereas fathers may not**[65]. This may be due to mothers tending to concentrate on day-to-day activities while fathers tend to concentrate on long-range problems and sometimes seek refuge in their work[66]. However, according to a Finland study**[67], only 7% of interviewed parents indicated that having a child with a chronic condition had decreased parental closeness. In fact, more adaptive family relationships and parental psychological adjustment are associated with positive psychological adjustment**[68,69].

Two longitudinal studies have suggested that individuals with a chronic illness in adolescence have poorer social outcomes in adult life, face more professional difficulties, are less likely to be married and more likely to be living with parents, in comparison with healthy teenagers***[57,70]. However, these results are based on historical cohorts and modern outcomes may have been enhanced by improved health care and social support.

Peer support is crucial during this period of intense socialization**[63], although the friends of adolescents with chronic illness are often younger and non-disabled*[62]. Many young people with chronic illnesses report having excellent peer relationships***[71], and there is evidence that some illnesses (e.g. cancer) may even increase peer acceptability**[72].

## 2.3 Effect of developmental issues on the course and management of chronic disease

If chronic disease can affect the growth and maturation of adolescents, conversely, developmental changes in physical, psychological and social capacities may impact upon the course and management of chronic illness in adolescence, including both self-management by the young person and supervision and treatment strategies available to health professionals. Although these concepts underpin much of adolescent clinical practice, it is not an area in which strong research evidence exists. While a significant body of work exists on areas such as adherence/compliance in adolescent chronic illness and health behaviours in young people with chronic illness, researchers have rarely taken a developmental perspective. Potential effects of developmental issues on chronic illness or disability are shown in Table 7.

### *2.3.1 Impact of growth and pubertal changes*

Puberty and the adolescent growth spurt pose a significant calorific and metabolic burden upon the healthy adolescent body, and may destabilize chronic illnesses. The evidence for this is clear in diabetes, where increased growth hormone levels cause insulin resistance**[73], but is lacking in other conditions (e.g. the more rapid reduction in forced expiratory volume (FEV1) seen in cystic fibrosis during puberty). Also, physicians not aware of the rapid growth rate and alteration of the hepatic and renal metabolism during puberty may underestimate the need for proper medication dosage.

### *2.3.2 Impact of psychological changes*

While many adolescents with chronic illnesses manage their disease and treatment regimens extremely well, reduced adherence to medical regimens and poor disease self-management can be seen as developmentally "appropriate" in adolescence*[74]. Adherence to a treatment regimen requires appropriate cognitive capacities and personal organization as well as a personal belief that the treatment is required and beneficial*[75]. Adherence is maximized when a professional-patient partnership decides management strategies in the light of the health beliefs and personal goals of the patient*[76].

Young people may have difficulty adhering to treatment regimens devised for them by health professionals and parents because of poorly developed abstract thinking, which may manifest as a relatively poor ability to plan and prepare for different situations using abstract concepts; an immature ability to imagine future consequences; and a concept of themselves as "bullet-proof" or not vulnerable to the usual rules of life. Together these cognitive issues may mean that the prevention of long-term complications of illness is a poor motivator for compliance**[77]. Additionally, adherence may be impaired because of a lack of shared health beliefs and goals with the young person's treating health professionals or family.

### *2.3.3 Impact of the socialization process*

The development of peer relationships and self-image issues (clothes, dress, public behaviours, etc.) may be in conflict with the demands of chronic illness treatment regimens or disabilities resulting from orthopaedic or neuromuscular defects. The extent to which such adolescent issues affect illness management and control will depend on how young people balance competing priorities. For example, modern diabetes regimens include lunch-time injections, which some young people find unacceptable for reasons of "fitting in" or because they prioritize social time over disease control**[78]. In chronic illnesses where young people may resort to devices or medication for regular treatment and monitoring, decisions about carrying inhalers (asthma or cystic fibrosis), insulin pens or glucometers (diabetes) or other medications may be influenced by how young people balance competing priorities*[79].

### *2.3.4 Exploratory and health-related behaviours*

Adherence and chronic illness control can be put at risk by developmental needs to explore possible modes of future behaviour, usually derogatively referred to as "adolescent risk-taking". Much morbidity in young people is generally considered to result from "risk-taking", impulsiveness, the rejection of parental values and the testing of boundaries. But the standard conceptions of adolescents as risk-takers with poor future-thinking abilities have been shown to be largely false*[80–83]. It is thus more helpful to understand so-called "risk-taking" behaviours in young people as developmentally-appropriate "exploratory behaviours"; i.e. young people exploring the diversity of possible adult behaviours open to them – behaviours that they may or may not continue as adults*[81,84]. Conversely, high family, community and school support (so-called "connectedness" or "social capital") are protective against most health-risk behaviours in adolescents***[85–87]. Identifying such "resilience" or protective factors is now the focus of public health interventions with young people in the primary care and policy settings. The search for protective factors applies equally to the management of acute or chronic illness in young people[86,88].

Substance use seems to be the same among healthy and chronically ill adolescents: adolescents with chronic conditions showed slightly lower rates of drug use (both legal and illegal) than their healthy counterparts with the exception of "ever having been drunk" that was slightly higher*[89]. A Canadian study**[55] showed higher rates of any drug use and misuse for chronically ill or disabled youth. An Australian study of risky behaviours among asthmatics found that at age 15 they were significantly more likely to use tobacco or alcohol than non-asthmatics**[42]. A number of studies have shown that young people with chronic illness and disability are no less likely than peers to be sexual active*[90] and that age of sexual debut, pregnancy involvement, patterns of contraceptive use, or sexual orientation are little different in those with different chronic conditions and the general population**[91]. The visibility of chronic conditions or disability does not appear to affect sexual behaviours in adolescents**[91].

Equally importantly, health behaviours around exercise and food are laid down in adolescence and track into adult life, including self-regulation of eating habits ***[92,93]. Adolescent obesity predicts adult obesity[94], which is strongly and independently predictive of cardiovascular risk***[95,96], and cardiovascular risk in young adulthood is highly related to the degree of adiposity as early as age 13 years***[94]. These concepts apply to healthy teenagers as well as those who suffer from a chronic disease and should be taken into account in the management of their condition. Finally, it is likely that chronic illness self-management behaviours are also partially laid down in adolescence, although there is no strong evidence that this is so. In diabetes, there is evidence that periods of good diabetic control during adolescence have long-lasting health benefits***[97], that the level of adjustment to illness in early adolescence predicts disease control in the transition into young adulthood**[98] and that psychosocial interventions to improve self-management produce long-term behaviour change*[99–101].

# 3.

# The treatment and management of chronic conditions during adolescence

In working with adolescents with any medical condition, the treatment of disease, the prevention of ill health and the promotion of healthy behaviours are played out against a background of rapid physical, psychological and social developmental changes. These developmental changes, which are unique to the adolescent period of life, thereby produce specific disease patterns, unusual symptom presentations, and above all, unique communication and management challenges. These issues are increasingly being recognized by health professionals[9, 102–105], but also by young people themselves. Qualitative research shows that adolescents experience extra effort, restriction, pain, and additional worries because of chronic illness[**106, 107]. Qualitative research with young people with a variety of chronic illnesses has also suggested a number of themes for health professionals to address when working with young people: (1) treat me like a person; (2) try to understand; (3) don't treat me differently; (4) give me some encouragement; (5) don't force me; (6) give me options; (7) have a sense of humour; and (8) know what you are doing[**106].

In clinical interactions with younger children, management decisions are made "adult to adult" by health professionals in consultation with parents, and day-to-day disease management is generally undertaken directly by parents. When working with adolescents, the wishes, desires, knowledge base, capabilities and rights of the young person involved must also be taken into account – as must the fact that these wishes, desires, knowledge, capabilities and rights are constantly evolving and changing. Different approaches are required to all aspects of the doctor-patient relationship. Specialized clinical communication skills are needed to take an accurate history, bearing in mind new life domains not applicable to children (sex and drugs) and adding communication and engagement of the young person to the standard paediatric communication with the family. Physical examinations of adolescents require consideration of privacy and personal integrity as well as requiring additional skills such as pubertal assessment, breast examination and possibly genital examinations[108–110].

Besides specific skills, the care of an adolescent with a chronic condition very often involves many professionals belonging not only to the health-care sector, but also persons and experts working in other domains such as the school, vocational and training centres, social services and specialized facilities. This part of the paper examines those aspects of the care that belong specifically to the management of the condition itself; the next part will then also present a psychosocial perspective of follow-up of the adolescent with a chronic condition, including the ways to address basic health and psychosocial needs. In fact, these two aspects (specific and primary care) are closely related and should be integrated.

## 3.1 The setting

In many cases, the management of chronic conditions requires the skills of experts, so that the main decisions regarding diagnostic and treatment procedures are normally taken by specialists from various fields. On the other hand, these specialists are not always available in the everyday follow-up, which is in many instances taken over by general practitioners or other health professionals (e.g., nurses, health workers etc.). Also, the care of adolescents exceeds the mere treatment of the condition and should include the treatment of adolescent-related health burdens and problems, preventive intervention and counselling, all activities grouped under the concept of anticipatory guidance. One way to meet these needs is to constitute a multidisciplinary team[111] which, in developed countries, is often run in specialized health-care centres and hospital and includes, as well as the specialist, various professionals such as public-health nurses, psychologists, physical therapists, dieticians, etc. The advantage of this type of setting is that it allows for integration over time of the different measures that are taken. In another care model, the specialist is responsible for the main tasks directly related to the care of the chronic condition while the management of other health and psychosocial needs is appointed to a primary care physician or another health worker who can, if needed, require the assistance of other professionals for specific duties****[112,113]. There are of course several variations of these two models but it should be stressed that the quality of the follow-up is greatly enhanced by three major factors*[84,114,115].

- Integrated and coordinated health interventions meeting the adolescent's needs overall;
- Continuity of care, that is, the persistence over time of one single, well-identified health professional who is responsible for the overall guidance of the adolescent, including discussion on critical general and specific issues;
- Privacy and confidentiality are among the features of care that are most often asked for by adolescents. The adolescent needs to establish a safe and trusting relationship with the health-care team and especially with the health professional who will be in charge of the main decisions regarding the management of the condition.

## 3.2 A developmental perspective: objectives and approaches

### *3.2.1 Tailoring information to developmental stages*

Identity forming is an essential part of the adolescent development process and implies the incorporation of any chronic condition in body image and one's self[116]. This process is gradual, and adolescence is a time during which new questions regarding the cause, the nature and the outcome of any disease or disability arise. Information and education regarding these aspects of chronic conditions must be given in a timely and appropriate manner**[114,117–119].

*Early adolescence* is characterized by heavy emphasis on physical changes prompted by the occurrence of pubertal events: during this period, information often relates to the physical and physiological nature of the disease as well as its short-term consequences. Some conditions have been present since conception but even in these instances, it is often important to provide the adolescent with extra information on issues that emerge with the rapid changes his/her body undergoes (see the section on sexual life). And when the condition occurs during adolescence, it is all the more important to accompany the teenager in the process of incorporating his/her new medical condition into his/her own identity. Also, it must be understood that, due to incomplete acquisition of cognitive abilities, the young adolescent lacks the time perspective that most adults have. As a consequence, young adolescents are mainly interested by their present state and situation and may not be able to imagine possible alternative futures. The information presented to the adolescent must take into account these specific characteristics and the physician should provide the patient with information relating to his/her present situation. For instance, stating to an adolescent with diabetes that he might have vision defects in the future if his/her glycaemia is not adequately controlled might be ineffective, whereas the physician may stress the fact that a good glycemic control may save him from hospitalization or improve his/her sports performance. Likewise, deterring a young person with a cystic fibrosis from smoking is best presented as maximizing respiratory function rather than depicting the horrifying consequences of tobacco smoke on the lungs.

While early adolescence is centred on physical changes, *middle adolescence* is intensely marked by the "individuation" (establishment of identity in his/her right) process, as witnessed by peer activities and, in some instances, rebellious attitudes. Many adolescents may feel too tightly controlled and may ask for more freedom in managing their condition. The relationship with the health-care team, even in instances where they have previously been smooth and marked by mutual respect, may be abruptly shattered by the teenager in an attempt to gain independence. When such things occur, empathy, patience and trust from the side of the health-care team are helpful: the physician should not feel personally attacked by his/her patient but should understand that these behaviours are attempts at gaining control over a condition that is difficult to accept. During these hard years for the patient, the physician may have to negotiate all aspects of the therapeutic regimen and even give up some components of treatment that are not crucial in order to maintain a relationship with the patient, with the hope that the reluctance or

**Box I**

Julia is sixteen years old and suffers from a severe lupus erythematosus. She has undergone a renal graft and takes a lot of medication including corticosteroids and immunosupressants. She was fed up with all the pills she has to swallow three times a day and asked for a reduction of the steroids which “make her look like a guinea pig”. Even though the original dosage was appropriate, her physician agreed to slightly decrease the dosage for a while. Julia was satisfied: she got the impression that her doctor understood her demand. Some weeks later, she accepted to return to the higher dose as her blood tests showed an increase in the inflammatory process.

even the opposition of his/her patient will not last too long (See Box I). Allowing young people to mix with friends and participate in peer group activities*[120] is one way to promote individuation without jeopardizing treatment. Also, in a multidisciplinary approach, roles can be distributed between several members so that one individual can become the “bad guy” whereas other members of the group may offer understanding and a place where the teenager can let go of his/her emotions and resentment.

*Late adolescence* is often marked by progressive acceptance of conditions. This can be better accomplished through several processes: In gaining more information on the medical aspects of his/her disorder, and in mastering the main aspects of his/her treatment, the adolescent progressively feels more in control of his/her situation. Intellectualization is a process through which the teenager is able to maintain some affective distance from the issues related to his/her condition and, as such, constitutes one efficient defence mechanism against the depression or anger that may result from realizing his/her differences from friends.

Thus, in the management of the patient, a delicate and continually renewed equilibrium must be found between the demands of the individualizing patient and the necessities of the treatment. Also, any encounter always includes emotional aspects alongside the medical or technical facets of the situation. Group discussions bringing together young patients with various chronic diseases have proven effective in raising the awareness of health professionals regarding the psychosocial part of the care of such young people, and may be helpful to the teenagers themselves in facilitating the expression of the emotional and psychological reactions to their condition***[121–124].

## 3.3 Disclosing and discussing the diagnosis

Breaking bad news and discussions about diagnosis are difficult tasks with patients of any age, particularly adolescents125, 126. Whether the condition is new or not, it may be appropriate to begin by asking the teenager what he/she knows about his/her condition and how they feel about it. Open questions allow the adolescent to express his/her feelings in a free way and also allow the physician to appraise his/her perceptions of his/her illness. Language must be adapted to the adolescent’s cognitive level and developmental stage. The doctor can check whether the information has been adequately integrated and retained by requiring the adolescent to reformulate what they have understood in their own language.

In many cases, the patient will want to tackle the issue of prognosis[127]. This constitutes a challenging task, especially when dealing with a potentially lethal condition or with diseases and disabilities that may impede expected professional activities, influence sexual life or have genetic implications. These issues should however be addressed as honestly as possible. The family (See Box II) should be involved as much as possible in the process*[86], but the adolescent has a right to full disclosure even though his/her parents may be reluctant to discuss these matters*[125,126,128–130].

Adolescents who suffer from invisible deficits (e.g. epilepsy, cardiac defects) sometimes have more difficulties in accepting and openly discussing their condition**[131]. In an attempt to look like their peers, they may make every attempt to avoid disclosing their disability. This can place them in difficult situations, such as not participating in peer activities for unusual or odd reasons, or experiencing unexpected medical situations that then place their peers or mentors in a difficult position (see part devoted to school health). The physician should be aware of this difficulty and encourage these young people to disclose their disease

**Box II**

John is 15 years old and has been followed up for an osteosarcoma of the femur for one year. He came to the hospital for his usual monthly chemotherapy. The resident received a note from the parents stating that John is not fully aware of his diagnosis and that the health-care team should be careful about the information that is given to him. What the young resident also learned is that John frequently suffers from severe side-effects and often gets aggressive toward the nursing team. Upon arrival, the resident asked John about how he felt about his condition and why he thought he had come the hospital. The answer was straightforward: "I have a bone cancer and I endure chemotherapy". "Did you ever discuss this mat-ter with anyone?" asked the resident. "No", replied John. "This is such a burden for my parents, I don't want to". Over the next weeks and months, with the agreement of the parents, all the issues related to the diagnosis, treatment, current and future potential side-effects of chemotherapy, and prognosis of the cancer were progressively and openly discussed with this clever and cooperative adolescent. Not surpris-ingly, the side-effects decreased and over the following years, John was eventually cured from his severe condition.

or disability to their closest friends as well as to selected representatives in their school or environment. Table 8 summarizes some of the important aspects of the patient's condition that apply here.

## 3.4 Improving adherence to therapeutic regimens

### *3.4.1 Assessment of compliance/adherence and its determinants*

Adherence to therapeutic regimens, also often named "compliance", is defined as "the extent to which a person's behaviour (in terms of taking medication, following diets, or executing lifestyle changes) coincides with medical or health advice". Bad compliance is a major cause of treatment failure[132]. Such treatment failure may induce unnecessary changes in the medical regimen and even lead to medication overdoses or underdoses. This issue is of utmost importance since it is during this period of their life that adolescents frame the way they behave towards medication and general medical measures. Concerns about adherence in adolescence have led to numerous studies of the factors linked with bad or good adherence (See Table 9)****[77,133–137]. The first task of the health professional caring for an adolescent with a chronic condition is to assess the young person's adherence to the various parts of the therapeutic regimen. In performing this important task, practitioners should keep in mind several factors. Treatment regimens involve not only the prescription of medication, but also various other measures such as physiotherapy, wearing an orthopaedic device (e.g. a brace), adopting precise nutritional patterns (such as in the case of a diabetes or gluten intolerance), avoiding certain situations (e.g. for those who suffer from hay fever, exposure to allergens) or restricting oneself from certain behaviours (e.g. for those who suffer from cystic fibrosis, not engaging in smoking), etc. Adherence to one aspect of the treatment does not necessarily mean adherence to all aspects of the regimen**[138]. For example, a young person who regularly attends all clinic appointments and seems very keen on fulfilling all aspects of his/her treatment, may in fact adhere very poorly in terms of medication taking or following nutritional guidelines. Of course, the more complicated the treatment regimen, the greater possibility for non-adherence.

There are many ways to measure adherence with medications, such as the concentration of various drugs and metabolites in the serum or saliva, or simply calculating the number of pills that the adolescent has used over time. But the most simple and efficient way is to ask the patient about how well they managed to adhere to the treatment and how they feel about the issues the treatment raises. As few people are able to achieve 100% compliance, the question should be formulated in such a way that the adolescent feels free to express himself: instead of asking "did you take your medication?", the health professional can ask "When was it the last time you were not able to take your medication?", or "How many times this week did you manage to take all your medication?" and "How often does it happen to you?"**[135–137]. Non-compliance does not mean distrust in the physician and the health-care team, nor does it equal rejection on the part of the patient. Poor adherence should be regarded as (unfortunately) relatively predictable in adolescence. Thus, when faced with a teenager who has been poorly adherent, the physician should not respond in an angry or disappointed manner. On the contrary, the health professional should thank him/her for their confidence and carefully examine with them the reasons they might not have adhered to the prescribed therapeutic measures[*138].

A lot of research has been devoted to factors associated with higher or lower adherence (Table 9)[****75,77,112,117,133,136,138,139]. Findings from these studies are conflicting, reflecting that each situation and each case and treatment are in some way different, and that it is difficult to identify features that can validly predict adherence. Most studies have focused on individual features such as cognitive factors, perception of the disease, emotional and psychological factors or characteristics of the adolescent's environment. In fact, the physician's characteristics and his skills in establishing an adequate relationship with the adolescent may be equally, if not more, important.

### 3.4.2 A contractual approach to improving adherence

Several studies suggest clues for improving adherence in general[***75,135,136,140] and of adherence of adolescents with a chronic disorder such as a diabetes, asthma or cancer[**74,132,134,135,141]. Keeping in mind what has been said before on the importance of letting the adolescent progressively gain his/her autonomy, most well-trained professionals adopt a practical tactic which processes through an ongoing assessment and negotiation of the various components of the treatment. This approach should be applied with the adolescent as well as with his/her parents/guardians, month after month. Adolescents have many personal resources [88,120] and often prove quite imaginative in suggesting avenues that may not have occurred to their health professionals. The concept of "self-management" has recently gained much attention and is a promising way to help the adolescent in his/her individuation process,[142,143] even if it has not always shown to be effective[***144]. The main avenues available to improve adherence (as described in Table 10) are as follows:

- It is not useful to provide the adolescent with information on his/her disease and treatment if he/she is not ready to integrate it: One may rather begin by asking the adolescent how they feel about his/her condition, what they already know and what they want to know (Box II). Information should be given gradually and framed according to the cognitive status of the patient. Adolescents may be given practical tools and advice as to how to control their condition and thus progressively get a sense that they are able to change positively or control their situation. Patient education and self-care (such as adolescents with diabetes setting their insulin dosage) is one of the most evidence-based, and promising avenues to improve compliance and disease outcome[***100,111].
- Emotional and psychological factors do play an important role in the management of any chronic condition. Some adolescents, confronted with a new or deteriorating disease, may refuse to acknowledge their condition, become aggressive and give up their treatment; other young people may claim that the doctors are wrong and that they can find a solution by themselves. These reactions are to a certain extent part of a normal adolescent process and should be clearly addressed as such. If these become overwhelming and cannot be managed by the usual health-care team, the adolescent should be offered psychological support.
- The parents confronted with the chronic condition of their adolescent child and its treatment tend to overprotect their son or daughter: The adolescent individuation process, which is ideally gradual, should be mirrored by a progressive distancing on the part of the parents. The skilled health professional is able to deal with this issue, which requires some help and support from the parents when the adolescent feels it is appropriate, and at the same time encourage the parents to back away when required. This means letting the parents express their anxiety or anger about the risk involved in sub-optimal compliance *vis à vis* a more tight control, which would be non-productive over the long-term.
- Tailoring the therapeutic regimen to the adolescent's needs and lifestyle is the last but most important opportunity to deal with the issue of adherence. Especially for diseases that require complicated treatments (e.g. HIV infection, control of a renal graft, advanced cystic fibrosis), every effort should be made to simplify the regimen and decrease side-effects[****137,139,145], taking into account the adolescent's current lifestyle. It is sometimes better to give up some part of the treatment than to lose the confidence and cooperation of the patient. This is particularly important as, after some weeks or months, the adolescent may regain more control over his/her emotional situation and become more

inclined to adhere to the optimal treatment. Thus, at times one may choose a slightly less efficacious regimen, but one which is much easier to take, or that one can take only once instead of three times a day, for example. One may chose to give up formal physiotherapy and encourage a youngster to engage in regular physical activity. One may allow an adolescent not to wear a brace for social events or tailor insulin dosages to important events, including the consumption of pastries, etc.

- One important issue regarding the medication doses is puberty, which involves rapid growth and hormonal changes and can greatly affect the effectiveness and metabolism of medication. The physician should always be alert to the fact that treatment failure may simply be linked with growth-related sub-effective dosage. Also, given both the importance of issues related to body changes and functioning as well as the quest for autonomy, many questions arise during adolescence, such as "what does the medication do to my body?"; "Wouldn't it be better to lower the dose of this drug, which may affect my body in a negative way?"; "Should I take the medication for a long time?"; "Wouldn't it be better to rely on natural products instead of drugs?". Feedback about the patient's understanding of the effect of the medication and of potential side-effects should be systematically elicited, focusing on those aspects that inhibit the developmental process, such as disfiguring medication which affects self-image and inhibits the teenager from engaging in social activities[116]. The duration, extent and reversibility of these effects should be discussed and an agreement should be found with the adolescent patient regarding dosage, the duration of the treatment and alternative approaches. One of the important limitations of this flexible approach is, of course, those situations in which adolescents are placed in specific rigid treatment protocols: This issue, and the constraints imposed by such situations should be openly discussed in advance with the adolescent as well as with his/her parents.
- Peer support may be of help in certain situations[120]: Self-help groups constitute a structured avenue for improving adherence and quality of life[****121,122]; the impact of mentoring from older patients suffering from a similar disease on the adolescent's self efficacy has been demonstrated[**146]. It is also possible from time to time to involve a good friend who really cares about the fate of the patient in the discussion and negotiation around the treatment. It is not always possible to set up such a group discussion or mentoring process, but there are simple ways to increase peer support: Some adolescents who become reluctant to be accompanied by their parents can be encouraged to come along with one of their friends. There is more and more evidence that patient education, group discussion and mentoring, are effective ways to increase self-confidence and autonomy, which ultimately lead to better adherence[****121,132,144,147].
- A communication style that is open, straightforward and trusting will help the teenager to elicit those circumstances or emotional factors that interfere with their treatment and help the young person to foresee avenues to solve his/her problems[****77]. Recent studies focusing on the issue of resiliency and coping strategies show that, in the long-term, close connectedness with the family circle, with peers as well as a good relationship with the health-care team, all play an important role in the emotional well-being of teenagers with chronic conditions, including better outcomes[***85,88].

## 3.5 Accompanying the family

The parents confronted with the chronic condition of their adolescent child may go back and forth between two opposite attitudes: On one hand, they may struggle to control their adolescent's disease as much as possible and become overprotective over time, which obviously interferes with the adolescent's individuation process. On the other hand, they may become nihilistic or uninterested in disease-control and even reject their son or daughter as a consequence of ongoing arguments or as a result of their own complex emotional response to the disease. The literature indicates that adequate family functioning tends to improve both emotional well-being as well as psychosocial and medical outcomes for adolescents[*86,148,149] and especially those who suffer from chronic disease[**150]. Functional parenting styles, which provide the adolescent with a firm and warm setting and that adapt in a flexible and gradual way to the teenager's individuation process, seem to increase the adolescent's coping process and his/her well-being[***62,88,151].

In fact, the arousal of feelings such as guilt, anger, injustice, depression or despair are also part of the normal reaction of parents[**152–154] to their children's chronic condition, and these feelings should be investigated. With the onset of adolescence, these feelings are often reactivated by the questions that teenagers may raise themselves or by complications that might occur as a result of the difficulty some adolescents have in accepting their condition. The health-care team should be trained and willing to deal with the parents' emotional and psychological responses to the situation[155,156]. Under severe circumstances it may be appropriate to use the skills of family therapists, if available. Parents should not – as is too often done – be viewed as a supplementary source of burden, but above all as a resource[85,149]: They have known their child since his/her birth and they observe the way s/he feels and behaves in everyday life. This precious information should not be discarded in favour of adolescent autonomy. Thus, the physician and the professionals involved in the care of the adolescent should organize areas and moments when they meet with the adolescent alone, and, depending on the state of affairs, other opportunities to meet with the parents alone, the parents with the adolescent, or the whole family. These comments are also valid for guardians/carers/parent substitutes.

Siblings should not be forgotten in this process, as they too may have important questions, as well as experiencing psychological reactions to their brother's or sister's disease, especially when faced with new events or a crisis situation[157–159]. They can act as "co-therapists" as well as their parents (even sometimes better) and provide support to the teenager facing a critical stage of his/her illness or a psychological crisis. On the other hand, they may themselves need psychological support on certain occasions[155, 160].

## 3.6 Special issues

### 3.6.1 Crises and emergencies

The adolescent developmental process tends to lead to the emergence of urgent situations and crises[161]: On the one hand, many adolescents, in an attempt to solve their problems themselves, may wait until the last minute to signal a critical situation or even precipitate medical emergencies because they ignore information that indicates a deterioration in their situation. Some emergencies arise as a result of the growth spurt and rapid pubertal changes, which can rapidly reduce an adequate dose to an inadequate and dangerous one. Other crises occur because of severe psychological distress, which may affect the adolescent alone or the family as a whole. Finally, in many instances, the situation is presented as an emergency, whereas in fact it is not: As part of the adolescent process, many teenagers tend to want immediate responses or cures to medical problems and their parents may collude in this process.

Under these circumstances, except when there is impending and immediate vital health risk, the health-care team should resist quick solutions, but instead invite the young person and his/her parents to analyse the situation, particularly the reasons for the emergence of the crisis and how it can be addressed in the best way. As a first step, the professional in charge of the overall care of the adolescent can organize a network meeting, during which all components of the problem can be discussed and several therapeutic options planned. Where things are more severe, some teams favour a short hospitalization, which will restore the medical condition of the patient both physically and emotionally, and will allow the family to take a break. Other approaches are to set up intensive outpatient treatment, usually involving all if not most involved professionals. It may prove useful for the team to plan in advance how such situations will be handled, and set up guidelines on how to handle crisis situations in different settings[162].

### 3.6.2 Management of chronic pain

For many years, the impact of chronic pain on the outcome of disease as well as on the quality of life of affected individuals has been underestimated. This is particularly true as far as children and adolescents are concerned. One major problem has become the professional fear of introducing adolescents to addictive analgesic substances (especially in countries where this issue has become pre-eminent), which has led to many young people being refused medication and other efficient measures that could greatly improve their well-being. This is all the more sad as the control of pain has been greatly improved over the past two decades, with a new focus on early intervention to control the pain at an early stage in order to escape chronicity and psychological deterioration, which may maintain a vicious circle between the origin of the pain itself and its effect on the patient's well-being.

It is beyond the scope of this paper to review the methods of pain control that are available for different circumstances**[163–165]. The psychological aspects of chronic pain should not be dismissed and one randomized study has shown effectiveness of hypnosis as an adjunct to classical analgesia in such situations***[145]. The aim of the treatment will be to discuss with the adolescent and his/her family the different options available for specific types of pain (e.g. neurogenic, nociceptive, mixed, psychosomatic, etc.) and the advantages and side-effects of various approaches. The regular monitoring of the effect of medical decisions in this area is essential, including the major issue of medication doses, which have to take into account the biological/pubertal status of the young patient, and not only his/her chronological age.

### 3.6.3 *Hospitalization and home care*

Any hospitalization constitutes a real challenge both for adolescents with a chronic condition and for the hospital staff[166–168]. In some instances, it results from failure of outpatient management (e.g. diabetic coma, severe lung infection in cystic fibrosis) and can result in acute emotional distress, with related anxiety, resentment and guilt. In other instances, the hospitalization is part of the normal treatment routine (e.g. chemotherapy, adaptation of orthopaedic device) but still constitutes a disruption in the customary flow of the youngster's life. The impact of hospitalization will depend on many factors including the purpose of the hospitalization, its length, the support the adolescent gets from their usual environment and the quality of the staff and facility.

As far as possible, even in situations that require emergency hospitalization, the purpose and practical terms of the stay should be thoroughly discussed with the adolescent and his/her family. This will help keep the patient aware that s/he has some control over the situation and encourage them to participate actively in the treatment*[114,166]. When confronted with treatment failure or unexpected complications, the adolescent should have the opportunity to discuss their causes, consequences and management. This should not be done at the onset of the hospitalization but rather once the medical condition of the patient has been improved. The progress of the disease and of the therapy should be shared on a continuing basis with the patient, and should involve the family, as long as the adolescent is offered the opportunity to discuss how he wants the information to be shared with his/her parents and relatives. If possible, one or two key members of staff should take responsibility for discussions regarding the evolution of the disease, the terms of the treatment and hospitalization and the psychological aspects of the situation*[114,166]. Adolescents should be encouraged to express freely their feelings and perception about their overall condition.

Hospitalization can result in psychological regression for children and adolescents, as it can for adults[167]. For some teenagers, it constitutes a real challenge and even a threat to their individuation process: The hospitalised youngster is abruptly separated from his/her friends and "abandoned" to the staff's control and decisions. Also, if the hospitalization lasts for several weeks or even months, it may have a negative impact on the adolescent's school and professional career. There are many ways to improve the quality of the care and environment of the teenager with a chronic condition – which will be reviewed in the last section of this paper – including specialized adolescent inpatient care units[169].

One good alternative to hospitalization is day care or home care [104,170,171]. Two studies have shown that such home care and/or home supervision improves the medical and psychosocial outcomes among children and adolescents who need continuing care***[104,112]. In this model, which may also constitute a cheaper alternative to hospitalization, health workers, usually specially trained nurses, go to the adolescent's home and administer medication (factor VIII concentrate for patients with haemophilia, chemotherapy for patients with cancer, physiotherapy for patients with cystic fibrosis). Also, the nurse can supervise ongoing treatment, answer questions, give advice regarding lifestyles, etc.

### 3.6.4 *The physically handicapped adolescent*

Even though adolescents who have non-visible defects may have more difficulties in accepting and sharing their condition; those affected by physical disabilities present with special needs that should be continuously addressed170, 172-176. Apart from those measures that can be taken within the environment, there are medical issues that need to be dealt with, such as whether the adolescent is psychologically fit to undergo a surgical intervention and what its risks are, whether they are willing to use/wear devices such as special glasses, a corset, or orthopaedic shoes, etc. The need to look similar to one's peers, to appear as

**Box III**

Ann is a 16 year-old adolescent suffering from very severe scoliosis. She was adequately followed up by a child and adolescent orthopaedist as well as by her paediatrician, but suddenly at the age of 15, she refused any further medical follow-up and her school results deteriorated. Her parents felt so guilty about her condition that they never dared to discuss the matter fully with her. The discussions were limited to short encounters during consultations at the hospital. Ann believed during her entire childhood that once she was grown-up, she would get rid of her disease. At 15, she suddenly realized that this was not going to happen. She was resentful towards her parents and the health-care team. Over some months of regular encounters with an adolescent physician, she was able to express her feelings, to accept the detailed information on her condition and finally to share her concerns with her parents in a very moving way, the parents expressing their helplessness and sadness, but at the same time their hope that she would cope with her condition and lead a fruitful and enriching existence. Little by the little, her school results improved and Ann was able to share her situation with her peers and to engage in more social activities.

"normal", which is especially powerful during adolescence, may lead the patient to abandon habits that s/he had previously accepted without much difficulty. Also, the physical limitations imposed by specific musculo-skeletal diseases (e.g. myopathy, dystrophy, severe scoliosis, neural tube defects, etc.) should be discussed and every attempt should be made to help the young patient lead a life similar to his/her peers (see Box III). The vocational aspects linked with the disability should not be dismissed*[177].

### 3.6.5 Life-threatening diseases such as cancer, AIDS and other conditions

The occurrence of a life-threatening condition before or during adolescence constitutes a real challenge for the patient, his/her family and the health-care team[178–180]. The issue of the diagnosis and of the potential outcome of the disease should be discussed, taking into account the developmental stages as well as the expectations of the adolescent[127]. The issue of HIV infection[181] deserves special consideration, such as guidance in the field of sexual and reproductive health, psychological stress both for the patient and his/her family, facing complex and potentially heavy medication, and coping with social stigma associated with HIV.

One difficult issue is the situation of an adolescent who has end-stage disease despite all possible treatment options. The approach to a dying adolescent must be multidisciplinary. The amount and nature of the information given to the patient should be discussed with the parents, especially for younger teenagers. Some patients may respond to the pending issue of their death by denying their situation, a common defence mechanism that should be respected. Other teenagers may recognize the imminence of their death and want to share their feelings openly, while their parents may not necessarily be ready to face this reality so openly. The staff should be ready to support both the family and the patient, taking into account in a respectful way their values and emotions. The management of the situation often raises ethical dilemmas, e.g. if a teenager decides to discontinue treatment while the parents don't want to, or if an adolescent asks for information that the parents feel they are not ready to deliver[128]. Also, the members of the health-care team, especially those who have managed the treatment of the adolescent over many months or years, should also be offered the opportunity for debriefing, expressing their sadness and, for some of them, their feeling of helplessness.

### 3.6.6 Offspring and genetics

In any disease with a genetic component there are questions that will arise specifically during adolescence that will have to be tackled by the physician in charge of the situation with the assistance, if needed, of a geneticist[182–184]. Additionally, the progress of gene technology may alter the treatment and outcome of several chronic conditions in the future. The first area the patient may want to explore is the one linked to the cause of the disease, as well as the physiological/genetic aspects of the transmission of an inherited condition. This questioning may also prompt other issues such as whether the patient will be able to have children, what the risk is that they might be affected by the same disease, and if there is any possibility to avoid such an outcome. All these concerns should be adequately addressed. One specific topic is the one of irradiation of the gonads or of chemotherapy that may impair fertility: Pubescent adolescents should be encouraged, if the technical facilities are available and the patient is able to give fully informed consent, to store sperm/ova to secure their future capacity to have children[185].

### 3.6.7 *Ethical aspects*

The United Nations Convention on the Rights of the Child says that: "State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child" (Article 12). The way this principle is applied differs from one context to another depending on the country's legislation: In some countries, the law stipulates that such a right is acquired at a clearly defined age, while in others, the health-care team should base its attitudes and decisions on an assessment of the patient's capacity for judgement/discernment. In any case, it is very important to take into account the stage of cognitive and affective development when making any decision. There are two main areas in which these ethical aspects play an essential role:

- **Privacy and confidentiality:** Adolescents should be offered all health care interactions in a private and confidential manner[186–189]. Specifically, the sense of modesty of the teenager should be secured by undertaking all physical examinations in an intimate setting, without the parents unless desired by the young person. Also – depending upon the age of the patient and applicable legislation – a policy regarding confidentiality should be clearly implemented, stating that some information that the adolescent shares with the health worker should not be disclosed to other people, including the parents, without his/her own consent (unless the young person discloses the possibility of harm). As many adolescents with chronic conditions have been treated for many years, sometimes since birth, this matter should be discussed well in advance with both the individual and his/her parents, so that with the occurrence of puberty and adolescence, the need for privacy and confidentiality will occur as a natural part of the therapeutic setting. Confidentiality is considered by many teenagers as a prerequisite for any trustful relationship with a health-care worker[190–192].
- The same principles apply to the issue of **information and informed consent.** The more mature the adolescent is, the more freedom he/she should enjoy as far as the choices regarding his/her treatment are concerned. It has to be stressed however that such decision-making autonomy is submitted to one condition: That the health-care professional provides the adolescent patient with detailed and individualized information, which gives them the opportunity to reflect soundly on the various options they have to make up his/her mind[190,191].

# 4.

# Global care of the adolescent with a chronic condition

## 4.1 An interdisciplinary network approach

The preceding section has mainly concentrated on the treatment of the chronic condition itself, whereas this section concentrates on the general health issues that all adolescents face, including those suffering from a long-lasting disease. While the bio-psychosocial adolescent process may interfere with the progress of chronic disease, the reverse holds true and any chronic condition can potentially affect the development of a teenager. The aim of the health-care team will be to reduce the impact of the disease and allow the adolescents to maintain a life as similar as possible to their friends and to encourage them to engage in a fruitful professional career as well as in meaningful affective and social relationships.

It is difficult for a single physician to tackle all the aspects of their young patient's health, especially if the treatment needs the intervention of highly sophisticated therapeutic tools and interventions. Moreover, some treatments require the intervention of several health-care professionals, including physicians from several specialties, psychologists or psychiatrists, physiotherapists, dieticians, etc. It is thus important to provide the patient with an integrated and coordinated approach to all these aspects. One person, a reference professional, usually a primary-care physician[113] or a nurse should be responsible for the coordination of the various aspects of follow-up. Ideally, meetings gathering the professionals in charge should take place on a regular basis to make decisions. Professionals outside the team, and from other fields, should also be involved in the follow-up. The reference person should establish and maintain connections with the school nurse, the teacher, or when needed a social worker or any adult in charge of specialized facilities**[16,103,114,118,166]. The contacts should be established with the approval of the patient and his/her family and key information should be shared openly with them (in accordance with privacy and confidentiality principles outlined above). Some of the network meetings can be held in the presence of the patient, especially when s/he gets older (See Box IV).

## 4.2 Primary-care needs and general guidance

### 4.2.1 General health needs

Adolescents with a chronic condition do not only have an illness or a disability, but also have the same needs, physical and psychosocial burden as their peers. Several studies have addressed this issue and shown that these needs are often not adequately met or may even be ignored in adolescents with chronic

**Box IV**

Sandra has been treated for type 1 diabetes for 12 years. At the age of 14, her condition deteriorated rapidly and she was admitted to the hospital several times over the course of one year. She smokes cigarettes and admits having occasional sexual intercourse with school friends. The parents were desperate and the school nurse pointed out that Sandra was missing school frequently. Her classmates were also very concerned about the situation. During a discussion with the psychiatrist, Sandra disclosed the fact that, one year before, she had been physically and sexually abused by a neighbour – a friend of her parents. She was appalled by the event but had not spoken about it to anyone until then. The psychiatrist, after some discussion, obtained from the girl a clearance for revealing the abuse and then organized a meeting with the parents, the school nurse, the family physician and the diabetologist. A regular psychiatric follow-up was planned and the patient's insulin dosage was checked for a while by the school nurse. An appointment with a gynaecologist was organized. Little by little the diabetes became better controlled.

Box V

A special programme has been set up in a European clinic to take care of adolescents with type I diabetes. A nurse educator meets adolescents in their daily settings (home or school). The nurse educator is felt to be different from the paediatric diabetologist, since her priority commitment is the contact with the adolescent and the assessment of his/her situation. Evaluation of diabetes control and treatment requirements is also a concern of the nurse educator but may not be perceived as the first priority by the patient, so that communication may be easier than in the outpatient clinic. The service is either ordered by the physician or requested by the patient (or family) and is community-based. The service gives priority to crisis situations. However, some adolescents in crisis do not use the service because they either refuse this type of assistance or because the critical nature of the metabolic or mental situation requires admission to hospital. It is part of a global problem-directed strategy to delay/prevent diabetes complications and to preserve a quality of life. The service in itself, however, targets the adolescent as a person more than in traditional care, which tends to prioritize the problem of diabetes. The service aims to assist an adolescent in the difficult setting caused by diabetes, to find his/her personal resources and strengths. This may be conceptually consistent with resilience. Following this experience, similar services were created for other chronic conditions (e.g. cancer, cystic fibrosis). The key supporters are a national institution aiming at preventive paediatric care, as well as hospitals and the national social security services. An annual multidisciplinary consultation meeting is held to review progress and outcomes, and involves nurses, dieticians and psychologists as part of the educational strategy.

conditions**[193,194]. Moreover, other studies have shown that a comprehensive holistic approach improves the outcome of the chronic condition itself***[87,100].

Initial issues may be related to growth and puberty: Mild to severe acne, which may contribute to further deteriorating self-image, questions related to the development of one's breasts and genitals (gynecomastia, breast asymmetry, dysmenorrhoea, etc.), or concerns about actual and future growth[116]. Similarly, these adolescents, because they are known to be already followed up by physicians, may escape the customary vaccination plan and general screening process that their peers undergo within the school or health-care system. Functional symptoms are common among teenagers with chronic conditions: Fatigue, sleep disorders, headaches, backaches and stomach-aches should be adequately addressed. One problem that arises frequently is that some of these complaints can mimic complications of the underlying disease itself and may thus lead to unnecessary worry and avoidable investigation. It is important to investigate simultaneously the physical and psychological aspects of these symptoms (See Box V).

The adolescent's mental health and psychosocial concerns, such as anxieties or depressive mood, should be taken into account. The patient should be offered the opportunity to express any distress related to his/her psychological development tasks and family/social relationships[195,196]. The family and siblings can provide the adolescent with much support**[150]. Educational and psychotherapeutic assistance can greatly improve the adaptation of the adolescent to his/her condition and situation**[100,197].

## 4.3 Lifestyles: anticipatory guidance and prevention

Several recent surveys have shown that adolescents with chronic disorders engage in experimental behaviour and place themselves in risky situations as often, or even more often, than their peers**[39,50,88,90,91,115,198]. Thus, while one may think that these teenagers are less involved in social activities or inhibited in their individuation process because of their disease and the possibility that their parents might overprotect them, this in fact may not be the case. It may well be that their tendency towards placing themselves in risky situations such as not wearing helmets and other protection devices, abusing substances or engaging in unprotected intercourse is linked with a unconscious desire to "be alike"**[198].

As a result of these findings, the health-care team in charge of patient follow-up should include surveying his/her health habits and lifestyles in the adolescent's regular assessment. This activity of anticipatory guidance requires specific knowledge and skills and may most effectively be delegated to a trained nurse or a general practitioner. Table 11 summarizes the main areas to be covered, using the concept developed under the acronym HEADSSS[82,199]. The team should be able to manage the current situation and provide the adolescent with adequate counselling in all these domains. They should also have identified appropriate professionals and institutions to refer the adolescent if needed[*103].

### 4.3.1 Sexuality

As discussed in the preceding section, several chronic disorders affect the sequence and development of puberty and as such interfere with the way the teenager integrates his/her image as a sexual being and the formation of his/her identity. Also, some diseases and disabilities impair the capacities to experience sexual pleasure, to have sexual intercourse and to conceive and give birth. Several studies have shown that teenagers with a chronic condition tend to engage in an active sexual life, including sexual intercourse, at an earlier age than their peers[**50,91,198]. It is very important, therefore, for the health-care provider to reflect on the meaning of sexuality for his/her patient: Whereas many doctors will naturally think of some issues related to sexual life among girls, including the areas of contraception and protection against sexually-transmitted infections (STI), they often tend to overlook the concerns of boys, who may feel less concerned by the issue of pregnancy or parenthood, but for whom the development of genitals, ongoing pubertal events and the emergence of sexual feelings and desire are of utmost importance. The question of "normality", with the development of a sexual body, is a central question that has to be addressed in both sexes.

#### *4.3.1.1 Contraception and protection*

The issue of contraception should not be dealt with in a different way from any other adolescents[90,200,201]. Even though many teenagers may be more aware of the importance of using condoms, many female adolescents prefer to use oral contraception, which still offers a higher rate of protection against pregnancy than any other measure. There are some special physiological and psychological considerations that should be kept in mind: The course of some illnesses (e.g. autoimmune diseases) may be affected by pregnancy, which makes the use of contraception particularly relevant; hormonal contraception can have a deleterious effect on the course of some conditions (e.g. among patients with diabetes); hormones can interfere with the metabolism of prescribed medications (e.g. anticonvulsants); some adolescents may feel that, because of their illness, they cannot have children: and, they may give up the use of any contraception, with the secret hope or possibly unconscious desire to induce a pregnancy. It is beyond the scope of this paper to review in detail the specific aspects of pregnancy and oral contraceptive prescription in each chronic disease, but Table 12 provides some examples of typical situations.

#### *4.3.1.2 Sexuality and physical disability*

Physical disability imposes very special challenges on the patient, the health-care providers and the parents[202–205]. As they suffer from various disabilities or chronic conditions, these adolescents are often not viewed as sexual beings by their parents. As they are often looked after in special facilities, they may not benefit from the sexual education and the guidance their healthy peers have access to. Some of them express their needs in a crude fashion that often creates unease among parents and other adults. In other cases, parents view adolescents with physical disabilities as individuals with no sexuality, while educators tend to consider them as hypersexual. Moreover, puberty forces the parents to face again their grief over the loss of what they might see as a "perfect" child and/or the fact that their child may not be able to have and raise children. Thus, the role of the health-care worker as well as surrounding educators will be to guide both the parents and their child in this process of identity formation, and the question of "normality". For those who have disabilities directly or indirectly affecting the reproductive system (spina bifida, malformation of the urogenital track), questions of sexual feelings and emotions as well as the capacity to experience sexual pleasure become a central concern during puberty.

Some situations raise difficult psychological and ethical issues as well. For example, at what time should these concerns be discussed and how should adolescents be provided with, for example, appropriate counselling? There are no straightforward answers to these issues, but a multidisciplinary approach with professionals who are familiar with these situations is helpful[*111,202–205]. The teenager should be encouraged and, if needed, helped to discover his/her body as soon as possible; the use of drawings, films, models, puppets, and mirrors may be helpful; techniques such as relaxing massages, can be of great value for severally disabled adolescents (if provided by experienced professionals with transparency and full consent), as well as a discussion of forms of sexual encounters other than penetrative intercourse. Because of their vulnerability, these adolescents constitute a high risk category in relation to paedophiles, and they should be specially informed about sexual abuse and the importance of being able to say no in situations where they may be sexually exploited.

## 4.4 School and training

The area of school, vocational prospects and professional training should be addressed in a timely way[206]. During early adolescence, as during childhood, the focus is on minimizing the impact of the condition on school education, while over the years, the question of the choice of a career becomes an increasingly important issue.

### *4.4.1 Adaptation to school, and school health*

The issue of school health should be tackled from a broad perspective*[100,207]. The first question that generally arises is related to the information which is given to the school health staff (if existing) and to the teachers and classmates. For understandable reasons, many parents and teenagers are reluctant to disclose some conditions, for fear that they may become labelled and stigmatized (e.g. in case of epilepsy, which is often confused with mental disease in certain cultures). More commonly, young people, from an understandable wish not to stand out, do not communicate any information on their disease, which may lead to the development of a crisis situation within the school (diabetic coma, cardiac failure, severe asthma attack, etc.). Both the parents and the teenagers should be strongly encouraged to disclose information in an appropriate and stepwise manner. The school health nurse or physician should be fully notified of the situation, whereas the briefing to the teaching staff should be restricted to those pieces of information that they need to know to support the pupil or to cope with critical events[52,207]. This process should be as open as possible and run with the consent, and if possible, with the assistance of the patient. In a regular fashion, information should be exchanged between the health-care team, the school health staff and the teachers.

The issue of absenteeism is of particular relevance. Severe chronic conditions often induce frequent hospitalizations and the health-care team should try to link with specialized in-hospital teachers (see below) or establish cooperation with teachers or classmates to allow the patient to cope with the schooling programme[100]. Some conditions require the adaptation of the physical environment or the use of technical devices. These themes should also be discussed. In rare instances, it may be more appropriate to educate some young people in special facilities and many countries have created special institutions for severely physically handicapped children. However, to avoid discrimination as much as possible, every effort should be made to integrate adolescents with a chronic condition – including those with physical disabilities – into a normal school environment.

### *4.4.2 Vocational aspects, choice of a profession*

While there are careers that are contraindicated for some adolescents because of potential interference with their condition, health-care professionals should be cautious about advising their patient too restrictedly[173,174]. In fact, many diseases that may at first glance appear to make career choices unsuitable do not represent an absolute obstacle. For instance, patients with a well-controlled epilepsy may not suffer more injuries than healthy subjects*[208]. The health professional should thus adopt the position of an advocate. Faced with a teenager who has specific wishes about a career, the doctor should examine the issues with workers from that profession to identify to what extent it is possible to adapt the situation to his/her patient's condition. In other cases, instead of discouraging the young person, he/she may explore with him/her and his/her parents possible alternatives to the expected career. This ergonomic and psychologically sound philosophy can be better developed through a multidisciplinary approach involving the whole family, representatives from the expected career, social workers and, if available, specialized vocational counsellors*[111].

Box VI

Tevfik is 15 years old and suffers from severe hay fever. For a long time, he planned to become a baker and had found a position as a trainee in a good bakery that is part of a shopping centre. He came to the doctor some months before the beginning of his training because the law requires a check-up. The physician was doubtful about encouraging him to take on this assignment because of his allergy and asked for the opinion of an allergologist, who warned the boy of the risk of developing a severe flour allergy, which might ultimately force him to abandon his career. The boy, as well as the parents, were distressed. Tevfik wanted to try this job notwithstanding the risks. The family physician gathered the parents, the boy and one of the members of staff of the shopping centre, who is in charge of younger bakery trainees. During the discussion it transpired that the member of staff had himself suffered from a severe flour allergy and had been forced to leave his position for another. He convinced the patient to change his mind and engage in a commercial track.

## 4.5 Socialization

One of the very best ways for any adolescent to engage in his/her individuation process is to rely on peer relationships[209]. Indeed, peers provide one another with support that enables them to break loose from their parents and adults in general[**62,120,121]. Moreover, it is with peers that adolescents exchange a lot of ideas and feelings and these encounters greatly contribute to identity formation. Adolescents with chronic conditions are no exception to this rule, and it is thus both important and helpful to encourage all forms of socialization. The health-care team can promote this process in several ways such as discussing this issue directly with both the parents and the patient, examining how the organization and the content of the treatment can be modified according to the adolescent's lifestyle or encouraging the young person to join informal and formal youth groups such as sports clubs, theatre and music associations, scout organizations, etc.

Self-help organizations that bring together the families of individuals with specific diseases can be useful to organize special events such as conferences, outings and tours, which promote exchanges between adolescents facing similar situations[210,211]. They also often provide information on the internet.[a] Some health-care teams, often with the support of self-help organizations, set-up special camps that constitute an opportunity to openly discuss issues related to therapeutic regimens and more general issues related to specific conditions. It has been shown that these camps can positively affect the medical condition of participants suffering from asthma or diabetes. In the same way, health-care facilities may set up special encounter groups that bring together teenagers suffering from the same condition, fostering discussions of issues such as adherence to therapy, relationships with healthy peers, school and vocational concerns, etc.[***120–122].

The whole issue of the social integration of adolescents with a chronic condition extends beyond the framework of the family, the school and health-care setting to the whole society and is discussed in the last part of the document.

## 4.6 Transition into adult life, moving into other health-care settings

As more and more adolescents with potentially lethal conditions (e.g. cystic fibrosis, cancer, renal disease, HIV infection) survive longer and enter adulthood with a reasonably good prognosis, the issue of the transition from the paediatric setting to the adult setting has become an important topic and has led to numerous recommendations[175–177,213–225]. There are specific questions that need to be addressed:

- To what extent are patients and their families ready and willing to leave the surroundings that have provided care, often for many years and which they usually trust? Many professionals are confronted with what they perceive as a resistance from the patient to the inevitable decision to move to another setting.

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[a] Such sites can be found on various lists of organizations such as www.self-help.org.uk/selfhelp.cfm or www.healthlibrary.com/favorites.html

### Box VII

Each year, a large US hospital runs a camp for young adolescents suffering from diabetes. The strategies set-up in the camp encompass several areas**[212]:

- videos followed by group discussions
- group sessions tackling specific treatment and compliance issues
- individual and group counselling targeting specific coping avenues and strategies:
  - sports activities to compensate for food intake
  - how to escape or cope with tempting situations
  - how to get pleasure in life apart from good food

Results suggest that the intervention has a reasonable impact. In addition, anchored instruction improved some people's dietary self-efficacy and changed adolescents' estimates of how often they would use selected cognitive and behavioural strategies to solve dietary problems.

- Are adult health professionals available to care for the specific needs of old adolescents/young adults? Are they ready to cooperate actively in the transition process?
- Has the health-care team developed specific strategies and policies for a smooth move towards the adult health-care setting?
- To what extent does this process include an emphasis on global care, including a multidisciplinary approach to issues such as compliance, school and professional concerns, as well as psychological well-being and quality of life?

There are several avenues to an integrative transition, but a recent study has shown that it is not so much the "resistance" of the patient and his/her family to give up a setting they have been accustomed to that constitutes an obstacle, but the lack of a structured transition programme224, 226. So-called resistance is often more derived from the professionals than the patient. The whole team should thus reflect on issues such as their own grieving processes and they should develop specific strategies to overcome barriers to adequate transition. Research within focus groups with young people has suggested a number of strategies (see Table 13)**[123,124,223–225]:

- The patient and his/her family should be brought face-to-face with the issues at an early stage, before the procedure actually takes place, as a long-term prospect. On a regular basis, the adolescent should be asked how s/he sees the organization of the transition process.
- The team should identify, as early as possible, professionals who are aware of the challenges that such a situation represents and who are in a position to cooperate actively.
- One or two adults, well aware of the situation, should accompany the adolescent and his/her family in the process, exploring the two settings, attending the consultation in both locations, and assisting the patient in expressing the main concerns s/he has and the main challenges s/he perceive.
- Supporting individuals, adults, peers or professionals outside the team should be identified, who will assist the patient in the transition and provide her/him with resources and encouragement[87,120].

There are transition programmes that have been evaluated and have proven effective over time, both in terms of medical outcome and quality of life**[226].

# 5.

# The organization of care for the adolescent with a chronic condition

Due to the increasing incidence and burden of chronic conditions, the issue of ample access to and adequate organization of health care, of appropriate follow-up and of social integration of this part of the population constitutes one of the major challenges that every health-care system will face over the next decades[3,227]. This part of the paper reviews some aspects specifically related to the situation of the adolescent with a chronic condition.

## 5.1 Youth-friendly services

Over the last few years, there has been a growing awareness of the importance of reframing the programmes and facilities directed at young people in a way that allows for better access and quality of care. Young people themselves have been actively involved in this process and have identified specific aspects and conditions that, if met, greatly contribute to their satisfaction with health care and, in the long term, help them to cope better with their situation[228,229]. In fact, adolescents have many ideas about how to make services user-friendly: Generally, they stress ethos over the technical quality of services[*230]. These principles are of particular relevance to teenagers with a chronic condition, because of their frequent use of health-care structures. Most of these principles apply to outpatient facilities as well as inpatient units, whether specialized in adolescent medicine or serving a general paediatric or adult population. Table 14 summarizes the most important aspects [*230–233]:

- Availability and accessibility to health-care services, a youth-friendly environment and friendly procedures can be developed in many ways: In making the community and the patients well aware of the existence of all available services, their objectives and service hours[**87]; in acknowledging the values that underpin the everyday work and making policies regarding privacy and confidentiality explicit[189]. Such measures contribute to creating a positive image of service functioning and make them more attractive. Easy registration/retrieval procedure, short waiting time, opportunity for "drop-in" without prior appointment and free or inexpensive services and flexibility about payment are important aspects as well. Among other factors, one may cite an appealing milieu, good facilities, convenient working hours and convenient location. Active participation of young people in the design of the environment and of the procedure increases the appeal of such services, despite impressions that the skills and capacities of the staff appear far more important than the physical appearance of the building.
- For adolescents, a youth-friendly staff is formed of professionals who are technically competent, interested and concerned, who are understanding and considerate, easy to relate to and trustworthy, as well as able and willing to devote adequate time. Moreover, they can be easily reached by phone for additional information. Ideally, the staff should not only be able to treat major illnesses but also to provide counselling in specific areas (e.g. sexuality, vocational issues, etc.) as well as general information on health topics[*114,166].
- Continuity of care is of particular relevance to adolescents with a chronic condition. An ongoing trusting relationship will ensure better adherence to the therapeutic regimen and allow for an in-depth understanding of psychosocial issues related to the illness and the patient's situation. Strong linkages to other health and social service providers are also considered very important.

All these principles can be more easily met within an environment that is specifically devoted to adolescent medicine, but it is quite possible to adapt units focusing on specific diseases to meet many of these conditions.

### 5.1.1 *Setting user-friendly facilities*

Many adolescent medicine outpatient units will bring together multidisciplinary teams[111], including physicians, psychologists, nurses, social workers, youth workers, etc. The effectiveness of such a multidisciplinary approach is enhanced by regular meetings taking place with the participation of the patient and his/her parents. When it is not possible to establish such a team, a close linkage should be set up with those professionals in charge of specific aspects of the patient's life, which still allows for a good collaboration between all these key people.

The hospital environment deserves special consideration[109,166]. It should be organized in a way that allows for high-quality health care, but at the same time facilitates social relationships with peers within and outside the hospital. As it is not possible to build distinct adolescent wards in every hospital[169], general hospitals and paediatric wards have been encouraged to set up special rooms and programmes devoted to adolescents. A close link should be established between the team responsible for both in-patient and outpatient care.

During longer stays, the adolescent should benefit from psychological support if needed, a link with the school system and opportunities for studying, the possibility to receive calls and visits from his/her relatives and his/her peers and finally, if the budget allows, leisure activities such as television, access to a local library, or access to computer/internet games. Such a global approach has been shown to improve the medical outcome, at least for certain diseases**[87,100]. In fact, affected young people often have their own ideas as to how to improve their stay, and even in the absence of specific areas, it is possible to provide the patient with specific adaptation and creative modification of the environment that improves his/her quality of life within the hospital**[229].

Day-care is an excellent alternative to hospitalization when an adolescent faces a critical situation. It allows him/her to keep a close relationship with the parents and peers. Also, more programmes now provide complex treatments (chemotherapy or chemoprophylaxis, antibiotherapy, etc.) administered at home or at school by trained outreach nurses****[104,112,170].

## 5.2 Reframing the health-care system

Apart from policies directed at the improvement of health-care facilities, there are other more general measures that can be taken to improve the situation of adolescents with chronic conditions. They include a change in the philosophy of health care and the training of professionals and policies directed at environmental modifications. The philosophy of health-care delivery should evolve from an "acute and fix" model towards a coordinated comprehensive system of care. Many countries have already developed policies, avenues and financial incentives to tackle this challenge[3,234]:

- The integration of primary care and treatment of the chronic condition is achieved through tight collaboration between primary care workers and specialized units/hospitals. Resources must be available for such a coordination process and in some instances, specialized professionals trained to achieve it.
- Day care is less expensive than hospitalization and in many instances can be moved to a location closer to the individual suffering from a chronic condition****[170].
- Home care***[104,112] is encouraged so that the rate of hospitalization is decreased. In certain instances, parents and relatives can take over some of the tasks that are traditionally done by health workers.
- As far as adolescents are concerned, a close link is required with other sectors such as the social sector (e.g. financial issues) and education**[100]. The school health system is pivotal to the integration of adolescents with chronic conditions and the school nurse plays a critical role of coordination between the adolescent, his/her parents, teachers and the health-care team.
- Some adolescents with severe chronic conditions – especially severe mental retardation and disability – cannot adapt adequately to standard living environments: Policy- and decision-makers should support the development of specialized centres that allow for an integration of health care and education[235].

Box VIII

Some years ago, the Adolescent Health Programme of the University of Minnesota, which has developed notable expertise in the care of adolescents with chronic conditions, set up an initiative to raise the awareness in the general population of the special needs and challenges that young people with chronic conditions face. Over two days, several journalists were asked to follow an adolescent in a wheelchair in his/her everyday activities: Getting out of bed, washing, going to school, engaging in a sport activity, etc. On their own, the adolescents had to prepare a short paper to recount what this experience had brought to them. The impact of the initiative on media coverage has been impressive and the experience has proven fruitful and enriching for the adolescents themselves.

- Medical schools and the school of nursing play a pivotal role in increasing their students' awareness of the issue of chronic disorders in adolescents. The training should not only deal with the care of the illness itself but also include the areas of quality of life and social integration[236–239].
- The issue of the financial burden that several chronic conditions impose on families should not be overlooked. While many developed countries have set up insurance systems to cover most of the medical costs, this is not the case in developing countries or poor communities. One alternative is to put as much emphasis as possible on close interdisciplinary collaboration at the community level**[87,104,171]. Even in developed countries in which insurance systems exist, the impact of certain chronic conditions is so large that many additional expenses are not covered[234].

## 5.3 A friendly environment

The production of an adolescent-friendly environment imposes two kinds of measures both at the physical and social levels. Environmental and architectural measures can be promoted to allow for a better integration of young people with chronic conditions/disabilities[234]: Promoting smoke-free schools and leisure facilities, for example, to take into consideration the presence of adolescents with chronic respiratory diseases (e.g. cystic fibrosis, asthma), as well as designing ramps and elevators for those with walking impairments. While for many years this was confined to facilities for those with physical disabilities, the trend over the last few years has been to expand this policy to all public spaces including shops, museums and theatres, public transportation, etc. The goal of such an approach is two-fold: On the one hand, it allows adolescents to live a life as similar as possible to their peers and to share activities with them; on the other hand, in allowing adolescents with a chronic condition to mix with their peers, it makes the latter more aware of what the life of affected teenagers is like and thus increases their social integration (see Box VIII). For instance, the city of Heidelberg (member of the WHO "healthy cities" network) has recently set up a programme that aims to avoid the stigmatization of young people with various problems by promoting the mix of generations[240].

# 6.

# Tables

**Table 1: Prevalence of chronic conditions among adolescents according to surveys carried out in school populations by self-administered questionnaires**

| Areas | Age group | Prevalence |
|---|---|---|
| France (1993)[241] [(a)] | 11–19 years | 8.3% (F)<br>9.0% (M) |
| British Columbia, Canada (1992)[242] [(b)] | 13–19 years | 11.0% (F)<br>7.0% (M) |
| Switzerland (1992)[243] [(c)] | 15–20 years | 11.3% (F)<br>8.3% (M) |

(a) Defined as youth with non-specified physical handicap or chronic illnesses.

(b) Includes conditions such as: diabetes, epilepsy, scoliosis, arthritis, asthma, hard of hearing, attention deficit disorder, physical handicap and hypertension that somehow limit their daily activities.

(c) Defined as youth with non-specified physical handicap or chronic illnesses.

**Table 2: Prevalence of type 1 diabetes mellitus**

| Areas | Type of survey | Age group | Prevalence |
|---|---|---|---|
| Alexandria, Egypt (1985)[244] | School-based | 14–16 years<br>15–19 years | 0.06%<br>0.14% |
| United States (1988–94)[245] | Population-based | 12–19 years | 0.41% |
| Benghazi, Libyan Arab Jamahiriya (1990)[246] | Population-based | 0–19 years | 0.059% |
| Manitoba, Canada (1985–93)[247] | Population-based | 0–14 years | 0.12% |
| Southern China (1991–1992)[248] | Population-based | <15 years | 0.0083% |
| Japan (1980–89)[249] | Population-based | 0–14 years | 0.01% |
| British Columbia, Canada (1991)[242] | School-based | 13–18 years | 0.07% |

**Table 3: Prevalence of asthma**

| Areas | Type of survey | Age group | Prevalence |
|---|---|---|---|
| Israel (1989)[250] | Retrospective survey | 17–18 years | 2.65% (M)<br>2.14% (F) |
| Rabat, Morocco (1992)[251] | School-based | (not known) | 3.4% |
| United States (1994–95)[252] | NHIS | 12–17 years | 1.63% |
| State of Guerrero, Mexico (1999–2000)[253] | School-based | 4–6/13–14 years | 33.55% |
| Mérida, Yucatan, Mexico (1994) | School-based | 6–12 years | 12.0% |
| Six cities, Brazil (2001)[254] | School-based | 13–14 years | 9.8% (M)<br>10.2% (F) |
| Campos Gerais, Brazil (1996)[255] | School-based | 13–14 years | 28.5% |
| Ten regions, Italy (1994–95)[256] | School-based | 13–14 years | 10.4% |
| Melbourne, Australia (1990)[257] | School-based | 15 years | 22.0% |
| St. Gallen, Switzerland (1990)[257] | School-based | 15 years | 4.3% |
| La Serena, Chile (1990)[257] | School-based | 15 years | 7.4% |
| China, province of Taiwan (1995-96)[258] | School-based | (not known) | 10.0% (M)<br>7.0% (F) |
| Chandigarh, India (2001)[259] | School-based | 9–20 years | 2.6% (M)<br>1.9% (F) |
| British Columbia, Canada (1991)[242] | School-based | 13–18 years | 18.2% (M)<br>25.8% (F) |
| United Kingdom (1992)[260] | National sample | 14–17 years | 13.5% |
| Patras, Greece (1978)[261] | School-based | 8–10 years | 1.5% |
| Patras, Greece (1991)[261] | School-based | 8–10 years | 4.6% |
| Patras, Greece (1998)[261] | School-based | 8–10 years | 6.0% |

**Table 4: Prevalence of cerebral palsy**

| Areas | Type of survey | Age group | Prevalence |
|---|---|---|---|
| China, singletons (1997)[262] | Population-based | <7 years | 1.6/1000 |
| China, multiples (1997)[263] | Population-based | <7 years | 9.7/1000 |
| Okinawa, Japan, singletons (1988–94)[264] | Live births | — | 1.6/1000 |
| Okinawa, Japan, multiples (1988–94)[264] | Live births | — | 10.1/1000 |
| Southern Sweden (1990–93)[265] | Live births | — | 2.2/1000 |
| Sweden (1991–94)[266] | Live births | — | 2.12/1000 |
| Shiga Prefecture, Japan (1977–91)[267] | Population based | 6 years | 1.34/1000 |
| The Netherlands (1977–79)[268] | Population-based | (not known) | 0.77/1000 |
| The Netherlands (1986–88)[268] | Population-based | (not known) | 2.44/1000 |
| Northern Ireland, United Kingdom (1981–93)[269] | Live births | - - | 2.24/1000 |
| Central region, Ethiopia (1986–88)[270] | Community-based | (not known) | 0.2/1000 |
| Metropolitan Atlanta, USA (1985–87)[271] | Population-based | 10 years | 2.7/1000 (M)<br>1.8/1000 (F) |

Table 5: Prevalence of overweight/obesity

| Areas | Type of survey | Age group | Prevalence |
|---|---|---|---|
| Native Canadian community (1993–95)[272] | Population-based | 10–14 years<br>15–19 years | 23.5% (M)<br>32.1% (F)<br>18.6% (M)<br>26.6% (F) |
| United States (1995–97)[273] | Practice-based | 12–17 years | 19% (M)<br>18% (F) |
| South Texas district, USA (1998–99)[274] | School-based | 12–17 years | 23.6% (M)<br>20.6% (F) |
| Calabar, Nigeria[275] | Population-based | 13–15 years<br>16–18 years | 4.0%<br>3.0% |
| China, Hong Kong SAR (1993)[276] | Population-based | 3–18 years | 11.28% (M)<br>8.93% (F) |
| Eight Provinces, China (1991 & 1993)[277] | Population-based | 10–18 years | 4.0% |
| Bahrain (2000)[278] | School-based | 12–19 years | 38.5% (F) |
| Tehran, Islamic Republic of Iran (2001?)[279] | (not known) | 10–19 years | 10.7% (M)<br>18.4% (F) |
| Brazil (1989)[280] | Home-based | 10–19 years | 4.8% (M)<br>10.6% (F) |
| Corrientes, Argentina[281] | School-based | Mean: 14.8 years | 10.9% |
| San José Province, Costa Rica (1996)[282] | School-based | 12–18 years | 20.0% |
| Sweden (1997)[283] | Population-based | 15 years<br>18 years | 11.6% (M)<br>5.5% (F)<br>11.4% (M)<br>4.8% (F) |
| Thessaloniki, Greece[284] | School-based | 11–17 years | 19.0% |
| Frosinone Province, Italy[285] | School-based | 11–19 years | 9.82% (M)<br>6.33% (F) |
| Hat Yai, Thailand (1992)[286]<br>Hat Yai, Thailand (1997)[286] | School-based<br>School-based | (not known) | 12.4% (M)<br>15.2% (F)<br>21.0% (M)<br>12.6% (F) |

Table 6: Developmental tasks of adolescence

| | Biological | Psychological | Social |
|---|---|---|---|
| **Early adolescence** | Early puberty<br>*Girls*<br>• breast bud and pubic hair development (Stage II)[287]<br>• initiation of growth spurt<br>*Boys*<br>• testicular enlargement, beginning of genital growth (Stage II) | • thinking remains concrete but with development of early moral concepts<br>• progression of sexual identity development:<br>  • development of sexual orientation – possibly by experimentation<br>  • possible homosexual peer interest<br>  • reassessment and restructuring of body image in face of rapid growth | • realization of differences from parents<br>• beginning of strong peer identification<br>• early exploratory behaviours (smoking, violence) |
| **Mid Adolescence** | *Girls*<br>• mid to late puberty (Stage IV–V) and completion of growth<br>• menarche (Stage IV event)<br>• development of female body shape with fat deposition<br>*Boys*<br>• mid puberty (Stages III & IV)<br>• spermarche & nocturnal emissions<br>• voice-breaking<br>• initiation of growth spurt (Stage III–IV) | • emergence of abstract thinking although ability to imagine future applies to others rather than self (self seen as "bullet-proof")<br>• growing verbal abilities; adaptation to increasing educational demands<br>• conventional morality (identification of law with morality)<br>• development of fervently held ideology (religious/political) | • establishment of emotional separation from parents<br>• strong peer group identification<br>• increased health risk behaviours (smoking, alcohol, drugs, sexual exploration)<br>• heterosexual peer interests develop<br>• early vocational plans<br>• development of an educational trajectory; early notions of vocational future |
| **Late Adolescence** | *Boys*<br>• completion of pubertal development (Stage V)<br>• continued androgenic effects on muscle bulk and body hair | • complex abstract thinking<br>• post-conventional morality (ability to recognize difference between law and morality)<br>• increased impulse control<br>• further completion of personal identity<br>• further development or rejection of ideology & religion – often fervently | • further separation from parents & development of social autonomy<br>• development of intimate relationships – initially within peer group, then separation of couples from peer group<br>• development of vocational capability, potential or real financial independence |

**Table 7: Reciprocal effects of chronic illness or disability and adolescent development[105, 114, 118, 288, 289]**

| Effects of chronic illness or disability on development | Effects of developmental issues on chronic illness or disability |
|---|---|
| *Biological*<br>• Delayed puberty<br>• Short stature<br>• Reduced bone mass accretion | *Biologically*<br>• Increased caloric requirement for growth may negatively impact on disease parameters<br>• pubertal hormones may impact upon disease parameters (e.g. growth hormone impairs metabolic control in diabetes) |
| *Psychological*<br>• Infantilisation<br>• Adoption of sick role as personal identifier<br>• Egocentricity persists into late adolescence<br>• Impaired development of sense of sexual or attractive self | *Poor adherence & poor disease control due to:*<br>• poorly developed abstract thinking and planning (reduced ability to plan and prepare using abstract concepts)<br>• difficulty in imagining the future; self-concept as being “bullet-proof”<br>• rejection of medical professionals as part of separation from parents<br>• exploratory (risk-taking) behaviours |
| *Social*<br>• Reduced independence at a time of when independence is normally developing<br>• Failure of peer relationships then intimate (couple) relationships<br>• Social isolation<br>• Educational failure & then vocational failure; failure of development of independent living ability | *Associated health risk behaviours*<br>• chaotic eating habits may result in poor nutrition<br>• smoking, alcohol & drug use often in excess of normal population rates<br>• sexual risk-taking, possibly in view of realisation of limited life span |

**Table 8: Aspects of the patient’s condition and situation that may be discussed in the long-term[16, 54, 87, 103, 113]**

1. Interference of the disease with pubertal processes
2. Degree of invalidity/incapacity
3. Visibility of the disease (including side-effects affecting self image)
4. Evolution (continuous, or sporadic)
5. Prognosis
6. Associated mental health problems
7. Everyday constraints (e.g. physical disability, complex treatment)
8. Beliefs and expectations
9. Defence mechanisms: denial, expectations, etc

**Table 9: Main factors that have been identified as potentially interfering with adherence[77, 133–137]**

*Factors related to the adolescent*
- Cognitive factors
- Perception of the disease
- Emotional/psychological factors
- Patient education

*Factors related to the teenager's environment*
- Family functioning
- Peer influence

*Factors related to the setting and communication*
- Setting
- Relationship with the health-care team, communication style
- Complexity of the therapeutic regimen
- Interference of the treatment with the adolescent's needs and lifestyles

**Table 10 : Strategies to improve compliance/adherence[74, 132, 135, 139–141]**

*Factors related to the adolescent*
- Provide information appropriate for the adolescent's maturational stage
- Take into account underlying psychological factors
- Tailor the treatment to the patient's individuation process and stage
- Communicate information in a straightforward way, trust the adolescent
- Tailor the doses of the medication to the patient's physiological status (puberty/growth)
- Adapt the therapy to the adolescent's lifestyle
- Ask for proposals from the patient

*Factors related to the teenager's environment*
- If needed, suggest the support of siblings, peers

*Factors related to the setting and communication*
- Keep the same professionals in charge of individual patients over time
- Assess adherence regularly and in a non-threatening manner, check for side-effects
- Simplify the therapeutic regimen as much as possible
- Negotiate

**Table 11: Primary care needs of the adolescent with a chronic condition[16, 103, 113, 193]**

**H**ome (nature and quality of family environment)

**E**ducation (school setting and problems, professional future)

**A**ctivity (sports and leisure activities)

**D**rugs (use and misuse of tobacco/alcohol/illegal drugs)

**S**exuality (sexual identity, expectation, behaviour)

**S**ecurity (risk-taking versus prevention of accidents)

**S**uicide and self-harm (mood, anxiety, depression, suicidal conducts)

### Table 12 : Issues related to contraception and pregnancy in some chronic illnesses[90, 91, 200]

*Cystic fibrosis:* Among girls, risk of interference between oral contraceptives (OC) and some antibiotics. Risks of deterioration in pulmonary function during pregnancy; among boys, high risk (~90–95%) of infertility

*Epilepsy:* Interference between some anticonvulsant drugs and OCs' effectiveness. Some anticonvulsants, if taken during pregnancy, can potentially affect the baby.

*Hepatic diseases:* Prescription of OCs contraindicated

*Hematologic diseases:* Sickle-cell anaemia is in principle a contraindication to the prescription of OCs, but medroxyprogesterone acetate (quarterly depot injection) is effective and may even improve the outcome of the disease. This method is also interesting in bleeding disorders, since it suppresses menses.

*Diabetes:* Some consensus on the lack of complications associated with the use of OCs (e.g. retinopathy, vascular disease), but OCs are, in principle, not prescribed to patients with proven vascular complications.

*Renal disease:* OCs contraindicated if severe hypertension or thromboembolic disease is evident.

### Table 13: Components of a good transition programme [59, 175–177, 213–218, 220, 222, 225]

1. Discuss the matter during childhood and as the young person grows up
2. Acknowledge issues facing both the patient and his/her parents
3. Identify colleagues who have an interest in (or responsibility for) young adults
4. Select a health worker (family practitioner, nurse, etc.) who can supervise the transition
5. Organize common meetings with the new care team
6. Plan ahead for some follow-up phone calls
7. Identify individuals, (adults, peers) who can give support to the patient during the transition

### Table 14: Youth-friendly services: some essential elements[230–233, 290]

1. Availability and accessibility, safe and supportive environment
2. Youth-friendly procedures (time schedule, dealing with emergencies, waiting time, confidentiality, anonymity)
3. Youth-friendly staff, multi-disciplinarity
4. Counselling services
5. Adequate and comprehensive information
6. Youth participation
7. Community support

# 7.

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